

**Quality Standards Care of people with dementia TEG 1 Day 1**

**Minutes of the meeting held on Monday 30<sup>th</sup> January 2012 at the NICE offices in Manchester**

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| <b>Attendees</b> | <p><b><u>Topic Expert Group (TEG) members</u></b><br/>         David Croisdale-Appleby [chair] (DCA), Alisoun Milne (AM), Allison Cowley (AC), Gill Boston (GB), Graham Stokes (GS), Jakki Cowley (JCo), James Cross (JCr), Jane McKeown (JM), Jennifer Wenborn (JW), Ken Clasper (KC), Mary Moss (MM), Sandy Caley (SCa), Sharon Blackburn (SB), Simon Williams (SW), Victoria Metcalfe (VM), Wendy Neil (WN)</p> <p><b><u>NICE Staff</u></b><br/>         Barbara Meredith (BM), Brian Bennett (BB), Craig Grime (CG), Daniel Sutcliffe (DS), Katie Williamson (KW), Lorraine Taylor (LT), Nick Staples (NS)</p> <p><b><u>Expert advisors to the TEG</u></b><br/>         Sarah Carr (SCr), Senior Research Analyst, Social Care Institute for Excellence</p> <p><b><u>Observers</u></b><br/>         Beth Shaw (NICE)<br/>         Carolyn Denne, Head of Service Quality, Social Care Institute for Excellence<br/>         Janice Clasper</p> |
| <b>Apologies</b> | <p><b><u>TEG members</u></b><br/>         Tim Sanders<br/>         Catherine Pascoe</p>  |

| Agenda item  | Discussions and decisions   | Actions  |
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| <p><b>1. Welcome, introductions and plan for the day</b></p> <ul style="list-style-type: none"> <li>• <b>Composition of the group</b></li> </ul>   | <p>DCA welcomed the attendees and reviewed the agenda for the day.</p> <p>DCA noted that it had been decided to invite an external speaker to present on the wider policy context for the topic at the next meeting.</p> <p>DCA outlined the recruitment process and composition of the group and noted that a GP would join the TEG at the next meeting.</p> |  |
| <p><b>2. Quality standards overview &amp; work to date on social care</b></p>  | <p>LT presented an overview of the quality standards programme and NICE's work to date on social care.</p> <p>The group raised queries on the status of the work programme, including its interaction with inspection frameworks and the status of guidance. The NICE team responded to these points.</p>   |  |
| <p><b>3. Overview of roles and responsibilities</b></p> <ul style="list-style-type: none"> <li>• <b>Topic Expert Group</b></li> <li>• <b>QS technical and support teams</b></li> <li>• <b>Other teams</b></li> <li>• <b>Confidentiality</b></li> </ul> | <p>DCA and LT presented an overview of roles and responsibilities of different participants in the quality standards process.</p> <p>The group raised queries and suggestions on implementation and dissemination of the quality standards. The NICE team noted these queries and suggestions to take to the Programme Board.</p>                             | <p><b>Action 1: NICE team to raise TEG dissemination and implementation suggestions and queries with Social Care Programme Board</b></p> |
| <p><b>4. Patient and Public Involvement Programme (PPIP) presentation</b></p>  | <p>BM presented an overview of the role of the Patient and Public Involvement Programme and the importance of involving service users in the development of quality standards.</p>  |  |

| Agenda item  | Discussions and decisions   | Actions |
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| <b>5. Media and Communications presentation</b>                                  | <p>KW presented an overview on the role of the press lead.</p> <p>The group raised queries on different media outlets and press queries. KW provided feedback on these points.</p>  |         |
| <b>6. Overview of the methods and processes for developing quality standards</b> | <p>DS outlined the methodology and process used to develop social care quality standards.</p> <p>The group raised queries on engagement with the sector and representation of different groups. The NICE team outlined the stakeholder engagement and field testing processes.</p>                |         |
| <b>7. Example of a quality standard</b>  | <p>CG presented an example quality standard.</p> <p>The group raised queries on process, use of outcomes, considering different groups and overlaps with existing quality standards. The NICE team responded to this comments.</p>  |         |
| <b>8. Drafting quality statements exercise</b>                                   | <p>CG, DS and BB led an exercise with TEG members to draft quality statements from guideline recommendations.</p> <p>The group raised queries on different versions of quality statements for different audiences. The NICE team provided details of alternative versions currently produced.</p> |         |
| <b>9. Summary of the day and plan for tomorrow</b>                               | <p>DCA provided a summary of the day and asked for any further comments or questions. Members were provided with copies of the declarations of interest policy and asked to consider this ahead of the next day's meeting.</p>  |         |

**Quality Standards Care of people with dementia TEG 1 Day 2**

**Minutes of the meeting held on Tuesday 31<sup>st</sup> January 2012 at the NICE offices in Manchester**

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| <b>Attendees</b> | <p><b><u>Topic Expert Group (TEG) members</u></b><br/>         David Croisdale-Appleby [chair] (DCA), Alisoun Milne (AM), Allison Cowley (AC), Gill Boston (GB), Graham Stokes (GS), Jakki Cowley (JCo), James Cross (JCr), Jane McKeown (JM), Jennifer Wenborn (JW), Ken Clasper (KC), Mary Moss (MM), Sandy Caley (SCa), Sharon Blackburn (SB), Simon Williams (SW), Victoria Metcalfe (VM), Wendy Neil (WN)</p> <p><b><u>NICE Staff</u></b><br/>         Brian Bennett (BB), Craig Grime (CG), Daniel Sutcliffe (DS), Lorraine Taylor (LT), Nick Staples (NS)</p> <p><b><u>Expert advisors to the TEG</u></b><br/>         Sarah Carr (SCr), Senior Research Analyst, Social Care Institute for Excellence</p> <p><b><u>Observers</u></b><br/>         Andy McAllister (NICE)<br/>         Carolyn Denne, Head of Service Quality, Social Care Institute for Excellence<br/>         Janice Clasper</p> |
| <b>Apologies</b> | <p><b><u>TEG members</u></b><br/>         Tim Sanders<br/>         Catherine Pascoe</p>  |

| Agenda item                                 | Discussions and decisions  | Actions |
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| <p><b>1. Recap and plan for the day</b></p> | <p>DCA welcomed the group and provided a recap of the previous day.</p>  |         |
| <p><b>2. Declarations of interest</b></p>   | <p>DCA asked the group to declare any new interests since appointment to the TEG. The following members declared interests:</p> <p>AM: Member of the standing commission on carers. Has written publications on care homes, dementia care.</p> <p>JM: Has published some articles on use of life story work for dementia care.</p> <p>JF: Has published articles on dementia care</p> <p>GS: Has published articles on the value of managed care</p> <p>AC: Owns a care home and is director of two care associations.</p> <p>SW: Is a member of the Association of Directors of Adult Social Services and has given evidence to All Party Parliamentary Groups. Partner is executive director on board of a NHS Foundation Trust.</p> <p>MM: Is a carer representative on Trafford Care panel.</p> <p>SCa: Is a trustee of the National Development Team for Inclusion and is on the National Survivors and Users Network. Has published papers on risk enablement.</p> <p>All other members confirmed that they had no new interests to declare.</p> |         |

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| <p><b>3. Scoping session</b><br/> <b>• Map of care</b></p> | <p>CG presented the Topic Overview including proposed parameters and areas of importance for the draft Dementia scope .</p> <p>The TEG suggested the following amendments be made to the proposed parameters for the draft Dementia scope:</p> <ul style="list-style-type: none"> <li>• Do not exclude secondary and tertiary NHS care from the scope, rather exclude the medical interventions that would be provided by these services.</li> <li>• Include those with suspected dementia in the focus of the scope.</li> <li>• Ensure the word ‘carer’ is clearly and precisely defined</li> <li>• Include those not receiving formal social care support in the population</li> <li>• Refine the example settings given</li> </ul> <p>The group raised queries on the healthcare quality standards process, integration of the two dementia quality standards, how queries outside of the scope of the TEG would be handled and how gaps in the evidence base would be dealt with. The NICE team provided responses to these queries.</p> <p>The TEG discussed the contextual framework of the Department of Health’s Quality Outcomes for people with dementia. The TEG agreed that this framework was a useful starting point to identify areas of importance for inclusion in the scope. The following were considered as potential areas for inclusion in the scope of the quality standard:</p> <ul style="list-style-type: none"> <li>• Taking concerns seriously – including requests for second opinion</li> <li>• Pre “formal diagnosis” stage, triggers, identification, understanding signs</li> <li>• Under 65 diagnosis and care</li> <li>• Sharing information with relatives/family/friends/carers</li> <li>• Opportunities to discuss and be given information on possibilities, risks, consequences of treatment and the possibility to revisit this.</li> <li>• Assessment – shared decision, changing condition, dynamic, consequence based.</li> <li>• Continuity of assessment</li> <li>• Outcomes, options of assessment</li> </ul> | <p><b>Action 2: NICE team to provide details of all published quality statements to the TEG when sending the briefing paper for TEG 2.</b></p> |
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|  | <ul style="list-style-type: none"> <li>• Proactive approach to support “acute points” in care such as changes in condition and carer and/or carer needs.</li> <li>• Respect and dignity – de-stigmatise, support from professionals</li> <li>• Self management – prolonging capabilities</li> <li>• Access to advocacy</li> <li>• Deprivation of liberty vs. safety</li> <li>• Safeguarding</li> <li>• Relationship centred care</li> <li>• I can enjoy life – active involvement, participation, new activities, identification and realisation of potential</li> <li>• Community involvement, and being an asset to one’s community</li> <li>• Participation in relevant research</li> <li>• End of life care – bring forward end-of-life planning because of the degenerative nature of dementia condition, - it is hard to predict the exact end of life date, dealing with resistance to pre-prepared choices.</li> <li>• Location of end of life care – training, support.</li> <li>• Usual vs. unusual behaviour – including end of life and changes in needs.</li> <li>• All aspects of health and wellbeing of the person with dementia</li> <li>• People with learning disabilities and dementia</li> <li>• People with other comorbidities</li> <li>• Influence of the built environment and other design considerations</li> <li>• BME communities, assessment and screening.</li> <li>• Accessibility – hard to reach groups</li> <li>• Accessibility - those becoming invisible due to their dementia condition.</li> <li>• Relationships and intimacy</li> <li>• Workforce planning – what do we want the future workforce to look like.</li> <li>• Workforce capacity - staff training and numbers and types of staff</li> <li>• Self-funders</li> <li>• H&amp;W Boards/joint strategic assessments and other functional considerations</li> <li>• Compassion and kindness</li> </ul> |  |
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|  | <ul style="list-style-type: none"> <li>• Physical health &amp; health promotion</li> <li>• Human rights and perception/understanding of rights, Mental Capacity Act</li> <li>• Integration of health and social care</li> </ul> <p>The group identified the following additional SCIE and NICE evidence sources which could usefully be considered:</p> <ul style="list-style-type: none"> <li>• SCIE guidance on Supporting carers</li> <li>• SCIE guidance on Learning disabilities</li> <li>• NICE CG on Service user experience in adult mental health services</li> <li>• NICE CG on Patient experience in adult NHS services</li> <li>• NICE QS on End of life care</li> <li>• SCIE guidance on Advocacy</li> <li>• NICE PHG on Physical Activity and the Built Environment</li> </ul> |                               |
| <b>4. Scoping session:</b><br><b>• Evidence sources, policy drivers and measures</b> | <p>The group discussed additional sources of information for policy background and measurement. The following sources were suggested:</p> <ul style="list-style-type: none"> <li>• APPG report on training of social carers 2009/10</li> <li>• Carers in the 21<sup>st</sup> century</li> <li>• Alzheimer's Society – Support, Stay, Save report (2010/11)</li> <li>• Assessing risk. Principles for risk assessment. KCL.</li> <li>• Royal College of Art – Betterhomes.org John Zeisel</li> </ul>  |                               |
| <b>5. Next steps</b><br><b>• TEG composition</b>                                     | <p>The group discussed whether any additional members needed to be considered for appointment to the group and/or as expert witnesses. The following were suggested:</p> <ul style="list-style-type: none"> <li>• Someone representing prisons</li> <li>• Someone representing the Care Quality Commission</li> <li>• Someone representing the BME community</li> </ul>  |                               |
| <b>6. Next steps</b>   | <p>DS and LT outlined the next steps in the development of the scope and quality standard.</p>   | <b>Action 3: NICE team to</b> |



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|               |  | <p>prepare draft scope based on TEG discussions and circulate for further comment.</p> <p><b>Action 4: TEG members to suggest potential stakeholders to NS</b></p> |
| <b>7. AOB</b> | DCA thanked the group and closed the meeting at 15.10. |  |