

Date and Time: 7th September 2012 10:00-16:00

Place: NCGC Boardroom, 180 Great Portland Street, London, W1W 5QZ

Present: GDG

1. Paul Cooper (Chair)	PC
2. Jeremy Chataway – present for notes 1-9	JC
3. David Kernick	DK
4. Wendy Hendrie	WH
5. Susan Hourihan	SH
6. Pamela Bostock	PB
7. Noreen Barker	NB
8. Richard Warner	RW
9. Aleks de Gromoboy	ADG
10. Ann Hodgson	AH
11. Emma Rowe	ER

NCGC Technical team

12. Norma O'Flynn	NOF
13. Sharon Swain	SS
14. Mark Perry	MP
15. Lola Adedokun	LA
16. Amy Kelsey	AK
17. Lina Gulhane	LG
18. Jaymeeni Solanki – present for notes 12-13	JS

NICE

19. Clifford Middleton	CM
20. Emma Chambers	EC

Observers

21. Krishna Chinthapalli	KC
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Apologies

22. Peter Brex	PB
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Minutes: Confirmed

Multiple Sclerosis GDG Meeting 1

1. The Chair welcomed the group to the Multiple Sclerosis Guideline Development Group (GDG) meeting 1 and asked members to introduce themselves. The Chair then briefed the group on the meetings objectives.
2. The Chair introduced Norma O'Flynn, NCGC Clinical Director, who gave a presentation introducing the NCGC and the Guideline Development Process and took questions from the group.
3. NOF then gave a presentation on declarations of interest and took questions from the group. The Chair thanked NOF for her presentation.
4. The Chair asked the GDG to declare any personal specific, personal non-specific, non-personal specific or non-personal non-specific interests

PC declared a personal pecuniary interest; his ISA manager holds on his behalf 925 shares in BTG (a pharmaceutical/technology company) as a managed portfolio). He also declared a personal family interest; his wife's ISA holds 400 GSK shares and 270 Shire shares (these are held on her behalf as part of a managed portfolio).

JC declared a personal pecuniary interest; he received ECTRIMS support for travel and accommodation costs. He declared a non-personal pecuniary interest, his department receives funding for clinical trials for Novartis/Biogen looking at disease modifying treatments e.g. Daclizumab, INFORMS; phase 4 trial for fampridine. He also declared 3 personal non-pecuniary interests: he carried out an RCT for outpatient versus home intravenous corticosteroids treatment for acute relapses 2006 (Lancet neurology) funded by the MS Trust; he developed an algorithm of urinary infection testing in acute relapse management published 2012 EJM; applications for LDN trials as part of a European collaboration to UK MS Society.

DK declared a personal pecuniary interest; he occasionally lectures to GPs funded by pharmaceutical industry on headaches. He also declared 3 personal non-pecuniary interests; he is a health champion for the Royal College of GPs, a NICE Fellow and is a member of the British association for the study of headache (BASH).

WH declared a personal pecuniary interest; she attended the annual MS Trust conference sponsored in part by their Therapists bursary fund. She also declared 2 personal non-pecuniary interests; she is a member of the Therapists in MS (TIMS) core group (part of the MS Trust) and she used oswestry standing frames as part of PhD research that were purchased by the University of East Anglia.

SH declared a personal pecuniary interest; she was the recipient of conference fees for the 2012 MS Trust annual conference from Therapists bursary fund. She also declared 2 personal non-pecuniary interests; she is a member of the Therapists in MS (TIMS) core working group and she is involved in a working group translating NICE guidelines for OT practice.

PB declared 3 personal non-pecuniary interests: she is an advisory member of the Staffordshire neurological alliance; she is a member of Therapists in MS (TIMS), supported by the MS Trust (who are paying for attendance at annual conference 2012); she is leading a team involved as a research site in a multi-centre research project,

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evaluating the effectiveness of an MS fatigue management educational programme sponsored by MS Trust. The team she leads has recently been involved in research lead by a social policy research unit.

NB declared 3 personal pecuniary interests: she attended CHARMS meeting in September 2011 sponsored by Merck Serono, accommodations and meals paid for; she attended MS Trust Annual Conference November 2011, conference fees paid for under the Risk Sharing scheme; she attended MS Trust Nurses conference March 2012, conference fees paid under the RSS; she attended UKMSSNA regional meeting June 2012, accommodation and meals sponsored by Biogen Idec; she is due to attend MS Trust Annual conference November 2012, conference fees paid under RSS.

RW declared 2 non personal pecuniary interests; he is a co-principal investigator for a study into the use of fampridine for tremor in MS. A research grant for this project has been awarded in principle by Biogen Idec. This project is scheduled to commence later this year and will be completed before the close of this year.

ADG declared a personal non pecuniary interest; he volunteers on the MS Society helpline.

AH declared a personal non-pecuniary interest; she is currently the chair of the MS Cymru Council for the MS Society, but will be stepping down from this role at the end of November 2012.

ER declared a personal pecuniary interest; she is paid to review 3-4 papers a year for the National Institute for Health Research.

5. The Chair introduced Clifford Middleton, NICE Guidelines Commissioning Manager, who gave a presentation on working with NICE and took questions from the group. The Chair thanked CM for his presentation.
6. The Chair introduced Emma Chambers, NICE Patient and Public Involvement Project Manager, who gave a presentation on Patient and Carer Involvement and took questions from the group. The Chair thanked EC for her presentation.
7. The Chair introduced Lina Gulhane, NCGC Joint Head of Information Science, who gave a presentation to the group detailing the role of the Information Scientist in guideline development. LG then took questions from the group. The Chair thanked LG for her presentation.
8. The Chair introduced Sharon Swain, NCGC Senior Research Fellow and Mark Perry, NCGC Research Fellow, who gave a presentation on the role of the research fellow and appraising the clinical evidence and took questions from the group. The Chair thanked SS and MP for their presentation.
9. The Chair introduced Lola Adedokun, NCGC Health Economist, who gave a presentation on the health economic process. LA then took questions from the group. The Chair thanked LA for her presentation.
10. The Chair presented the outline of the scope to the GDG and took questions from the group.
11. MP then presented the protocols process to the GDG and took questions. MP and SS then led discussion with the GDG on the research protocols for 4 clinical questions. The following research protocols were agreed and signed off by the group:
 - For young people and adults with MS, what is the clinical evidence and cost

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effectiveness of pharmacological treatment of mobility with fampridine compared to usual care?

- For adults with MS, what is the clinical evidence and cost effectiveness of pharmacological management with vitamin D?
 - For adults with MS and their carers, what information, education and support would they find useful?
 - For adults with MS, what is the clinical evidence and cost effectiveness of rehabilitation provided in different settings?
12. The Chair then introduced Jaymeeni Solanki, NCGC Project Coordinator who gave a short introduction to Claromentis, a web-based intranet site for document sharing, version control and forums.
13. There was no other business to discuss. The Chair closed the meeting and thanked everyone for attending.

Date, time and venue of the next meeting

14. Friday 19th October 2012, 10:00-16:00, NCGC Boardroom, 180 Great Portland Street, London, W1W 5QZ.