NICE National Institute for Health and Care Excellence

Quality Standards Advisory Committee 4

Prostate cancer – post-consultation meeting

Minutes of the meeting held on 27th February 2015 at the NICE offices in Manchester

Attendees	**Standing Quality Standards Advisory Committee (QSAC) members** Damien Longson (DL) [Chair], Julie Rigby (JR), Zoe Goodacre (ZG), Tim Fielding (TF), Allison Duggal (AD), Alaster Rutherford (AR), Alison Allam (AA), John Jolly (JJ), Harry Allen (HA), Frances Garraghan (FG), John Walker (JW), Michael Varrow (MV), Jane Bradshaw (JB), Nicola Hobbs (NH), Moyra Amess (MA), David Weaver (DW) **Specialist committee members** Sarah Cant (SC), Peter Hoslin (PH), Jonathan Richenberg (JRi), John Graham (JG), Brian McGlynn (BM), Jonathan Rees (JRe), Sanjeev Madaan (SM) **NICE staff** Sabina Keane (SK), Karyo Angeloudis (KA), Lisa Nicholls (LN), Rachel Neary–Jones (RNJ) **Topic expert advisers** None **NICE observers** None
Apologies	**Standing Quality Standards Advisory Committee (QSAC) members** Rubin Minhas, Roger Hughes **Specialist committee members** None **NICE staff** None

Agenda item	Discussions and decisions	Actions
1. Welcome, introductions and plan for the day (private session)	DL welcomed the attendees and the Quality Standards Advisory Committee (QSAC) members introduced themselves. DL informed the Committee of the apologies and reviewed the agenda for the day.	
2. Welcome and code of conduct for members of the public attending the meeting (public session)	DL welcomed the public observers and reminded them of the code of conduct that they were required to follow. It was stressed that they were not able to contribute to the meeting but were there to observe only. They were also reminded that the Committee is independent and advisory therefore the discussions and decisions made today may change following final validation by NICE's guidance executive.	
3. Committee business (public session)	**Declarations of interest** DL asked standing QSAC members to declare any interests that were either in addition to their previously submitted declaration or specific to the topic(s) under consideration at the meeting today. DL asked the specialist committee members to declare all interests. The following interests were declared: <u>Standing committee members</u> • None <u>Specialist committee members</u> • SC – employee at Prostate Cancer UK. 3 manufacturer companies have supported activities for PCUK, which makes up less than 0.02% of income. Is a media spokesperson for PCUK and husband is employed by a company that manufactures vaccines. • PH – received research grants from Astellas, Bayer and Varian. Member of Royal College of Radiologists committees. • JG – Director of National Collaborating Centre for Cancer. Involved in research on Radium 223 which is funded by Bayer. • JRi – GE work on fusion techniques and guest at European congress radio. No fees involved but received travel and subsistence. Member of Royal College of Radiologists committees. • JRe – advisory work and speaker fees from pharmacy companies relating to GNRH. Clinical adviser for Tackle Prostate Cancer. Chair of PCUK Education Committee, • BM - none **Minutes from the last meeting** The committee reviewed the minutes of the last meeting held on 19th December 2014 and confirmed them	

Agenda item	Discussions and decisions	Actions
	as an accurate record.	
4. Topic session – prostate cancer (public session)	The committee then moved on to discuss prostate cancer.	
4.1 Recap of prioritisation exercise	SK and KA presented a recap of the areas for quality improvement discussed at the first QSAC meeting for prostate cancer **At the first QSAC meeting on 20th October 2014 the QSAC agreed that the following areas for quality improvement should be progressed for further consideration by the NICE team for potential inclusion in the draft quality standard:** • Information and support – access to a clinical nurse specialist (CNS) • Localised and locally advanced prostate cancer – active surveillance • Localised and locally advanced prostate cancer – combination therapy • Managing adverse effects of prostate cancer • Metastatic prostate cancer The full rationale for these decisions is available in the prioritisation meeting minutes which can be found here: http://www.nice.org.uk/Media/Default/get-involved/meetings-in-public/quality-standards-advisory-committee/qsac4/qsac-4-minutes-20-oct-2014.pdf	
4.2 and 4.3 Presentation and discussion of stakeholder feedback and key themes/issues raised	SK and KA presented the committee with a report summarising consultation comments received on prostate cancer. The committee was reminded that this document provided a high level summary of the consultation comments, prepared by the NICE quality standards team, and was intended to provide an initial basis for discussion. The committee was therefore reminded to also refer to the full list of consultation comments provided throughout the meeting. The committee was informed that comments which may result in changes to the quality standard had been highlighted in the summary report. Those comments which suggested changes which were outside of the process, were not included in the summary but had been included within the full list of comments, which was within the appendix. These included the following types of comment: • Relating to source guidance recommendations • Suggestions for non-accredited source guidance	

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	• Request to broaden statements out of scope • Inclusion of overarching thresholds or targets • Requests to include large volumes of supporting information, provision of detailed implementation advice • General comments on role and purpose of quality standards • Requests to change NICE templates	
4.4 Commissioning implications	KA presented to the committee ~~on~~ the supporting documentation that would be developed and published alongside the quality standard.	
4.5 Discussion and agreement of final statements	The committee discussed each statement in turn and agreed upon a revised set. **These statements are not final and may change as a result of the editorial and validation processes.**	
	Draft Quality Statement 1: Men with prostate cancer have a named nurse specialist who can provide information and support on treatment options and their adverse effects The group discussed the feedback from stakeholders on this statement in relation to the men with prostate cancer having a named nurse specialist. In general stakeholders welcomed this statement but raised the issue of access as there is a current lack of prostate cancer nurse specialists and queried whether the named person needed to be a clinical nurse specialist. The committee also queried whether the named nurse should be an oncology nurse or if a urology nurse would be appropriate. It was also queried whether a radiographer could fulfil this role. Another suggestion was to change this to an appropriately trained person but the committee raised concerns with this and agreed that nurses were the main point of contact that should be highlighted. A definition was felt to be needed of a 'specialist nurse' which was consistent across all quality standards to aid measurability. The committee agreed that the nurse specialist should be either an oncology or urology nurse. The committee suggested removing 'who can provide information and support on treatment options and their adverse effects' and replacing this 'discussed' to make this more action focussed. They also agreed that it was important to ensure that men not only have a named specialist but can access them too. It was therefore agreed that an additional outcome measure should be added to the statement to measure the patient's satisfaction with access to the named specialist and the information they received. It was felt that the National Cancer Patient Experience Survey 2014 could be used to measure this.	**NICE team to progress this statement and add a definition on support services. Also add an outcome measure on 'patient satisfaction with access'.**

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	The committee discussed the range of support options such as websites and cancer support groups which they felt must be acknowledged in the definitions to make it clear that the named specialist would act as a gatekeeper to lots of other support resources. The committee also suggested including the word 'desired' in front of provision of information but it was thought it will be difficult to define and may vary by patient. The committee concluded that 'support services' must be defined and to include an outcome measure on 'patient satisfaction with access'. It was agreed to progress the statement.	
	Draft Quality Statement 2: Men with low-risk localised prostate cancer for whom radical prostatectomy or radical radiotherapy is suitable are offered the option of active surveillance Stakeholders welcomed this statement with possible data collection however comments also suggested that the statement had the potential to create an imbalance, with active surveillance being highlighted too much over and above other treatment options. The committee discussed this statement and agreed that the intent was to encourage the option of active surveillance. However they also felt the statement needed to reflect a balance between treatment options and patient choice, with sufficient information given about all treatment options. The committee discussed whether 'also offer the option' should be included in the statement wording. One suggestion was to focus the statement on shared decision making but it was raised that this may also be covered by one of the statements in Patient Experience Quality Standard (QS15) so it has to reflect more than this to be retained in this Quality Standard. The committee discussed adding the importance of 'shared decision making' in the rationale section. Patient choice and adequate support to make the decision is important and the committee felt that the statement captured this. The overall theme from the stakeholder consultation comments was about choice with patients being offered more choice, being informed of risk and how the treatment options are presented. The committee asked whether treatment options could be included in the wording of the statement and listing 3 options was discussed. There was also discussion about what active surveillance is and whether this could be defined. The committee felt including in 'also' or 'equally' to the statement wording was an option. However, it was discussed that the term 'equally' could have potential risks. The committee mentioned the option of cryotherapy which was raised by stakeholders but the committee highlighted that the NICE clinical guideline in this areas recommends that this should only be used in	**NICE team to progress this statement and consider including the word 'are also offered' to the statement wording and adding further detail to the rationale. Also outcome measure on 'patient satisfaction with their treatment option'**

Agenda item	Discussions and decisions	Actions
	clinical trials. Therefore it was agreed not to include it within the statement. It was agreed to add 'are also offered' the option of active surveillance to the statement wording and make it clear that combination therapy is not the only option. It was also agreed to include more detail in the rationale to make it clear that all three treatment options should be presented and to add an outcome measure to capture whether men felt they had been given information about all three options before making a decision. It was agreed to progress the statement.	
	Draft Quality Statement 3: Men with intermediate or high-risk localised prostate cancer are offered a combination or radical radiotherapy and androgen deprivation therapy The current statement wording was discussed by committee along with consultation comments suggesting that it could be seen as confusing. The quality improvement issue was agreed as being that patients who get either radiotherapy or androgen therapy, get it in combination. They also discussed that these patients have a number of effective treatment options and not just the ones offered in this statement and agreed with stakeholder suggestions that clarification is needed that combination therapy is only one treatment option**.** They agreed that the rationale of the statement should make this clear. The committee discussed how combination therapy positively offers better survival but clarification is needed when to use combination therapy. The committee also discussed patient choice so the man is offered combination therapy, surgery or an alternative. There was a suggestion to exclude the term 'intermediate' and specifically focus on high-risk localised prostate cancer as current variation in practice is around high-risk men. However, it was felt that this could be seen as excluding men with intermediate localised prostate cancer from combination treatment which is not the intention. The wording of the statement was discussed by committee and whether 'offered in combination' should be included and the word 'appropriate'. It was agreed that 'where combined' should be included in the statement wording to emphasise the importance of offering these treatments in combination. It was agreed that the definition of androgen therapy needed amendment.	**NICE team to progress this statement and consider adding 'where combined' in the statement. An emphasis on offering these treatments in combination was agreed.**

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	The committee further discussed shared decision making and patient choice about treatment options as this was a theme that had consistently been raised as important by stakeholder. The committee discussed whether an additional statement should be included on this issue however NICE highlighted that a separate quality standard on patient experience in adult NHS services (QS15) already included statements on shared decision making, treatment options and provision of adequate information, which are important for all patients no matter what the condition. These issues would therefore not be included within a topic specific quality standard unless there was something over and above what is included within QS15 relevant to a specific condition. It was agreed to progress the statement.	
	Draft Quality Statement 4: Men with prostate cancer have access to specialist services and interventions to manage the adverse effects of treatment In general stakeholders welcomed this statement however a number reported difficulty in focusing on managing one adverse treatment effect as this will vary by patient. This variation was also agreed by the committee due to the fact that side effects can be so wide ranging and have different impacts on different men. The committee discussed the psychological and emotional impact of treatment and agreed that these need to be considered alongside physical side effects. There were also a number of additional physical side effects raised by stakeholders which the committee agreed should be included. It was therefore agreed to add anxiety (especially as a result of active surveillance), loss of libido, incontinence, impotence, and cardiovascular side effects to the definitions section. Adding more information on the impact of active surveillance in the rationale was also agreed. The committee also discussed particular equality and diversity considerations for this statement and the effects prostate cancer would have on men who have sex with other men and on transgender women. Although this is a smaller part of the population, the committee agreed that the psychological support needs to be considered and tailored to individuals as side effects vary by patient and that the needs of gay, bisexual and transgender men should be included in the equalities section plus age. It was agreed to progress the statement.	**NICE team to progress this statement. Add the impact of active surveillance in the rationale. Also include a list of other suggested effects in the definitions section. In terms of the equality and diversity section, the needs of gay, bisexual and transgender men should be included plus age.**
	Draft Quality Statement 5: Men with biochemical evidence of hormone-relapsed metastatic prostate	**NICE team to progress**

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	cancer have their treatment options discussed by the urological cancer MDT Stakeholders welcomed the multidisciplinary team (MDT) approach implied by this statement but raised concerns over the MDT capacity and queried whether the full MDT would be needed in all cases. The committee discussed the statement and felt the purpose wasn't clear. They agreed that the quality improvement issue was that men with metastatic prostate cancer are discussed with a specialist. MDTs are simply one way of achieving this outcome. It was agreed that the rationale should make this clear in line with guideline recommendation 1.5.10. The committee felt that the statement did not need to state 'biochemical evidence' as this would exclude some men that this statement should apply to. The NICE team agreed to consider this outside of the meeting because the guidance CG175 does state that there needs to be biochemical evidence. It was agreed to progress the statement.	**this statement. Consider removing 'biochemical evidence' from the statement and definitions section.**
	The committee were presented with the equality considerations for this topic and asked if any others should be taken in to consideration. The committee felt sexual orientation and gender reassignment were particularly important protected groups. It was agreed to change the wording on this in the Equality Impact Assessment (EQIA) document to transgender people not gender reassignment to include people who had not yet had surgery. Accessibility by LBGT groups was discussed and it was felt providers needed to make information accessible. Committee felt statement 5 was less of an equality consideration for LBGT than statements 1- 4.	**NICE team to amend EQIA to state 'transgender' rather than the current wording of 'transgender reassignment'**
5. Supporting the quality standard (part 1 – open session)	RNJ presented a summary of the organisations who have expressed an interest in supporting the quality standard and asked the QSAC to consider whether any key organisations were missing. The following organisations were highlighted: • Royal College of Radiologists • National LGBT partnership	

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	• Primary Care Urology Society • British Uro-Oncology Group	
6. Next steps and timescales (part 1 – open session)	LN outlined what will happen following the meeting and any key dates for the prostate cancer quality standard.	
7. Any other business (part 2 – Private session)	The following items of AOB were raised: • None raised DL thanked the specialist committee members for their input into the development of this quality standard, **Date of next QSAC 4 meeting: 26th March 2015**	