

National Institute for Health and Care Excellence

Suspected cancer (update)

Question 1 - Does this draft quality standard accurately reflect the key areas for quality improvement?

Question 2 - Can data for the proposed quality measures be collected locally? Please include in your answer any data sources that can be used or reasons why data cannot be collected.

Question 3 - Do you think each of the statements in this draft quality standard would be achievable by local services given the net resources needed to deliver them? Please describe any resource requirements that you think would be necessary for any statement. Please describe any potential cost savings or opportunities for disinvestment.

Questions about the individual quality statements

Question 4 - For draft quality statement 1: How is provision of safety netting advice being monitored in practice?

Implementing NICE guidelines

Question 5 - What are the challenges to implementing the NICE guidance underpinning this quality standard? Please say why and for whom. Please include any suggestions that could help users overcome these challenges (for example, existing practical resources or national

Comments on the draft quality standard

| Comment number | Statement or question number Or 'general' for comments on the whole document | Comments |
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| | | Insert each comment in a new row. Do not paste other tables into this table because your comments could get lost – type directly into this table. |
| <i>Example 1</i> | <i>Statement 1</i> | <i>This statement may be hard to measure because...</i> |

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| 1 | General | <p>Healthwatch Birmingham are pleased to see this consultation on quality standards for suspected cancer. Our key role is to make sure that the people of Birmingham are at the heart of service improvement in health and social care.</p> <p>We feel from feedback we have heard from the people of Birmingham that difficulties with primary care have not been taken into account for these quality standards, specifically accessing GP practices and receiving continuity in care ahead of referral for suspected cancer.</p> <p>We have heard from people across Birmingham who have experienced great difficulties accessing their GP practices. We have previously reported these difficulties, which showed that people with long term conditions, and people living in more deprived areas, encountered more barriers to care: People's views on access to GP services in Birmingham.</p> <p>Since writing this report we have continued to hear high levels of feedback with people unable to access their GP in a timely manner on a consistent basis.</p> <p>We have also heard from patients who attribute late referral for diagnosis of cancer due to a lack of continuity in care from their GP practice <i>"I knew something was wrong and said so but wasn't listened to and each doctor that I spoke to was different and wouldn't read the history of my calls and would see each call as a separate one because it was a different doctor"</i> <i>"He had raised concerns multiple times about his health but said he was never taken seriously. He went again and was seen by a student doctor who said she was unhappy with the way he had been treated and ordered further tests. He was then diagnosed with cancer."</i></p> <p>We would like to see further work to allow all patients with suspected cancer symptoms to access their GP in a timely manner and for their concerns to be addressed.</p> |
| 2 | Question 1 | <p>We would like to see a clearer mechanism ascribed to assessing cases where these quality standards are not met, or not able to be met, by local providers and commissioners. It is only through close examinations of these cases, the demographics of the people involved, and examination of any barriers people faced, that further quality improvements are able to be made. We feel this key area of a full assessment when standards are not met needs to be included.</p> |
| 3 | Question 2 | <p>Whilst we are unable to comment on the specifics of data collection locally for the quality measures, we would like to see that that all data is triangulated with patient feedback. This is needed to ensure that the</p> |

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| | | quality measures are having the desired affect on people's experiences of diagnosis of suspected cancer, regardless of quantitative measures. This is particularly important in the case of several of these quality standards, where assessing if the standard is met in full needs feedback from people experiencing these pathways. |
| 4 | Question 3 | No comment |
| 5 | Question 4 | Healthwatch Birmingham would like to see meaningful ongoing patient engagement with patients who have been offered safety netting. This would allow providers and commissioners to continual assess and improve the information given to patients and ensure that all patients fully understand when to return for re-evaluation. This should be driven be a national directive, but engagement and analysis need to be done at a local level to ensure providers are catering for their local populations best. Providers and commissioners should fully utilise existing networks to gather feedback and conduct engagement (such as community organisations or the Healthwatch network) but should also be using up to date demographic information for their local area to ensure they are forming new ways engaging with populations where needed. Those provided with written safety netting information should also be provided with a point of contact or signposting, if they need to discuss their condition further, or help understanding the information given. |
| 6 | Question 5 | <p>A challenge for implementation for these quality standards is for patients and the public to understand how these quality measure's function, and changes from any previous ways of working. This can be achieved with engagement with the public on both local and national levels to ensure clear communication of what they can expect.</p> <p>As stated above we are concerned about patients being able to access primary care in a timely manner when experiencing concerning symptoms. We feel further work is needed in this area to allow all patients to see a GP when experiencing concerning symptoms in a timely manner.</p> |
| 7 | Statement 1 | <p>Healthwatch Birmingham are pleased to see the commitment to personalised information and support at all stages of the diagnostic pathway. We would like to see further commitment by providers to continuously develop the information provided through co-production and engagement with people in receipt of the information to ensure it is understandable and meets their needs.</p> <p>Information should also inform people about their rights to choose as part of the diagnostic pathway and any implications choices might have.</p> <p>We have continuously heard from people in Birmingham with sensory difficulties affecting language, problems with getting consistent information and support at appointments when they require</p> |

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| | | <p>interpretation. We are pleased to see the mention of additional support including the use of interpreters in the quality standard.</p> <p>Healthwatch Birmingham and Healthwatch Solihull sought to understand people's experiences of using NHS prostate cancer services in Birmingham and Solihull by listening to their views of using screening services, care and treatment, and support services. We also sought to identify and understand barriers or challenges faced when using these services. Our full report can be found here: Experiences of the NHS prostate cancer pathway in Birmingham and Solihull. As part of this report, we heard how there was a lack of care and information during the diagnostic pathway.</p> <p><i>"The GP service was more or less non-existent, but once I was in the 'hands' of the Birmingham-Solihull Hospital system I was treated superbly."</i></p> <p><i>"Initial appointment at the doctor was not very helpful- no examination and only given phone number to arrange appointment for the PSA test."</i></p> <p><i>"A letter arrived detailing an appointment with a prostate oncologist, but other than this there was no communication, no offer of support, no communication about what might happen. Had I not researched things myself, I would have been completely in the dark, sitting for two weeks knowing nothing and fearing the worst. After I had an appointment with the oncologist, life was more certain, as he was extremely professional, explained likely outcomes, what probable treatments I would undergo, and set the process of scans in train."</i></p> <p><i>"The doctor and nurse were kind, but the process was about information sharing about the cancer, treatment and support. It didn't take into account the fact that after you hear the word cancer, you can't really hear anything else. It all becomes blah, blah, blah."</i></p> |
| 8 | Statement 2 | <p>Healthwatch Birmingham are pleased to see this issue being addressed, as it can lead to inequalities in people's previous experiences.</p> <p>We would like to see further clarity for people if they are switched pathway during the diagnostic process, so they know what to expect.</p> |
| 9 | Statement 3 | <p>We are pleased to see this option further developed for people to access diagnostics. However much more clarity needs to be given on timescales to expect if people do not meet the urgent referral criteria. It also needs to be clear on how results will be communicated with people following these tests. As we have</p> |

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| | | described above people are facing difficulties accessing their GP services and would have problems following up on results in some instances unless they are contacted directly. |
| 10 | Statement 4 | Healthwatch Birmingham would like to see measures in place to ensure patients are receiving parity as part of this pathway where possible. People would also like to be reassured that there is an ability to act more swiftly when needed, even within the 28 days. We are concerned about delays people currently have accessing GP services before this process is measured may also increase their risks of mortality and morbidity. |
| 11 | Statement 5 | We are pleased to see the need for clear information highlighted in this quality measure, especially for information to meet the accessible information standard. Clear communications about what symptoms people should approach their GP about is always needed. |
| 12 | Statement 6 | Healthwatch Birmingham would like to see further awareness and communication with the public about symptoms for women to look out for and report to their GP, especially given the generalised nature of some of these symptoms. If patients know more about this quality standard, they can advocate for their own care. |
| 13 | Statement 7 | We would like to see clear guidance about moving patients to another diagnostic pathway if ovarian cancer is ruled out, to ensure any other conditions that result in raised CA125 (such as Endometriosis) are also diagnosed in a prompt fashion. |

Insert more rows as needed

Checklist for submitting comments

- Use this form and submit it as a Word document (not a PDF).
- Complete the disclosure about links with, or funding from, the tobacco industry.
- Combine all comments from your organisation into 1 response. We cannot accept more than 1 response from each organisation.
- Do not paste other tables into this table – type directly into the table.
- **Clearly mark any confidential information or other material that you do not wish to be made public. Also, ensure you state in your email to NICE that your submission includes confidential comments.**
- Do not include medical information about yourself or another person from which you or the person could be identified.
- Spell out any abbreviations you use

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