National Institute for Health & Clinical Excellence

Sickle Cell

First Guideline Development Group (GDG) meeting
Tuesday 30th & Wednesday 31st August 2011

Level 1A, City Tower, Piccadilly Plaza, Manchester, M1 4BD

GROUP MEMBERSHIP

In Attendance	
GDG Members	
Damien Longson (DL) (Chair)	Brigitta Brandner
Jo Howard	Asaah Nkohkwo
Michelle Afif	Hellen Adom
Louise Smith	Russell Keenan
Kofi Amie	
NICE Staff	
Lynda Ayiku (LA)	Sarah Chalmers (SC)
Lyn Knott (LK)	Abitha Senthinathan (AS)
Emma Banks (EB)	Kathryn Chamberlain (KC)
Gabriel Rogers (GR)	Mendwas Dzingina (MD)
Dylan Jones (DJ)	Mark Baker (MB)
Michael Heath (MH)	Victoria Gillis (VG)
Rachel Ryle (RR) Day 2	
Apologies:	
Jimmy Stuart	Kate Ryan
Rachel Ryle – Day 1	

MINUTES OF THE MEETING

Tuesday 30th August 2011

1.1 Agenda item 1:Introductions & GDG working

DL welcomed the group and all GDG members and NICE staff introduced themselves and described their interest in this guideline. Apologies for were received from Jimmy Stuart, Kate Ryan and Rachel Ryle (for day 1).
DL gave a presentation of GDG working including his role as the chair of the group.

1.2 Agenda item 2:

- **Literature searching:** LA gave a presentation on literature searching.
- **PPIP:** SC gave the presentation on the patient and public involvement programme.
- **Role of the Editor:** LK gave a presentation on the role of the editor, the different versions of the guideline and the NICE pathway.

- **Process of guideline development:** AS gave a presentation on clinical guidelines and process development, indicating how the process with work for this guideline.

- **Role of the Guidelines Commissioning Manager (GCM):** EB discussed the role of the GCM on behalf of RR who was unable to attend day 1 of the meeting.

- **Role of the Project Manager:** KC gave her presentation on the role of the Project Manager, the timelines for this guideline and an overview of the declarations of interest policy. Following this DL asked all GDG members and NICE staff if they had any additional DoI's.

- **Health Economics:** GR gave a presentation on health economics. Further information about the health economics specific to this guideline will be discussed at a later stage in the meeting.

1.3 Agenda item 3: Summary of the scope

VG presented a summary of the scope. The GDG discussed whether other agents should be included, such as oxygen and fluids. DL explained that following the workshop we had amended the title of the guideline, however this had yet to be agreed by the Centre for Clinical Practice. The GDG agreed with the new title.

There was discussion about the patient information and at what stage this would start. This will be discussed more fully at a later meeting when the evidence for this question is presented.

1.4 Agenda item 4: Patient Pathway

AS presented the draft pathway and gained GDG opinion on what happens in current practice. Three main groups were identified:

- Adults
- Children
- Pregnant women

Although many adults will present to A&E departments and day hospitals, children may often take a different route and go directly to the ward, and are often advised not to go to A&E. Women who are more than 18 weeks pregnant may go directly to a maternity unit.

There was a discussion about who is involved in the care. The GDG explained that the timing was very important, as is reassessment and monitoring.

1.5 Agenda item 5 : Research recommendations

DJ gave a presentation on research recommendations

1.6 Agenda item 6: Review Protocol

AS presented the review protocol and the GDG discussed the clinical questions. Question 1 should include the appropriate dose, timing and choice.

1.7 Agenda item 7: Summary of Day

DL closed the meeting.

<u>Wednesday 31st August 2011</u>

1.8 Agenda item 1: Review of Day 1

DL opened the meeting with a brief summary of the previous day's discussions, and discussed the plan for the day. There were some new attendees at the meeting who were introduced.

1.9 Agenda Item 2: An introduction to GRADE

AS gave a presentation on GRADE. Explaining to the group what GRADE is and how it will be used for the evidence in this guideline. The GDG also had a discussion on the outcomes.

1.10 Agenda item 3: Health Economics

MD discussed the health economics with specific reference to this guideline and the group considered the health economics to be included in the guideline. He asked the group questions in the areas he needed more information, and will give an update at the next GDG meeting. He explained that he did not find any economic evaluations on this topic so will need to develop a model.

1.11 Agenda item 4: Evidence presented & Discussion of evidence – Q3 (Settings)

AS presented the evidence for question 3, the GDG went on to discuss the evidence for these questions. They talked about the differences in healthcare within the USA.

1.12 Agenda item 5 & 6: Agree Evidence Statements/ Drafting recommendations – Q3

The group discussed the evidence statements, and then continued to draft recommendations. These recommendations will be revisited in the final meeting.

1.13 Agenda Item 7: LETR tables

After drafting some recommendations, AS explained that we need to link the evidence to the recommendations and we did this using a LETR table. The GDG assisted in completing the table.

1.14 Agenda Item 8: Research recommendations – Discussion/generate ideas

The GDG had a general discussion on where there was a lack of evidence for this question, to generate ideas for possible research recommendations.

1.15 Agenda Item 9: Any other business

The next meeting will be held in the NICE Manchester Office, on Monday 31st October & Tuesday 1st November 2011.

DL closed the meeting.