NICE Collaborating Centre for Social Care

Social care of older people with multiple long-term conditions
Guideline Development Group meeting 5
Wednesday 23rd July 2014, 10.30am – 4.00pm
SCIE Offices, Shared Meeting Space, 206 Marylebone Rd, London NW1 6AQ

Minutes

Guideline Development Group Members		
Name	Role	
Bernard Walker (BW)	GDG Chair	
Beth Britton (BB)	Carer	
Kevin Minier (KM)	Carer	
Ann MacFarlane (AM)	Service user	
Diana Robinson (DR)	Service user and carer	
Gillian Crosby (GC)	Researcher	
Deborah Read (DRe)	Social Worker	
Karin Tancock (KT)	Occupational Therapist	
Maggie Winchcombe (MW)	Occupational Therapist	
Chris Wood (CW)	Researcher	
Janet Reynolds (JR)	Social Worker	
Philippa Thompson (PT)	Home care provider	

The NCCSC is a collaboration led by SCIE











Other invitees					
Name	Role	Organisation			
Beth Anderson (BA)	Senior Lead	NCCSC (SCIE)			
Palida Teelucknavan (PTe)	Project Manager	NCCSC (SCIE)			
Naila Dracup (ND)	Information Specialist	NCCSC (SCIE)			
Deborah Rutter (DRu)	Lead Systematic Reviewer	NCCSC (SCIE)			
Isabel Quilter (IQ)	Research Assistant	NCCSC (SCIE)			
Kim Rutter (KR)	Dissemination and Adoption Lead	NCCSC (SCIE)			
Carol Vigurs (CV)	Systematic Reviewer	NCCSC (EPPI)			
Marija Trachtenberg (MT)	Economist	NCCSC (PSSRU)			
Nick Staples (NS)	Project Manager	NICE			

Apologies	
Name	Organisation
Kim Curry (resigned)	GDG member (Local authority manager)
Belinda Black	GDG member (Care home provider)
Jeremiah Kelleher	GDG member (Local authority manager)
Lelly Oboh	GDG member (Consultant Pharmacist)

No	Agenda Item	Minutes	Action/Owner
1.	Welcome and apologies	BW welcomed all attendees to the meeting and the apologies were noted as above.	
		The following members declared some additional interests:	
		BB is now a member for the following organisations: Health+Care, PHE, Care England and PHE MHDNIN Programme Board.	
		DR is currently doing some research work.	
		KT now works full time rather than part-time.	
2.	Minutes and matters arising	A correction was noted in the minutes on page 5 in relation to the Quality Standard on older people in care homes. NS clarified that this work was not in collaboration with the CQC. PTe to delete and amend.	Action 1: PTe to correct page 5 of the minutes.

		The GDG discussed the use of terms in relation to Action 5 and agreed that this would be covered by the Glossary that will be developed for the guideline. The GDG also requested for PTe to re-circulate the TLAP Jargon Buster. BW informed everyone that Kim Curry has resigned from the GDG. LO was unable to attend the current meeting and has circulated some useful papers. PTe will circulate these to the GDG. It was agreed that user perspectives will be a standing item in each meeting.	Action 2: PTe circulate TLAP Jargon Buster. Action 3: PTe to circulate info from LO.
3.	A perspective from users	AM presented two film clips from SCIE TV highlighting the importance of the needs of service users. The key themes from the films were then discussed.	
4.	Revisiting evidence: Assessment & planning of care & Social isolation	The evidence was revisited for Assessment and planning of care and Social isolation and additional evidence was presented to the GDG. a) Assessment & planning of care: • Proactive planning for services needs to start early. • Ensure that language is clear in the guideline especially for lay people e.g. 'proactive care' is preventative care planning. • Carer assessments are done by social workers which might not be appropriate. • Research is usually approved by the ethics committee and this could be a barrier for evidence. • Research evidence is skewed towards health rather than social care. • There is some good evidence on service user views from countries outside the UK and it was suggested that the search strategy should be broadened to include international literature. • Care co-ordinators are effective. Options to address gaps in the evidence: • Expert witnesses can be invited to meetings to provide more information on a particular topic. • Call for evidence with stakeholders – this is highly recommended. • Approach researchers who have published recent research as they might give us useful insights.	

		b) Social isolation: Peer support programme for people with dementia All older people should be able to live how they have always done despite their age. They just need to be given the correct tools to do so. There is evidence that personal budgets are good for people who live in care homes. Practice-based evidence is just as important as academic evidence. This would be more essential for social care. Need to consider this when we do a call for evidence. Dementia Action Alliance is a key organisation. 'Age-friendly society' is a WHO initiative. Areas where additional evidence could be valuable: Contribution of social care: Accessibility and usefulness of direct payment/support provided Outcomes-based personal budgets Rights-based approaches Proactive care/preventative care planning Social isolation in care home context The Review Team will do further work to explore the practicalities and NICE requirements of calls for evidence and will provide an update to the GDG.	Action 4: Review Team to consider how to obtain additional evidence on themes identified (call for evidence; expert witnesses) and to discuss the logistics further. To update the GDG at the next meeting.
6.	Review evidence for Carer support	The GDG reviewed the evidence for Carer support (Q3.2). Results showed that most studies were from the USA and little was found from the UK. Furthermore, none of the studies met the date criteria for inclusion nor were there any published after 2003. KM suggested that it would be worth looking at the evidence on carer assessment which might provide some useful insight for this review question.	Action 5: Review team to look at evidence on carer assessment.
5.	Economic modelling	The GDG reviewed the economic evidence for Assessment care planning and Service delivery frameworks which was discussed at GDG 4. In particular, the GDG reviewed the Glendinning (2008) study and agreed that it	

		would be more beneficial to look at more recent studies including US evidence. It was agreed that a call for evidence would be beneficial.	
6.	Writing recommendations	The GDG discussed the following areas for drafting recommendations: Social isolation Locality and continuity Community and activity Care homes in the community – there needs to be a sense of openness and community Holistic approach Different spaces to encourage interaction and activity Co-production Sign-posting to local services Older people have the choice to co-produce their package of care Integration and personalisation – services need to have one system in place and needs to be about the individual (person-centred care). The use of language and ensure that it is clear for all audiences (e.g. respite as 'holidays'). There is evidence around care co-ordinating services. Widening people's skills Re-visit risks. Everyone needs to be around the table to discuss that person's care.	Action 6: Review Team to refine the discussions into recommendations for social isolation.
7.	AOB	None.	

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Appendix A: Social care of older people with multiple long-term conditions Guideline Development Group: Register of interests

Name	Personal pecuniary interest	Personal family interest	Non-personal pecuniary interest	Personal non-pecuniary interest
Philippa Thompson	None	None	None	Member of the English steering committee of the Campaign for a Fair Society – campaigning for a fair approach to welfare provision for disabled people.
Ann McFarlane	None	None	Work for: Care Quality Commission on work commissioned by Age UK Trustee at SCIE. Ad hoc, usually one-day assignments, often for non-payment, only travel expenses, with NHS, DoH. At local level in Kingston upon Thames, Patron of Kingston Centre for Independent Living. Ex officio on Board, Healthwatch – Member, Kingston at Home. RBK Older Peoples' Reference Group member. People at Risk Group – interim Chair: service user group that reports to Kingston's Adult Safeguarding Partnership Board, Better Services Better Value: Member for South West Commissioning Group.	None

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Diana Robinson	Has a small shareholding in Reckitt Benckiser (yields less than £1,000 pa) PPI work - the following may pay expenses and/or honorariam for meetings, workshops or conference attendance; and for reviewing	Sister-in-law works for UCL in Credit Control Section	None	None
	research proposals. National Institute for Health Research. PGfAR funding panel (replaces RfPB panel, ended Sept '13) - from June 14. Occasional lay peer reviews. National Cancer			
	Research Institute. National Cancer Intelligence Network, NICE UK DUETs Steering Group. Health Research Authority, University of Leeds (IMPACCT study); Leeds Clinical Research Facility			
	Executive (from Feb 14); CQC; NHS England; Health Quality Improvement Partnership - Service User Network. Cancer Research UK (Research Coach from June 2014); Royal College			
	of Radiologists Academic Committee and Lay Network (from September 2014)			
Bernard Walker	Occasional consultancy work for local authorities and other bodies in the social care field. Associate Research in Practice for Adults Provide advice to HSA Global	None	Chair Adults Faculty. The College of Social Work	None
	(Health Care Consultancy) on integration of Local Government with NHS.			

Beth Britton	Freelance consultant on LD/Dementia and Ageing - MacIntyre. In the last 12 months: I have been part of events or done work for: UK Gov G8 Dementia Summit, NHS IQ (Commitment for Carers), NCPC (Dementia and EOL), Guideposts Trust (Dementia Awareness), Age UK Brent (Dementia and Ageing), Crossroads Care, Sensory Plus, Gracewell Healthcare, Swan Advocacy (Dementia and Advocacy), NHS/BMA 'Timely Diagnosis of Dementia', GB Care Shows, Care Show Bournemouth. Part of events or done work for: GE Healthcare, NHS Expo, CQC and RCPSY MSNAP (Memory Service Peer Review). Since my last DOI of 30/4/14, I have been part of events or done work for: Local Gov Digital Dept, Bucks New University, RCN, RCGP, Age UK and Carewatch. Health+Care, PHE, Care England.	None	None	Member of: Dementia Post Diagnosis Support Working Group (Dept of Health), Dementia Friends - Dementia Friends Champion, CQC - Member Adult Social Care Co-Production Group, DAA - Member of the DAA and support the CC2A, BRACE - Ambassador, Alzheimer's Society - Volunteer. Member of: PHE National Mental Health Intelligence Network Dementia Expert Reference Group. PHE MHDNIN Programme Board
Kevin Minier	None	None	None	None
Gillian Crosby	None	None	None	None
Belinda Black	None	None	None	None
Deborah Read	None	None	None	None

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Karin Tancock	Works part time (17.5 hours) for the College of Occupational Therapists as the Professional Affairs Officer for Older People. Responsibilities include: providing advice and information to members to support best practice and highlighting service innovation. Mapping and keeping up to date with national policy and legislation and communicating this to members through briefings and other protects. Coordinating responses to government consultations. Ensuring COT and member participation at key influencing events related to older people. Developing and maintaining professional networks with key organisations and government departments	None	None	None
Kim Curry	None	None	None	None
Jeremiah				
Kelleher	None	None	None	None
Lelly Oboh	None	None	None	None
Maggie				
Winchombe	None	None	None	None
Chris Wood	None	None	Works at Action on Hearing (formerly RNID) as a Senior Research and Policy Officer, and hence receive a salary from them. Action on Hearing Loss is a voluntary sector provider of care services and a campaigning organisation for people with hearing loss.	None
Janet Reynolds	None	None	None	None