NICE National Institute for Health and Care Excellence

Quality standards advisory committee 1

Physical health of people in prisons – post-consultation

Parkinson's disease – prioritisation

Minutes of the meeting held on 1 June 2017 at the NICE offices in Manchester

Attendees	**Quality standards advisory committee (QSAC) standing members** Bee Wee (chair), Gita Bhutani, Tim Fielding, Phillip Dick, Hazel Trender, Teresa Middleton, Ian Reekie, Sunil Gupta, Tessa Lewis, Rhian Last, John Jolly, Ruth Halliday, Simon Baudouin, Lauren Aylott, Zoe Goodacre. **Specialist committee members** Physical health of people in prisons: Suzy Dymond-White, Sophie Strachan, Jane De Burgh, Denise Farmer, Jake Hard Parkinson's disease: Ivan Benett, Paul Cooper, Richard Grunewald, Jane Little, Matthew Sullivan, Lynne Osborne, Fiona Lindop, Richard Walker **NICE staff** Nick Baillie, Eileen Taylor (Items 1-10), Craig Grime (Items 1-10), Melanie Carr (Items 11-17), Shaun Rowark (Items 11-17), Esther Clifford **NICE observers** Leslie Hayes (Items 11-12)
Apologies	**Quality standards advisory committee (QSAC) standing members** Nicola Hobbs, Hugo Van Woerden, Alyson Whitmarsh, Ruth Bell

Agenda item	Discussions and decisions	Actions
1. Welcome, introductions and plan for the day	The Chair welcomed the attendees and the quality standards advisory committee (QSAC) members introduced themselves. The Chair informed the committee of the apologies and reviewed the agenda for the day.	
2. Welcome	The Chair explained that there were no public observers joining the morning session of the committee meeting.	
3. Committee	**Declarations of interest**	

Agenda item	Discussions and decisions	Actions
business	The Chair 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. The Chair asked the specialist committee members to declare all interests. The following interests were declared: **Standing committee members** John Jolly • Head of London Joint Working Group on Hepatitis C and Substance Misuse Tessa Lewis • Chair of NG46 Controlled drugs: safe use and management Lauren Aylott • Involved in research project relating to serious mental illness in adults **Specialist committee members** Sophie Strachan • Trustee of The Sophia Forum • Lay member of NHS England Clinical Reference group Health & Justice • Member of steering group for the health and wellbeing of transgender people Denise Farmer • Employed by NHS England as national pharmaceutical adviser Jake Hard • Leading procurement of new clinical IT systems for prisons • Chair of the Royal College of GPs Secure Environments Group • Involved in the Health and Justice Clinical Reference Group Jane De Burgh • Is the Lead for Prisons in London Suzy Dymond-White • Member of Health and Wellbeing Board for Women's Prisons	

Agenda item	Discussions and decisions	Actions
	Minutes from the last meeting The committee reviewed the minutes of the last meeting held on 4 May 2017 and confirmed them as an accurate record.	
4. QSAC updates	There were no updates from the NICE team.	
5.1 Recap of prioritisation exercise	ET and CG presented a recap of the areas for quality improvement discussed at the first QSAC meeting for physical health of people in prisons: **At the first QSAC meeting on 2 February 2017 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:** • Second stage health assessments • Medicines reconciliation before second stage health assessment • STI risk assessment and BBV testing • Provision of medication or an FP10 prescription • Lead care coordinator for people with complex health and social care needs The full rationale for these decisions is available in the prioritisation meeting minutes which can be found here: https://www.nice.org.uk/guidance/gid-qs10045/documents/minutes.	
5.2 and 5.3 Presentation and discussion of stakeholder feedback and key themes/issues raised	ET and CG presented the committee with a report summarising consultation comments received on the physical health of people in prisons. 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 • Request to broaden statements out of scope • Inclusion of overarching thresholds or targets	

Agenda item	Discussions and decisions	Actions
	• 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 ET summarised the significant themes from the stakeholder comments received: • Quality standard overall well received • General feedback was that the appropriate areas for quality improvement had been identified • Statements focus on first few days in prison • Distinguish between types of prison establishment • Include pregnancy and pharmacy technicians in the quality statement • Most of the measures generally felt to be feasible • Prison service funding cuts • Understaffed prison healthcare departments	
5.4 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 statement 1	Themes raised by stakeholders	Committee rationale	Statement revised (Y/N)
People entering prison have a medicines reconciliation carried out before their second-stage health assessment.	• Agreement with statement • Some medication will need to be given sooner • Some institutions carry out the second stage assessment within 72 hours • Include pharmacy staff in audience descriptors • Equalities issues • Data collection	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: • Population to cover people entering prison for first time and those transferring between prisons • Inclusion of pharmacy staff in audience descriptors • Inclusion of advocacy in equalities section • Alignment with other quality standards focusing on medicines reconciliation	**Y**

		• Whether undertaking the second stage assessment prior to a medicines reconciliation is an appropriate action that should be reflected. The committee agreed that prescription of critical medications is a vital component of care. However it should be addressed at the first stage health assessment and whenever clinical need arises. It therefore does not need to be reflected in this statement.	
Draft statement 2	**Themes raised by stakeholders**	**Committee rationale**	**Statement revised (Y/N)**
People entering prison have a second-stage health assessment within 7 days.	• Agreement with statement • Different timescales for assessment suggested • Clarity that statement applies to transfer and first reception • Include weight management and vaccinations in the rationale • Additions to the assessment • Equalities issues • Additional outcomes • Data collection	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: • Population to cover people entering prison for first time and those transferring between prisons • Include issues relating to an ageing population in the equalities section	**Y**
Draft statement 3	**Themes raised by stakeholders**	**Committee rationale**	**Statement revised (Y/N)**
People entering prison are offered blood-borne virus testing and assessment for risk of sexually transmitted infections.	• Agreement with statement • Clarity that people transferring between prisons are included • People receiving several short sentences would be tested frequently • Address blood-borne virus (BBV) testing and STI assessment separately • BBV definition	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: • Population to cover people entering prison for first time and those transferring between prisons • Include reference to the BBV opt-out testing programme	**Y**

	• Additional measures • Data collection • Consultation question: should measurement of performance against this statement focus on the second-stage health assessment?	which has completed phase 2 evaluation. The committee agreed that this was still a quality improvement area as the programme is a recent development. • In relation to the question asked at consultation the committee agreed that the denominator be amended to reference the second stage health assessment.	
Draft statement 4	**Themes raised by stakeholders**	**Committee rationale**	**Statement revised (Y/N)**
People in prison who have complex health and social care needs have a lead care coordinator.	• Agreement with statement • Support is already in place • Definition of 'complex health and social care needs' • Clarification of staff groups • Data collection • Consultation question: should this statement focus on a specific subpopulation of people in prison who have complex health and social care needs? If so, what should this population be?	The committee discussed the statement and stakeholder comments and agreed that though the statement was broad, practice was currently varied and therefore was an area for quality improvement. This was especially the case for people who had more than one condition, and therefore coordination was required with multiple teams/agencies. The committee agreed that as there was support for the statement from stakeholders it should be progressed for inclusion in the final quality standard and the following issues explored by the NICE team: • Removing mental health from the definitions • Focusing on the population who had more than one condition, using the definition of multimorbidity from the NICE guideline and quality standard.	**N**
Draft statement 5	**Themes raised by stakeholders**	**Committee rationale**	**Statement revised (Y/N)**
People being transferred or discharged from prison are given a minimum of 7 days' prescribed medicines or an FP10	• Agreement with statement • Difficulties obtaining medication shortly after release • FP10 for people with substance misuse may be dangerous • On transfer, some medications may not be permitted in the next prison	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: • Focusing the denominator on people with a current prescription.	**N**

prescription.	• Data collection		

Additional statements suggested	Committee rationale	Statement progressed (Y/N)
Robust pathways for people diagnosed with a BBV	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**
'In-reach' treatment provision for people with hepatitis C and commencement of treatment within eight weeks	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**
Provision of take home naloxone kits and referral to drug counselling services on transfer or discharge	The committee agreed that this area was out of the scope of this quality standard.	**N**
First-stage health assessments	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**
Promoting health and wellbeing	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**
Continuity of healthcare	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**
TB screening	The committee agreed that this was not a priority in relation to the five quality improvement areas already agreed for inclusion in the final quality standard.	**N**

6. Resource impact	The committee considered the statements in the final quality standard achievable by local services given the net resources required to deliver them.	
7. Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on physical health of people in prisons. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
8. Equality and diversity	The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the committee to consider any relevant issues. The committee agreed the following groups should be included: the traveller population, which was included in a recent Prisons and	

	Probation Ombusdman bulletin; those whose first language is not English; the transgender population, in relation to access to hormone treatment; and those with substance misuse issues. It was agreed that the committee would continue to contribute suggestions as the quality standard was developed.	
9. Next steps and timescales	ET outlined what will happen following the meeting and key dates for the physical health of people in prisons quality standard.	
10. Close of morning session	BW thanked the physical health of people in prisons specialist committee members for their input into the development of the quality standard.	
The specialist committee members for the physical health of people in prisons quality standard left and the specialist committee members for the Parkinson's disease quality standard joined.		
11. Welcome	The Chair explained that as the underpinning guideline which will be used as the development source for the quality standard is not yet published the afternoon session would be held as a closed meeting and therefore there would be no public observers.	
12. Committee business	**Declarations of interest** The Chair 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. The Chair asked the specialist committee members to declare all interests. The following interests were declared: **Standing committee members** Bee Wee • Is NHS England National Clinical Director for end of life care • Working with the Right Care Programme team to publish a case-study of a person with Parkinson's disease throughout the trajectory to the end of life • Highlighted that the committee vice-chair has been briefed to take over chairing of the committee if required at any point during discussions. **Specialist committee members** Fiona Lindop • Sits on National Parkinson's UK Excellence Network Group for Service Development (representing physiotherapy); National Oversight Board (representing allied health professionals); and Parkinson's UK Steering Group for the National Parkinson's UK Audit of NICE Guidelines for Physiotherapy • Brother-in-law owns a business called Attainability UK which is the only UK company marketing walking aids that are specifically designed for people with Parkinson's and similar neurological	

	conditions (the USTEP walker and the laser cane). No financial (or otherwise) interest in the business. • In September 2016, UCB pharmaceutical company granted funding of registration fee to attend the World Parkinson's Congress in Portland, Oregon, USA. • Recently awarded free place to attend Positive Steps Conference, held at Hinkley Island Jurys Hotel on 3 and 4 March. This was organised by Parkinson's UK and Bamboo. • Co-led a day-long conference on Parkinson's disease for Association of Physiotherapists in with an Interest in Neurology (AGILE) regional group, held in Llaneli, Wales and received a fee of £250 for running the course. • Co-led day-long conference on Parkinson's disease for a group of physiotherapists in the Manchester region in March 2017, paid £250 for running the course, along with travel expenses. • Member of the NICE Parkinson's disease clinical guideline Jane Little • Member of the NICE Parkinson's disease guideline committee Richard Walker: • Withdrew previously declared membership of BIAL Advisory Board as no longer involved. • Member of the NICE Parkinson's disease guideline committee Richard Grunewald • Member of the NICE Parkinson's disease guideline committee Lynne Osborne • Facilitates Parkinson's disease nurse specialist group funded by a pharmaceutical company. • Member of the NICE Parkinson's disease guideline committee Matthew Sullivan: • Works with Parkinson's UK on a voluntary basis advocating and facilitating patient involvement by researchers. • Working academic on projects at Manchester Metropolitan University relating to movement in people with Parkinson's disease funded by the Greater Manchester Academic Health Sciences Network. • Member of the NICE Parkinson's disease guideline committee Paul Cooper: • Chair of the NICE Parkinson's disease guideline committee • Specialist clinical adviser to NICE	

	• In 2014 received support from Britannia Pharmaceutics to attend the European Federation of Neurological Societies • In 2016 received support from Bial Pharmaceutics to attend the American Epilepsy Society Meeting • He and wife have modest shareholdings in a range of pharmaceutical companies, held within ISA funds, and managed on their behalf, without their involvement in any investment decisions • All support was within Association of British Pharmaceutical Industry guidelines, and was declared under the NICE declaration of interest's policy. • Currently Principal Investigator for a trial of a novel agent for cataplexy, funded by Jazz Pharmaceuticals, and Co-Investigator for a trial of a treatment for super refractory status epilepticus, funded by Sage Therapeutics. • Joint supervisor for a doctoral student at Manchester Heart Centre funded by Medtronic; • Receives no personal financial benefit for any of these roles. Ivan Benett • Member of the NICE Parkinson's disease guideline committee	
12.1 and 12.2 Summary of topic engagement responses	MC presented the topic overview and a summary of responses received during engagement on the topic.	
12.3 Prioritisation of quality improvement areas	BW and MC led a discussion in which areas for quality improvement were prioritised. The QSAC considered the draft areas as outlined in the briefing paper prepared by the NICE team. The outcome of discussions is detailed below.	

Suggested quality improvement area	Prioritised (yes/no)	Rationale for prioritisation decision	If prioritised, which specific areas to be included?
Referral to a specialist	No	The committee discussed the comments received at topic engagement relating to quick referral to a specialist from general practice. The committee discussed how timeliness of referral to a specialist would be defined and measured, given that the timescales have been removed from the updated guideline and how a statement in this area would impact on current neurological practice. There was agreement	**No action**

		from the committee that this referral is happening in current practice and therefore wasn't a priority area for quality improvement. The committee therefore agreed not to prioritise this area.	
Specialist support and care management	Yes	The committee discussed the comments received at topic engagement relating to variability in accessing a Parkinson's disease specialist nurse, having access to a multidisciplinary team (MDT), having a care plan that empowers and maintains independence for people with Parkinson's disease, and having regular reviews. The committee agreed that the Parkinson's disease specialist nurse is an important point of contact and also oversees the plan of care for the person with Parkinson's disease. The committee discussed whether people have access to MDTs and whether having a recorded care plan can ensure that this happens. It was agreed that an MDT should be available, however there are difficulties in defining the composition of an MDT. It was agreed that nationally a care plan will vary and therefore it would not be appropriate as a quality improvement area. The committee agreed that while regular reviews should take place, when they happen will depend on the person with Parkinson's disease. Trying to set a standard on when reviews take place could adversely affect the quality of care. The committee agreed that access to an MDT and having a key contact are the most important areas for quality improvement and therefore should be progressed for inclusion in the draft quality standard.	**Key contact** **Access to a multidisciplinary team**
Identifying symptoms and complications	Yes	The committee discussed the comments received at topic engagement relating to the need to use standardised assessment tools at reviews and to increase awareness of impulse control disorders (particularly when medications may have been started or changed). The committee agreed that impulse control disorders is an important and often overlooked area. The committee agreed that information should be provided on impulse control disorders when people start	**Impulse control disorders**

		treatment for Parkinson's disease, and progressed this area for inclusion in the draft quality standard.	
Treatment for symptoms	Yes	The committee discussed the comments received at topic engagement relating to pharmacological management for drooling of saliva, Parkinson's dementia and psychotic symptoms, specifically the need for improved access to clozapine, and the limited access available to deep brain stimulation for management of advanced Parkinson's disease. The committee discussed that Clozaril requires specialist prescribing and monitoring and as a result people with Parkinson's disease may be referred to mental health services for treatment. This can lead to them being managed differently for example in the same way as a person with schizophrenia, receiving alternative antipsychotics which may adversely affect the person's motor control. The committee acknowledged the potential adverse effects and that monitoring of clozapine may have a cost impact but agreed it was acceptable in comparison with the cost of nursing home care for a person with Parkinson's disease whose dependency had increased. The committee agreed that this was an important area for quality improvement and progressed it for inclusion in the draft quality standard. The committee agreed that as the guideline recommendations on deep brain stimulation were 'do not do' and 'consider' recommendations and as this would be difficult for development as a quality statement agreed not to progress for inclusion in the draft quality standard.	**Access to clozapine**
Medicines management in hospital	Yes	The committee discussed the comments received at topic engagement relating to the need to improve medication management for people with Parkinson's disease admitted to hospital as there can be serious consequences if a patient cannot take their medication on time or if they are stopped. The committee acknowledged that a statement in this area could prove	**Timing of medications in hospital**

		complex to measure but agreed it could be audited. The committee agreed that this was a quality issue for people with Parkinson's disease as medication is time-critical and the effects of missing a dose by even a short time can have a very significant impact and be difficult to correct. The committee agreed that this was an important area for quality improvement and therefore progressed it for inclusion in the draft quality standard.	
Information and support	No	The committee discussed the comments received at topic engagement relating to long term therapeutic options and disease management both at diagnosis and as the disease progresses, to support self-management and informed decision making. The committee acknowledged NICE QS15 patient experience in adult NHS services and agreed it was important not to duplicate the issues covered by these quality statements. The committee discussed the importance of carers being aware of the care pathway and the potential ways in which the disease might progress and acknowledged that carers can often be left out during consultations due to the focus on disease management. The committee agreed that this was an important area for quality improvement but agreed that it can be covered by the statement on impulse control disorders.	**No action**

13. Additional areas suggested	**Committee rationale**	**Area progressed (Y/N)**
Planning for end of life	This committee agreed that it is difficult to provide an accurate prognosis for people with Parkinson's disease and this is reflected in the guideline. End of life care is also covered by QS13 end of life care for adults.	**N**
Employment support	The committee agreed that this cannot be progressed because there are no recommendations available for development into a quality statement.	**N**
Data collection	The committee agreed that this will be covered overall by the development and	**N**

	publication of the quality standard.	
NHS Continuing Healthcare service	The committee agreed that this is beyond the scope of the quality standard.	**N**

14. Resource impact	The committee considered that resource impact assessment for the updated guideline suggested that the costs of implementing the guideline would not be significant and were satisfied that none of the areas prioritised for statement development would have a significant impact on resources.	
15. Overarching outcomes	The NICE team explained that the quality standard would describe overarching outcomes that could be improved by implementing a quality standard on Parkinson's disease. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
16. Equality and diversity	The NICE team explained that equality and diversity considerations should inform the development of the quality standard, and asked the committee to consider any relevant issues. It was agreed that the committee would contribute suggestions as the quality standard was developed.	
17. Any other business	No items of AOB were raised: BW thanked the attendees for their input and closed the meeting. **Date of next meeting for Parkinson's disease: 2 November 2017** **Date of next QSAC1 meeting: 6 July 2017**	