Quality standards advisory committee 3 meeting

Date: 16 May 2018

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

Morning session: People's experience using adult social care services – prioritisation of quality improvement areas

Afternoon session: Pancreatic cancer – prioritisation of quality improvement areas

Minutes: Draft – unconfirmed

Attendees

Quality standards advisory committee 3 standing members:

Hugh McIntyre (Chair), Ben Anderson, Barry Attwood, Deryn Bishop, Nadim Fazlani, Malcolm Fisk, Madhavan Krishnaswamy, Keith Lowe, Ann Nevinson, David Pugh, Jim Stephenson (vice-chair), Darryl Thompson, Julia Thompson (*am only*), Ivan Benett (*am only*)

Specialist committee members:

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

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

NICE staff
Mark Minchin (MM) [1-17], Eileen Taylor (ET) [1-9], Anna Wasielewska (AW) [10-17], Alison Tariq (AT) [1-9], Nicola Greenway (NG) [10-17], Jamie Jason (notes)

NICE observers
Mark Rasburn

Apologies standing members: Helen Bromley, Amanda de la Motte, Ulrike Harrower, Jane Ingham, Asma Khalil, Susannah Solaiman, Eve Scott

Apologies SCMs: Mark Callaway

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 prioritise areas for quality improvement for the people's experience using adult social care services quality standard. The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.
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 using adult social care services specifically: • Care and support - needs assessment • Care and support - planning • Care and support - provision • Access and involvement

The Chair asked standing QSAC members and specialist members 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.

- Darryl Thompson noted that he has been selected as a Fellow for the Health Foundation's GenerationQ Leadership Programme

The Chair congratulated Darryl on his appointment.

3. Minutes from the last meeting

The committee reviewed the minutes of the previous QSAC 3 meeting held on 21 March 2018 and confirmed them as an accurate record.

4. QSAC updates

The Chair informed the standing members that since the last meeting was not quorate the NICE team did consult with those who were not present and all decisions were ratified.

The Chair gave an update on the eating disorders quality standard.

As there was a parliamentary review which was published after the consultation meeting the NICE team added 2 new statements for this topic. There was a second consultation to address this and a further meeting with the specialist members. It is to be noted that it was felt another committee meeting was not necessary but the committee were offered the option should it be required.

5. Prioritisation of quality improvement areas – committee decisions

ET provided a summary of responses received during the people's experience using adult social care services topic engagement, referred the committee to the full set of stakeholder comments provided in the papers and the committee then discussed each of the areas in turn. The committee discussed the comments received from stakeholders and specialist committee members at topic engagement **(in bold text below)**.

Before the areas were discussed the committee noted that the focus of the title and introductory section of the topic were mis-matched as the title is about people's experience however the introduction refers to people receiving care and services being delivered. The Chair explained that the focus is how the care is delivered to people individually and their experience of the care.

The committee noted that 3 of the key stakeholders identified by the NICE team had not participated in the topic engagement exercise – ADASS, Care England and LGA. The committee requested MM engage with these 3 organisations and try to secure their input during consultation on the draft standard.

The committee noted that it should be made clear that the quality standard applies to people receiving funding from local authorities and people who are self-funding.

Care and support - needs assessment

- **Timing of assessment – Not prioritised**
- **Person-centred assessments – Prioritised**

The committee did not prioritise timing of assessments and felt the specific area raised was not a priority. They noted that the stakeholder who suggested this area highlighted this should be done for older people starting a complex care package or on arrival in a care home. The committee concluded that assessment itself, for all people who may need to use adult social care services, was the priority area.

The committee agreed that assessments often focus on the services available rather than what the person needs. Aware of inconsistencies in the available current practice data the committee discussed whether person centred assessments, which are carried out by the local authority and care providers were already being done well.

The committee felt that assessments are currently frequently carried out from the provider's point of view and not the person receiving the care. The assessment should be based on what the person needs, taking account of their strengths and the outcomes they wish to achieve.

The committee agreed that person centred assessments are an area for quality improvement.

ACTION: NICE team to progress a statement on person centred assessments focusing on the individual's preferences.

Care and support – planning

- **Person-centred planning – Not prioritised**
- **Personal budgets – Prioritised**

The committee discussed named care coordinators and noted that this is included in two other quality standards (QS101 and QS132). This is a consider recommendation in the source guideline for this quality standard. The committee did not feel this was an area to be taken forward in this quality standard.

The committee discussed focussing care and support planning on what matters most to people using services and their carers. It was agreed that a quality statement on people having control over their personal budget could contribute to this area.

The committee discussed that personal budgets are sometimes in name only and they are not always used for what they are intended for. A personal budget can be seen as an option but it is not the default position.

The committee discussed the importance of a personal budget and having control of that budget. It was highlighted that people should have control over the service they receive.

The committee heard that people are often given the option to manage their personal budgets but they are offered limited information or support to do so. People can reluctant to manage their own budget as they do not have any guidance on how to do this effectively and / or may have concerns about 'becoming an employer'.

The committee agreed that managing personal budgets is an area for quality improvement.

ACTION: NICE team to progress a statement on personal budgets focussing on the control and including supporting information to help people to manage the personal budget.

Care and support – provision

- **Participation and relationships – Not prioritised**
- **Communication and continuity of services – Prioritised**
- **Delivery of care – Not prioritised**
- **Protection from abuse – Not prioritised**

The committee discussed participation and relationships. The committee agreed that loneliness and social integration was an area for quality improvement although it was felt a quality statement on these areas may not be effective. It was agreed that a statement on continuity of services could contribute to this area.

It was discussed that constant changes of care workers is an issue and that care is inconsistent when different people are delivering it. It was acknowledged that continuity of care is an issue. The committee discussed the different skills care workers may need, for example, some care workers may be required to assist in administering medication and some are not trained to deal with the needs of people who require different and often specific types of care.

The committee discussed the delivery of care and how delivering a service such as a breakfast meal at the wrong time can have an impact on a person's needs and social activities. It was agreed that a statement on continuity of services could contribute to this area.

The committee agreed that lack of continuity frequently results in people having a poor experience.

It was noted that that protection from abuse is important but there are other quality standards that address

this issue. It was agreed that a statement on continuity of services could contribute to this area.

The committee agreed that continuity of services is an area for quality improvement.

ACTION: NICE team to progress a statement on continuity of services.

Access and involvement

- **Access to care – Not prioritised**
- **Information on services – Not prioritised**
- **Involvement of people using services – Prioritised**

The committee discussed difficulties accessing services because of geography. Ensuring people are aware of services should be more than just giving out a phone number or advertising on posters etc. It was not felt a statement on giving information would be effective.

It was agreed that the most effective way of improving services and increasing access is to involve people using services. This can help to identify the barriers people face when accessing care and can help to improve services.

The committee agreed that involvement of people using services is an area for quality improvement.

ACTION: NICE team to progress a statement on seeking people's views of service and informing people what has been done to improve them.

6. Additional quality improvement areas suggested by stakeholders at topic engagement

The following areas were not progressed for inclusion in the draft quality standard:

- Carers – a separate quality standard on carers will be developed following publication of the Carers: provision of support for adult carers guideline
- Training - quality statements focus on actions that demonstrate high quality care or support, not the training that enables the actions to take place.
- Polypharmacy - Quality standards have been developed on medicines optimisation (QS120) and medicines management in care homes (QS85) which include quality statements on medication reviews. In addition a quality standard on medicines management for people receiving social care in the community is in development and expected to publish in June 2018
- Severe learning disabilities and behaviour that challenges - a quality standard has been developed on Learning disabilities: challenging behaviour (QS101).
- Changes to guideline recommendations, electronic records and landscape of services – these areas are outside the scope of the quality standards process.

Although NICE do not progress statements on training it was noted that there can be training issues for social care staff and, if appropriate, this will be included in the supporting information of quality statements.

7. Resource impact and overarching outcomes

The committee discussed the overarching outcomes:

- Quality of life of people using adult social care services
- Experience of people using adult social care services

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.

Hospitalisation - unplanned readmissions to hospital was suggested as an outcome.

NICE will ask at consultation whether the draft statements are achievable.

The committee noted a concern with resource impacts in this quality standard and it was agreed that this

would be considered again following consultation, when stakeholders have provided their comments on resource impact.

8. Equality and diversity

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

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

It was agreed that the committee would continue to contribute suggestions as the quality standard was developed. The following suggestions were made:

- 18-24 transition age groups
- Prison community
- Travelling community
- Disability – people with different types of disability have different needs which need to be considered.

9. Close of morning session

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

10. 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 prioritise areas for quality improvement for the pancreatic cancer quality standard.

The Chair welcomed the public observers and reminded them of the code of conduct that they were required to follow.

11. 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 pancreatic cancer specifically:

- Diagnosis and staging
- Care planning
- Cancer management
- Support

The Chair asked standing QSAC members and specialist members to declare verbally any interests that have arisen since the last meeting and all interests specifically related to the matters under discussion during the afternoon session.

12. Prioritisation of quality improvement areas – committee decisions

AW provided a summary of responses received during the pancreatic cancer topic engagement, referred the committee to the full set of stakeholder comments provided in the papers and the committee then discussed each of the areas in turn. The committee discussed the comments received from stakeholders and specialist committee members at topic engagement **(in bold text below)**.

Diagnosis and staging

- **Diagnosis – Not prioritised**
- **Staging – Prioritised**

The committee discussed early diagnosis as being important but the recommendations in the NICE suspected cancer guideline (NG12) would not allow writing an achievable statement on GP referrals for people with suspected pancreatic cancer. GP access to diagnostic tools is covered in the suspected cancer guideline and quality standard (QS124) so this area will not be progressed.

The committee agreed that CT scans are already being done and this is not an area that needs improvement. It is the time it takes after the first scan to then receiving any treatment or a decision on what should happen next that needs to be addressed.

The important step is that the people with pancreatic abnormalities on imaging are referred to a specialist pancreatic multidisciplinary team (MDT). This should be the first statement. The staging would be carried out based on MDT's decisions.

The committee discussed staging as an area for quality improvement. Poor availability of Endoscopic ultrasound (EUS) in the UK was highlighted as an issue because EUS is important for people who have not been diagnosed and for those having chemotherapy. The committee also discussed using FDG-PET/CT as a way of improving staging and practice that has a potential to impact on management and limit unnecessary surgeries. The committee agreed that using FDG-PET-CT for staging should be prioritised an area for quality improvement.

ACTION: NICE team to progress a statement on using FDG-PET-CT for staging as the second statement.

Care planning

- **Specialist pancreatic multidisciplinary teams – Prioritised**
- **Clinical nurse specialist – Not prioritised**

As discussed in the previous section, the committee agreed that referring people to specialist pancreatic multidisciplinary teams is an area of improvement.

The committee agreed not to prioritise a clinical nurse specialist as the MDT will cover this area.

ACTION: NICE team to progress a statement on people with pancreatic abnormalities on CT scan being referred to a specialist pancreatic multidisciplinary team.

Cancer management

- **Resectable and borderline resectable pancreatic cancer – Prioritise**
- **Unresectable pancreatic cancer - Prioritise**

The committee discussed the importance of performing the resectable surgery as soon as possible. Carrying out biliary drainage is a procedure which may cause a delay, increase complications in people with resectable pancreatic cancer and is associated with avoidable cost. However, given the demands on the system it is not always be possible to do the surgery straight away and the drainage is performed whilst the person awaits surgery. The issue with the delay in such a rapidly progressing disease is that the person may no longer be suitable for surgery by the time it becomes available.

The committee agreed that it is a priority for people with resectable pancreatic cancer to undergo the resectable surgery without unnecessary delays that may be caused by the biliary drainage. The SCMs advised the committee that it was important to highlight that some people may be involved in clinical trials which may require the biliary drainage.

The committee agreed that it is also a priority for people with unresectable pancreatic cancer to have some form of active treatment.

The committee discussed that people should be offered chemotherapy which may prolong life or help managing some of the symptoms. The committee heard that not everyone is offered chemotherapy as some clinical staff may feel it unnecessary at their stage of the disease. The committee agreed that the people should be given the choice.

The committee agreed to progress a generic statement to offer chemotherapy to people with unresectable pancreatic cancer.

ACTIONS: NICE team to progress a statement on carrying out resectional surgery without preoperative biliary drainage when possible (based on recommendation 1.7.1). NICE to progress a statement on offering chemotherapy to people with unresectable pancreatic cancer.

Support needs

- **Psychological support – Not prioritised**
- **Pain management – Not prioritised**
- **Nutritional management – Prioritised**

The committee discussed the need for psychological support. Pancreatic cancer is rapidly progressive and people can deteriorate very quickly which causes a lot of emotional distress. The committee discussed that support groups may not be helpful as people may be at many different stages of the disease and not always able to relate/support each other. It was noted that psychological support is important in all people with cancer but the committee felt it was an area for improvement due to the potential for very rapid deterioration. The committee agreed to look into including psychological support within the body of the quality standard.

The committee discussed nutritional management as an area for quality improvement. Improving nutritional status can improve quality of life and wellbeing of people with pancreatic cancer. The committee agreed that offering people pancreatic enzyme replacement tablets should be an area of quality improvement.

ACTON: NICE team to progress a statement on offering pancreatic enzyme replacement tablets and look into including psychological support within the body of the quality standard.

13. Additional quality improvement areas suggested by stakeholders at topic engagement

The following areas were not progressed for inclusion in the draft quality standard:

- Support for doctors and nurses - this suggestion has not been progressed. Quality statements focus on actions that demonstrate high quality care or support, not the education and advice that enables the actions to take place. However, support for GPs and primary care professionals may be referred to in the audience descriptors
- Clinical trials - this suggestion has not been progressed. Increasing the opportunities for people to participate in research is within the remit of the National Institute for Health Research. However, this area will be addressed by referring all cases of suspected and diagnosed pancreatic cancer to specialist pancreatic MDTs which have the knowledge and potential to engage people with relevant clinical trials.

14. Resource impact and overarching outcomes

The committee discussed the overarching outcomes:

- Cancer staging
- Pancreatic cancer survival rate
- Pancreatic cancer mortality rate
- Pain management of patients with pancreatic cancer
- Nutritional status of patients with pancreatic cancer
- Health-related quality of life
- Patient satisfaction with their care

There were no significant resource impacts to note.

15. Equality and diversity

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

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

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

16. AOB

No other business.

17. Close of meeting