Trans CA GDG 11 - Minutes of GDG 9 & 10

## NICE Collaborating Centre for Social Care

Transition from children's to adult services Guideline Committee meeting 9 Wednesday 29<sup>th</sup> April 2015 10.30am – 5.30pm SCIE Offices, Shared Meeting Space, 206 Marylebone Rd, London NW1 6AQ

## Minutes

Guideline Committee Members		
Name	Role	
Swaran Singh (SS)	GC Chair	
Theresa Culverwell (TC)	Carer	
Bryony Beresford (BB)	Topic Adviser	
Carrie Wilson (CW)	Care Leaver and Carer	
Debbie Kinsella (DK)	Transition Lead	
Eugenia Lee (EL)	Clinical Commissioner & GP	
Helena Gleeson (HG)	Consultant Endocrinologist	
Julie Turner (JT)	Social Worker	
Kathie Drinan (KD)	Physiotherapist	
Caroline Bennett (CB)	Transition Lead	
Clare Lamb (CL)	Child and Adolescent Psychiatrist	
Thines Ganeshamoorthy (TG)	Service User	

The NCCSC is a collaboration led by SCIE







research in practice research in practice for adults

Date of document: 22.06.15

Alun Williams (AW)	Paediatrician
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Name	Role	Organisation
Amanda Edwards (AE)	Director	NCCSC (SCIE)
Beth Anderson (BA)	Senior Lead	NCCSC (SCIE)
Palida Teelucknavan (PT)	Project Manager	NCCSC (SCIE)
Kristin Liabo (KL)	Lead Systematic Reviewer	NCCSC (EPPI)
Nadira Sharif (NS)	Systematic Reviewer	NCCSC (SCIE)
Marija Trachtenberg (MT)	Economist	NCCSC (PSSRU)
Isabel Quilter (IQ)	Research Assistant	NCCSC (SCIE)
Peter O'Neill (PO)	Technical Adviser	NICE
Sarah Richards (SR)	Economist	NICE
Jaimella Espley (JM)	Editor	NICE
Julie Pointer (JP)	Expert Witness	Preparing for Adulthood
Robert Carr (RC)	Expert Witness	Guy's & St Thomas' Hospital Foundation Trust
Luhanga Musumadi (LM)	Expert Witness	Guy's & St Thomas' Hospital Foundation Trust

Apologies		
Name	Role	
Amy Moore (AM)	Commissioner	
Charlotte Gatherer (GC)	Service user	
Philippa Williams (PW)	Carer	

No	Agenda Item	Minutes for NICE website	Action/Owner
1.	Welcome, introductions and potential conflicts of interest	<ul> <li>The Chair welcomed all attendees to the meeting. The aim of the next two days is to review all recommendations that have been drafted to date.</li> <li>The following committee members declared new interests:</li> <li>SS has joined the Research and Evaluation Board Advisory Committee for HEADSPACE. HEADSPACE is an Australian initiative led by Professors McGorry and Brewer. It is a health charity and was established for the purpose of promoting the improved health and mental health outcomes for young people in Australia, including through the funding of early intervention and prevention programs. SS will be joining about 4 teleconferences a year and there is a small remuneration for the role.</li> <li>SS is a member of a research and evaluation group evaluating Birmingham 0-25 mental health service.</li> <li>CW is standing as a local candidate for the council election in Doncaster for the Labour Party.</li> <li>KL will be leaving the NCCSC this coming July.</li> <li>CL is a member of NHS England CAMHS Transition group, speaker at the Royal College of Psychiatrists International Congress (July 2005) on youth mental health &amp; transition and also a member of the Research and Evaluation Group evaluating Birmingham 0-25 mental health &amp; transition and also a member of the Research and Evaluation Group evaluating Birmingham 0-25 mental health Service.</li> </ul>	Action 1: PT to update DOI records.
2.	Minutes and matters arising	<ul><li>The members reviewed the minutes from the last meeting which took place on the 26th March.</li><li>All other actions were completed and the committee members accepted the minutes as a true record of the meeting.</li></ul>	
3.	Expert witness: Preparing young people for a positive transition to adult life.	There was a lack of evidence to show how transition was well managed for young people with disabilities, including those with mild disabilities who may not qualify for adult services, nor did they explore how to implement best practice. Julie Pointer (Preparing for Adulthood Regional Lead) was invited to attend	

		the meeting as an expert witness to share her experience of best practice	
		and how local strategies were implemented.	
4.	Reflections & draft recommendations on expert witness testimony	The committee discussed the expert witness testimony and thought about the information in relation to the recommendations.	
5.	Expert witness: Transition from child and adolescent mental health services to adult mental health services	Robert Carr and Luhanga Musumadi from Guy's & St Thomas' NHS Trust were invited to attend the meeting as expert witnesses to provide good examples of support models, frameworks and interventions designed to improve transition from children's to adult services. In their testimony, they described the development of a young adult cancer service which was successfully implemented in their organisation, the lessons learnt and barriers to developing the service.	
6.	Reflections & draft recommendations on expert witness testimony	The committee discussed the expert witness testimony and thought about the information in relation to the recommendations.	Action 2: Economic implications for implementation - note on D&A issues log and also include as a research recommendation.
7.	Economic evidence	The cost-effectiveness of interventions to manage the transition from children's to adult's diabetes services among individuals diagnosed with type 1 diabetes (T1D) in childhood was presented to the committee. Due to the lack of good quality studies no recommendations were made. Further research in this area was however recommended by the committee.	
8.	Review of recommendations 1 - 17	The committee separated into 2 groups to review the draft recommendations. The groups then reconvened to review and agree changes to recommendations. KL recorded the changes by editing the recommendations live on the screen.	Action 3: NCC to make agreed changes to recommendations and re-circulate an updated version.
10.	AOB	None.	

## Transition from children's to adult services Guideline Committee meeting 10 Thursday 30<sup>th</sup> April 2015 09.30am – 5.30pm SCIE Offices, Shared Meeting Space, 206 Marylebone Rd, London NW1 6AQ

## Minutes

Name	Role	
Swaran Singh (SS)	GDG Chair	
Theresa Culverwell (TC)	Carer	
Bryony Beresford (BB)	Topic Adviser	
Carrie Wilson (CW)	Care Leaver and Carer	
Charlotte Gatherer (CG)	Service User	
Debbie Kinsella (DK)	Transition Lead	
Eugenia Lee (EL) – attended from 11.45am – 4.45pm	Clinical Commissioner & GP	
Helena Gleeson (HG)	Consultant Endocrinologist	
lulie Turner (JT)	Social Worker	
Kathie Drinan (KD)	Physiotherapist	
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Marija Trachtenberg (MT)	Economist	NCCSC (PSSRU)
Isabel Quilter (IQ)	Research Assistant	NCCSC (SCIE)
Justine Karpusheff (JK)	Programme Manager	NICE
Helen Crimlisk (HC)	Expert witness	Sheffield Health and Social Care Foundation Trust

Apologies	
Name	Organisation
Amy Moore (AM)	Commissioner
Philippa Williams (PW)	Carer
Clare Lamb (CL)	Child and Adolescent Psychiatrist

No	Agenda Item	Minutes for NICE website	Action/Owner
1.	Recap of day 1	Following the previous meeting, the NCC review team revised the recommendations as agreed by the committee. A revised version was circulated and further edits were suggested.	Action 1: NCC to make agreed changes to recommendations and re-circulate an updated version.
2.	Review of recommendations 18 - 39	The committee separated into 2 groups to review the draft recommendations. The groups then reconvened to review and agree changes to recommendations. KL recorded the changes by editing the recommendations live on the screen.	
3.	Expert witness: Transition from child and adolescent mental health services to adult mental health services	From the evidence, there were very few studies that focused on transition from Child and Adolescent Mental Health Services (CAMHS) in particular. Helen Crimlisk (Consultant Psychiatrist, Sheffield Health and Social Care Foundation Trust) was invited to provide an expert witness testimony on this subject. HC gave an insight into how local strategies were implemented in Sheffield.	
4.	Reflection & draft recommendations of expert witness testimony	The committee discussed the expert witness testimony and thought about the information in relation to the recommendations.	
5.	Review of recommendations 40 - 60	The committee separated into 2 groups to review the draft recommendations. The groups then reconvened to review and agree changes to recommendations. KL recorded the changes by editing the recommendations live on the screen.	
6.	Research recommendations	The committee reviewed the research recommendations and also suggested some changes.	
7.	Gaps in evidence	The committee discussed the gaps in the evidence and agreed on an approach.	

8.	AOB & next steps	The NICE editors will also be developing a version of the guideline for the public.	
		SS went over the aims for the next Guideline Committee meeting on the 11th June. The purpose of this meeting will be to review and finalise all recommendations prior to consultation. Committee members will also look at other sections of the guideline including the implementation section.	