Quality standards advisory committee 3 meeting

Date: 19 September 2018

Location: NICE office, Level 1a City Tower, Piccadilly Plaza, Manchester, M1 4TD

Morning session: People's experience using adult social care – review of stakeholder feedback

Afternoon session: Pancreatic cancer – review of stakeholder feedback

Minutes: Draft

Attendees

Quality standards advisory committee 3 standing members:

Hugh McIntyre (Chair), Ivan Benett, Deryn Bishop, Nadim Fazlani, Malcolm Fisk, Ulrike Harrower, Keith Lowe, Ann Nevinson, David Pugh, Eve Scott, Jim Stephenson (vice-chair), Darryl Thompson, Phil Taverner

Specialist committee members:

Morning session – People's experience using adult social care services:
Paul Jays
Anne Pridmore
Martha Wiseman

Afternoon session - Pancreatic cancer:
Lesley Goodburn
Anna Jewell
Somnath Mukherjee
Derek O'Reilly
John Primrose

NICE staff

Mark Minchin (MM) [1-15], Eileen Taylor (ET) [5-8], Julie Kennedy (JK) [5-8], Anna Wasielewska (AW) [11-15], Nicola Greenway (NG) [11-15], Jamie Jason (1-15)

NICE observers
Paul Daly (am only)

Apologies Amanda de La Motte, Julia Thompson, Barry Attwood, Madhavan Krishnaswamy

SCMs (am) – Mary Gardner, Alec Porter
SCMs (pm) – Dawn Elliot

1. Welcome, introductions objectives of the meeting
The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the meeting, which was to review stakeholder comments on the people's experience of adult social care quality standard. The Chair confirmed that there were no public observers joining the morning session of the committee meeting.
2. Confirmation of matter under discussion and declarations of interest
The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the morning session was the people's experience of adult social care. The Chair asked the committee to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion during the morning session. MM noted that he was a standing member of the Quality Matters priority 2 work programme.

3. Minutes from the last meeting	
The committee reviewed the minutes of the last QSAC3 meeting held on 20 June 2018 and confirmed them as an accurate record.	
4. QSAC updates	
The Chair noted the following: • Ulrike Harrower's last meeting • Phil Taverner's first meeting • Asma Khalil and Susannah Solaiman have resigned from QSAC. MM advised that following responses from the Royal College of Physicians a new specialist member has been appointed to the sexual health quality standards advisory committee.	
5. Recap of prioritisation meeting and discussion of stakeholder feedback	
ET provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the people's experience of adult social care draft quality standard. ET summarised the significant themes from the stakeholder comments received on the people's experience of adult social care draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers. **General note** The committee asked the NICE team whether there were any significant differences between the quality standard and Quality Matters. The NICE team will ensure that they align.	
5.1 Discussion and agreement of amendments required to quality standard	
Draft statement 1: **Care and support needs assessment** **People using adult social care services have a care and support needs assessment that takes into account their personal strengths, preferences, aspirations and needs.**	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team. It was noted that a variety of comments had been received. **Draft statement 1** The committee discussed the wording and noted that not all people that have an assessment are already using social care services and the statement wording needs to address that. The committee agreed that 'takes into account' should be removed and replaced by 'discuss and document'. This gives the person more autonomy and opportunity to self-manage. The committee discussed the person having a copy of the assessment and suggested this could be included as an outcome measure. **ACTION: NICE team to check alignment to Quality Matters.** **ACTION: NICE team to progress the statement and explore the suggested wording.** **ACTION: NICE team to include additional outcome measure.**
Draft statement 2: **Empowering people to manage their care package**	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team.

funds **People using adult social care services have as much control as possible over their allocated funds for purchasing care packages.**	The committee discussed the wording of the statement. It is important there is a strong focus on the person's voice. It was suggested that 'autonomy' is used instead of 'as much control as possible'. It was noted not all people want to have full control. The committee agreed to reword 'purchasing care packages' as this is an outdated term. The committee discussed 'having as much control as possible' may not be very clear, although there is a definition of this in the supporting information. It was agreed the wording of the statement would still include this phrase to match the guideline recommendation but the rationale would be updated to make the meaning clearer. **ACTION: NICE team to progress the statement with amended wording and additional detail in the rationale.**
Draft statement 3: **Continuity and consistency of care and support** **People using adult social care services have continuous and consistent care and support.**	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team. The committee discussed whether this was already being done and was therefore not an area for quality improvement. It was agreed there is wide spread variation. It was acknowledged that providing continuity of care can be difficult. It was agreed that the statement supporting information should make it clear that continuous does not mean lifelong. It was felt that the wording of the statement had caused confusion and it was therefore agreed that the statement should be reworded to say 'continuity of care' and that consistency would be removed. **ACTION: NICE team to progress the statement with amended wording.** **ACTION: NICE team to explain in the rationale that the service would change according to people's needs.**
Draft statement 4: **Using people's views to improve services** **People using adult social care services' views are used to inform service improvement.**	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard, with the following amendments and issues to be explored by the NICE team. The committee discussed the statement and noted that the supporting information needs to be clear that this will need to include both qualitative and quantitative data. A definition of 'used to inform service improvement' will be added and the committee felt this would help to strengthen the statement. The committee agreed that the rationale would also be updated to emphasise that people are involved in service improvement throughout. **ACTION: NICE team to progress the statement and add a definition explaining informing service improvement.**
5.2 Additional quality improvement areas suggested by stakeholders at consultation	

The following areas were not progressed for inclusion in the final quality standard as the committee agreed that they were not a priority in relation to the four quality improvement areas already included and some could be incorporated into the supporting information for the existing quality statements:

1. Prevention support for people with hearing loss – not progressed as there is a quality standard in development on hearing loss
2. Providing information in a suitable format – this is addressed in the equalities section of each statement
3. Separating means-testing from the care and support needs assessment and having a simplified process – not progressed as this is outside the remit of Quality Standards
4. Dementia training and person-centred training for care support assessors and social care practitioners – not progressed as quality statements focus on actions that demonstrate high quality care or support, not the training that enables this.
5. Seamless and well co-ordinated care – not progressed as this should be addressed in part by statement 3. There are also quality standards on transition periods.
6. Improved access to care and support assessment – not progressed as no recommendations to support a statement on this identified.
7. Frequent review of care needs for people with dementia – this can be incorporated in to the supporting information of one of the quality statements, not just for people with dementia, but for everyone using adult social care services.
8. Ensuring people get the care they need following assessment – not progressed as this is addressed by statements 1 and 2 being implemented.

The committee discussed three potential additional areas for quality improvement in detail:
The committee discussed at some length the reason why timing of assessments was not included. An element of this was discussed at the first meeting and not progressed. It was noted that there are no recommendations to support a quality statement on the timing of the assessment and this was therefore not progressed. However, as the committee felt this is an important area, MM advised that this would be fed back to the NICE surveillance team so that this area can be considered when the guideline is updated.

The committee discussed prevention but this was also not included in the guideline, as it was outside the scope, and it was noted that there was a general lack of evidence.

The committee discussed frequency of review of care needs. There is a recommendation in support of this. The committee suggested adding some detail about this into the supporting information of one of the quality statements and agreed it should not be a standalone statement.

6. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard.

The committee noted that matching services to people's needs may result in less waste.

The committee discussed it wasn't about implementing new services but changing culture and using the resources already available. Overall the committee found the statements to be achievable.

The committee discussed the overarching and agreed they are.

- promotion of independence and wellbeing
- experience of services
- choice and control

ET requested that the committee submit suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.

7. Equality and diversity

The committee agreed the following groups should be included in the equality and diversity considerations:

1. Age

2. Gender reassignment
3. Pregnancy and maternity
4. Religion or belief
5. Marriage and civil partnership
6. Disability
7. Sex
8. Race
9. Sexual orientation

It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.

The committee noted the following:

The term promotion of independence is now a regularly used term.

LBGT population need to be considered under statement 1.

Carers who are associated with people who have learning disabilities can experience indirect discrimination. This may not directly relate to any of the statements but will be considered.

Some females from ethnic minorities may prefer not to mix with males. This will be considered when the quality standard is being updated.

8. Close of morning session

The specialist committee members for the people's experience using adult social care quality standard left and the specialist committee members for the pancreatic cancer quality standard joined.

9. Welcome, introductions and objectives of the afternoon

The Chair welcomed the pancreatic cancer specialist committee members and QSAC members introduced themselves. The Chair informed the committee of the apologies and outlined the objectives of the afternoon, which was to review stakeholder comments on the pancreatic cancer quality standard and finalise areas for quality improvement to be included in the final quality standard.

The Chair confirmed that there were no public observers joining the morning session of the committee meeting.

10. Confirmation of matter under discussion and declarations of interest

The Chair confirmed that, for the purpose of managing conflicts of interest, the matter under discussion in the afternoon session was pancreatic cancer.

The Chair asked the committee to declare verbally all interests specifically related to the matters under discussion during the afternoon session.

11. Recap of prioritisation meeting and discussion of stakeholder feedback

AW provided a recap of the areas for quality improvement prioritised at the first QSAC meeting for potential inclusion in the pancreatic cancer draft quality standard.

AW summarised the significant themes from the stakeholder comments received on the pancreatic cancer draft quality standard and referred the committee to the full set of stakeholder comments provided in the papers.

11.1 Discussion and agreement of amendments required to quality standard

Draft statement 1: **Specialist pancreatic**	The committee acknowledged support from stakeholder for this statement but also highlighted that some comments received from stakeholders implied that this was already common practice rather than an area for

multidisciplinary teams **Adults with suspected pancreatic cancer have their diagnosis and care determined by a specialist pancreatic cancer multidisciplinary team.**	quality improvement. The committee referred back to discussions from the prioritisation meeting when it had been agreed that variation in practice still existed and a quality statement addressing this area is needed. The committee discussed stakeholders' suggestion that core members of the specialist MDT should be defined. The specialist committee members highlighted that cancer peer review measures already defined the roles required and adding it to the quality standard would not be beneficial. It was also noted that the roles were not specified in the guideline. The committee concluded that Hospital Episode Statistics did not include information about diagnosis and care being determined by specialist pancreatic cancer MDTs. The committee concluded that Systemic Anti-Cancer Therapy Database did not include information about adults with pancreatic cancer being offered access to clinical trials. **ACTION: NICE team to progress the statement and keep current wording.**
Draft statement 2: **Staging using FDG-PET/CT** **Adults with localised pancreatic cancer who can have cancer treatment have staging using fluorodeoxyglucose positron emission tomography/CT (FDG-PET/CT).**	The committee agreed that stakeholders were supportive of this statement and it should be included in the final quality standard. The committee discussed stakeholders' concerns that current wording may result in some FDG-PET/CT scans being carried out unnecessarily. The committee confirmed that the FDG-PET/CT should be carried out in people who are put forward for treatment after CT scan indicated the cancer was localized to confirm that they are suitable for surgery, radiotherapy or systemic therapy. The committee discussed the notion of measuring unnecessary surgery and agreed that current process measure b was not feasible. The committee agreed to add a measure on people who were found to have metastatic disease on FDG-PET/CT scan and could not proceed to surgery. **ACTION: NICE team to progress statement but explore amending the wording.** **ACTION: NICE team to remove process measure b.** **ACTION: NICE team to add a measure around people who were found to have a metastatic disease and didn't have surgery.**
Draft statement 3: **Biliary obstruction and resectable pancreatic cancer** **Adults with resectable pancreatic cancer and obstructive jaundice do not have preoperative biliary drainage unless specifically indicated.**	The committee agreed that stakeholders were supportive of this statement and it should be included in the final quality standard. The committee discussed the need to amend wording of the statement as it didn't capture the importance of prompt surgery. The committee discussed stakeholders' comments asking to define the term 'being fit enough for surgery'. The committee agreed that this term could not be defined and it would be a clinician's decision. It was agreed that the focus of the statement should be on prompt surgery as biliary drainage carried out unnecessarily in people suitable for resectional surgery negatively impacts patient's outcomes and increases cost. **ACTION: NICE team to progress statement but review the wording to highlight that surgery should be done without delay.**

Draft statement 4: **Unresectable pancreatic cancer** **Adults with unresectable pancreatic cancer have a discussion about chemotherapy options available to them.**	The committee agreed not to progress this statement for inclusion in the final quality standard. The committee discussed the issue of people with pancreatic cancer not having any conversations about potential treatment options and a large proportion not receiving any treatment. The reason for a statement was more a need for a discussion about options rather than a specific conversation about chemotherapy. The committee felt that as this was an area important for all health conditions and has already been covered in patient experience in adult NHS services (QS15), it should not be included in the final quality standard. It was agreed that the reference to patient experience quality standard would be highlighted in the introduction.
Draft statement 5: **Pancreatic enzyme replacement therapy** **Adults with unresectable pancreatic cancer are prescribed enteric-coated pancreatin.**	The committee agreed that stakeholders were supportive of this statement and it should be included in the final quality standard. The committee discussed stakeholders' suggestions to broaden this statement to include people with resectable pancreatic cancer. The committee agreed that due to lack of evidence showing effectiveness in people with resectable pancreatic cancer, it is not appropriate to include them in the statement. The committee agreed that there were no beef based PERT alternatives available and it should be removed from the equalities section. **ACTION: NICE team to progress statement as it is.** **ACTION: NICE team to include something about the need to support people to take PERT effectively within the supporting information.** **ACTION: NICE team to remove reference to beef based products in the equalities section.**
Draft statement 6: (placeholder): **Effective interventions to address psychological needs**	The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard as a placeholder statement. The committee discussed whether this was a standalone statement or more of a generic statement that could be applied across all cancers. The committee discussed differences between pancreatic cancer and other life limiting disease. They noted that the rapid decline, limited treatment options and very short life expectancy make psychological needs particularly high. The committee agreed that similar support was needed for all people at the end of life and receiving palliative care and agreed to make a reference to a statement included in end of life care quality standard. The committee agreed that there is a need for interventions to address psychological needs in this group but noted that due to lack of guidance, this quality standard could only include a placeholder statement. The committee agreed to progress a placeholder statement and strengthen the rationale highlighting the high prevalence of depression in this population.

11.2 Additional quality improvement areas suggested by stakeholders at consultation

The following areas were not progressed for inclusion in the final quality standard as the committee agreed that they were not a priority in relation to the five quality improvement areas already included:

- Palliative care – not progressed as QS13 covers palliative care (statement 10)
- End of life care – not progressed as a specific QS on end of life care has already been published – QS13
- Pain management – not progressed as already discussed in first meeting, lack of strong evidence and guideline recommendations to support a statement on it.
- Local accurate staging – not progressed as FDG-PET/CT seen as more of a priority to improve staging
  - multiphase CT prior to stenting
  - endoscopic ultrasound
- MRI of liver to detect occult liver metastasis too small for CT and PET/CT as part of staging - not progressed as FDG-PET/CT seen as more of a priority to improve staging.
- Standardising radiology reporting – developing a proforma.- not progressed as this is a process improvement rather than area for quality improvement suitable for a quality statement.

12. Resource impact and overarching outcomes

The committee considered the resource impact of the quality standard.

It was discussed that there would be cost savings from reduced stenting and savings from PET/CT from reduced surgeries.

The committee confirmed the overarching outcomes are those presented in the draft quality standard.

- cancer staging
- pancreatic cancer survival rate
- pancreatic cancer mortality rate
- nutritional status of adults with pancreatic cancer
- health-related quality of life
- patient satisfaction with their care

AW requested that the committee submit suggestions to the NICE team relating to the overarching outcomes of the quality standard when it is sent to them for review.

13. Equality and diversity

The committee agreed the following groups should be included in the equality and diversity considerations:

- Age
- Gender reassignment
- Pregnancy and maternity
- Religion or belief
- Marriage and civil partnership
- Disability
- Sex
- Race
- Sexual orientation

It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.

14. Any other business

None.

15. Close of meeting