

# NICE Collaborating Centre for Social Care

**Transition from children's to adult services**

**Guideline Development Group meeting 8**

**Thursday 26<sup>th</sup> March 2015**

**10.30am – 5.00pm**

**SCIE Offices, Shared Meeting Space, 206 Marylebone Rd, London NW1 6AQ**

## *Minutes*

| <i>Guideline Development Group Members</i> |                                 |
|--|---------------------------------|
| <b>Name</b>                                | <b>Role</b>                     |
| Swaran Singh (SS)                          | GDG Chair (left meeting at 3pm) |
| Theresa Culverwell (TC)                    | GDG member (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)                           | Clinical Commissioner & GP      |
| Helena Gleeson (HG)                        | Consultant Endocrinologist      |
| Julie Turner (JT)                          | Social Worker                   |
| Kathie Drinan (KD)                         | Physiotherapist                 |
| Philippa Williams (PW)                     | Carer                           |

The NCCSC is a collaboration led by SCIE



| <b>Other invitees</b>    |                            |                          |
|--------------------------|----------------------------|--------------------------|
| <b>Name</b>              | <b>Role</b>                | <b>Organisation</b>      |
| Beth Anderson (BA)       | Senior Lead (morning only) | NCCSC (SCIE)             |
| Amanda Edwards (AE)      | Director (afternoon only)  | NCCSC (SCIE)             |
| Palida Teelucknavan (PT) | Project Manager            | NCCSC (SCIE)             |
| Kristin Liabo (KL)       | Lead Systematic Reviewer   | NCCSC (EPPI)             |
| Nadira Sharif (NSh)      | Systematic Reviewer        | NCCSC (SCIE)             |
| Marija Trachtenberg (MT) | Economist                  | NCCSC (PSSRU)            |
| Isabel Quilter (IQ)      | Research Assistant         | NCCSC (SCIE)             |
| Nick Staples (NSt)       | Project Manager            | NICE                     |
| Janet McDonagh (JM)      | Expert Witness             | University of Manchester |

| <b>Apologies</b>           |                                   |
|----------------------------|-----------------------------------|
| <b>Name</b>                | <b>Organisation</b>               |
| Caroline Bennett (CB)      | Transition Lead                   |
| Clare Lamb (CL)            | Child and Adolescent Psychiatrist |
| Thines Ganeshamoorthy (TG) | Service User                      |
| Alun Williams (AW)         | GDG member                        |
| Amy Moore (AM)             | Commissioner                      |

| <b>No</b> | <b>Agenda Item</b>  | <b>Minutes for NICE website</b>  | <b>Action/Owner</b>  |
|-----------|---|--|--|
| 1.        | <b>Welcome, introductions and potential conflicts of interest</b> | The Chair welcomed all attendees to the meeting at the apologies were noted as above. There were no new potential conflicts of interest.   |  |
| 2.        | <b>Minutes and matters arising</b>                                | BA provided an update on Action 2 (seek clarification from NICE on whether gaps in research can be shared with the NIHR) and informed the GDG that this is still in discussion with NICE.<br><br>All other actions were completed and the GDG accepted the minutes as an accurate record of the meeting. |  |
| 3.        | <b>Recommendations so far</b>                                     | A full set of the draft recommendations were circulated to the GDG with the meeting papers. It was agreed that the GDG will review and provide comments on the draft recommendations by the 7th April (prior to the next   | <b>Action 1: GDG to review draft recommendations and submit comments to the NCC by the 7<sup>th</sup> April.</b> |

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|    |  | meeting). The recommendations will then be reviewed as a group at the next meeting.   |  |
| 4. | <b>Economic update</b>   | <p>MT provided an update on the economic analysis and informed the GDG that they will have a full presentation on the work at the next meeting.</p> <p>HG suggested that data from the National Retinal Screening Programme might be useful and will forward this to MT.</p>                          | <b>Action 2: HG to forward data from the National Retinal Screening Programme to MT.</b> |
| 5. | <b>Expert witness: Transition from children's to adult health services for young people with long-term conditions or disabilities: Effectiveness of service models or interventions.</b>   | Janet McDonagh (senior lecturer in Paediatric and Adolescent Rheumatology, University of Manchester) provided an expert witness testimony on effective service models and interventions of for young people with long-term conditions or disabilities.  |  |
| 6. | <b>Reflections on expert witness testimony &amp; possible draft recommendations</b>  | The GDG discussed some possible implications of the expert witness testimony in terms of recommendations.   |  |
| 7. | <b>Review of the evidence: What factors help and hinder purposeful and planned transitions from children's or adolescent to adult services, as identified by young people, their families and carers, practitioners and research? (Q4.5.3)</b> | <p>KL presented the evidence for Review Question 4.5.3.</p> <p>Most of the studies were mainly UK-based which were also largely descriptive.</p> <p>KL informed the GDG that there will also be an update search of all evidence later this year and we are also waiting for the Cochrane review.</p> |  |
| 8. | <b>Developing recommendations for Q4.5.3</b>   | The GDG drafted recommendations in two groups. Recommendations were drafted based on the evidence statements and were then shared with the rest of the group in the plenary session.  |  |
| 9. | <b>Developing recommendations – plenary feedback</b>   | <p>The facilitators from each group fed back the drafted recommendations and suggested edits to each recommendation.</p> <p>The NCC will make the changes as suggested by the GDG and will circulate an updated version of the recommendations at the next meeting.</p>                               |  |

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| 10. | D&A issues | None. |  |
| 11. | AOB        | None. |  |

## Appendix A: Register of declaration of interests

| Name                  | Personal pecuniary interest   | Personal family interest | Non-personal pecuniary interest   | Personal non-pecuniary interest   |
|-----------------------|---|--------------------------|---|---|
| Swaran P Singh        | Have received lecture Honoraria from Janssen, Otsuka and Roche Pharmaceuticals. None of the lectures were related to any healthcare product or promotion of any healthcare product. | None                     | Member of NHS England CAMHS Transition Group, Commissioner for the Equality and Human Rights Commission, Mental Health Lead for the South Warwickshire CLRN, Joint Mental Health Speciality Lead for the West Midlands Clinical Research Network, member of an expert group advising a pharmaceutical company on how outcomes of young people with early psychosis can be improved. | Have led and currently lead several transition related research projects funded by NIHR, West Midlands SHA and EU.<br><br>Co-lead on a transition pilot project on looked after young children (LYNC Project) and will be submitting a full programme grant and NIHR this year. |
| Bryony Beresford      | None  | None                     | None  | None  |
| Jane Green            | None  | None                     | None  | None  |
| Caroline Bennett      | None  | None                     | None  | None  |
| Teresa Culverwell     | None  | None                     | None  | None  |
| Kathie Drinan         | None  | None                     | None  | None  |
| Thines Ganeshamoorthy | None  | None                     | None  | Member of the Royal College of Paediatrics and Child Health Youth Advisory.   |

|                    |  |  |  |   |
|--------------------|--|--|--|---|
| Charlotte Gatherer | None   | Dr A Gatherer (Aunt) is a Director of Psychologist Services, Birmingham and Solihull Mental Health Foundation Trust. | None   | Presented at an international conference (with other members from GIFT) on young people's experiences moving from CAMHS to AMHS.<br><br>Recently joined a working group on the Milestones project for GIFT. |
| Debbie Kinsella    | None   | None   | None   | None  |
| Clare Lamb         | None   | None   | A member of the Royal College of Psychiatrists working group looking at good mental health services for young people. Has also received payment as an expert adviser on the Birmingham CCG clinical panel for the procurement of 0-25 mental health services which finished in Dec 2014. | None  |
| Eugenia Lee        | GP Partner - Thamesmead Medical associates, GP Appraiser - NHS England, GP Clinical Commissioner - NHS Greenwich, Clinical Governance Lead - Grabadoc. | None   | None   | Trustee - Christian Medical Associates, Trustee - Volunteer Centre Greenwich  |
| Amy Moore          | None   | None   | None   | None  |
| Julie Turner       | None   | None   | None   | None  |
| Alun Williams      | None   | None   | Forthcoming 250 Euro fee from Springer for publication on transitional urology (co-editing a textbook). Previous and forthcoming honoraria for speaking on neuropathic urology at sponsored meetings by Coloplast.   | Co-editing a textbook as above  |
| Philippa Williams  | None   | None   | None   | None  |
| Carrie Wilson      | None   | None   | None   | None  |

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| Helena Gleeson | None | None | None | None |
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