Date and Time: *11th September 2012, 10:00 – 16:30*

Minutes: DRAFT

Guideline Development Group Meeting 1
Place: Boardroom, NCGC, 180 Great Portland Street, London, W1W 5QZ

GDG Present:	Anthony Wierzbicki (Chair)	(Present for notes 1 – 11)
	Rajai Ahmad	(Present for notes 1 – 11)
	Lindsay Banks	(Present for notes 1 – 11)
	Liz Clark	(Present for notes 1 – 11)
	Martin Duerden	(Present for notes 1 – 11)
	Eleanor Grey	(Present for notes 1 – 11)
	Michael Khan	(Present for notes 1 – 11)
	Emma McGowan	(Present for notes 1 – 11)
	Dermot Neely	(Present for notes 1 – 11)
	Nadeem Quershi	(Present for notes 1 – 11)
	Alan Rees	(Present for notes 1 – 11)
	David Wald	(Present for notes 1 – 11)
NCGC Present:	Angela Cooper	(Present for notes 1 – 11)
	Martin Harker	(Present for notes 1 – 10)
	Norma O'Flynn	(Present for notes 1 – 11)
	Silvia Rabar	(Present for notes 1 – 11)
	Alison Richards	(Present for notes 1 – 11)
	David Wonderling	(Present for notes 1 – 2, 8)

In attendance:

NICE Staff:	Emma Chambers	(Present for notes 1 – 6)
	Clifford Middleton	(Present for notes 1 – 6)

Observers:

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1. **Welcome introductions and apologies**
   Anthony Wierzbicki welcomed the group to the first meeting of this GDG and thanked them for their time and commitment to the guideline. Anthony Wierzbicki asked each member to introduce themselves. No apologies were received from the group.
2. **Declaration of Interests**
   Norma O'Flynn gave a presentation on declarations of interest (DOIs) and detailed the importance of them. The group then verbally declared their DOIs:

Anthony Wierzbicki. - Non-personal pecuniary interest - Clinical trials (FH) – HPS2 – THRIVE (BHF/HSD) (Sanofi – Aventis, Amgen, Pfizer), Mipomersen (Genzyme), Ezetimibe (MSD). - Personal non-pecuniary interest - Editorials on topics of cardiovascular disease and Lipids. Academic publications.
Rajai Ahmad. - Personal pecuniary interest - Received speaker fees from Bayer and Boehringer

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Ingelheim for providing educational presentations and from Bayer for participation in advisory board during 2012. Scheduled to participate on (M.S.D) symposium on commissioning in CVD (out 2012) prevention peri-med.
Lindsay Banks. - Personal non-pecuniary interest - Editor, NICE bites – independent bulletin
Liz Clark. - None
Martin Duerden. - Personal non-pecuniary - Have written a number of articles and editorials on subject of Lipid modification. (None for several years).
Eleanor Grey. - None
Michael Khan. - Personal pecuniary interest - Advisory board 3 months ago – Genzyme on high risk FH. 2 half day meetings. Non-specific fee paid on Mipomersen. Advisory board for Amgen on PCSK9 monoclonal and B. - Non-personal pecuniary interest - Previous support for FH cascade nurse (AZ + Pfizer) specialist for 12 months. Now supported by the trust with no industry contribution. Lecture to Lipid nurses on FH at Astra Zenara next week. Clinical trial of PCSK9 MAB – Amgen starting 2013.
Emma McGowan. - Personal pecuniary interest – I received personal payment from Merck Sharp Dohm 27/02/2012 for speaking at a meeting for nurses. It was non promotional discussing the nurse led service for Familiar Hypercholesterolemia (FH). I received personal payment from Astra Zeneca UK 19/04/2012 to enable me to attend the Heart UK Annual conference. The payments were made personally as I have been informed they are unable to pay into a departmental fund. All of the personal payments I have received have been used to pay for meetings and conferences I have attended as I do not receive any funding for these events from my employer. - Non-personal pecuniary interest – My post was originally sponsored by a Pharmaceutical Company for one year. This was from November 2010 until November 2011. Since then I have been employed by UHCW NHS Trust. As previously discussed, my post was originally sponsored by the Pharmaceutical company Astra Zeneca for the first 12 months. It has now been adopted by UHCW NHS trust. The FH services have been in discussion with Astra Zeneca with reference to a working partnership and provision of nurse support. My post was originally sponsored by Astra for 12 months. The FH service is in discussion with Amgen in Relation to conducting a clinical trial in 2013.
Dermot Neely. - Personal pecuniary interest – In the past 12 months I have participated in one-off advisory boards for pharmaceutical companies developing lipids modifying therapy for specialist use in poorly treatment responsive and/or severe inherited lipids disorders, including Roche Pharma (dalcetrapib), Genzyme (mipomersen), and Aegerion (lomitapide). However I have no ongoing contractual relationships with any pharmaceutical companies and do not intend to undertake any further advisory work during in the period relevant to participation in the GDG, if offered a position. Sponsorship to attend European Arteriosclerosis society (May 2012 - Merck). - Non-personal pecuniary interest – Newcastle upon Tyne hospital NHS foundation trust/Newcastle university clinical research facility participates in commercial clinical trials including those of novel lipid lowering therapy for Familial Hypercholesterolemia, for which I have had responsibility for recruiting some of the eligible patients. - Personal non-pecuniary – I am a Trustee and board member of the Heart UK the Cholesterol Charity and Co-Chairman of the Familiar Hypercholesterolemia Guideline implementation group, a multi-disciplinary team which since 2008 has campaigned for the full implementation in England of the NICE Clinical Guideline CG71 and has developed and published a Guideline implementation toolkit on the Heart UK web site. I have participated and I am a member of Newcastle FATS guideline group on cholesterol

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lowering treatment.
Nadeem Quershi. - Non-personal pecuniary interest - I have received research grants to assess the implementation of familial hypercholesterolemia in primary care, and the clinical utility of the family history in primary care. I have published in both areas. - Personal non-pecuniary interest - I have published a paper on the primary care research evidence underpinning NICE guidelines. (Scullard et al. BJGP 2011) I am collaborating on an NIHR Research for Patient Benefit grant exploring the topic further.
Alan Rees. - Non-personal pecuniary interest - Previously been member of advisory board for MSD and Pfizer (12 months ago). Advisory board for Genzyme in the last 12/12. Previously received assistant to attend international meetings sponsorship. - Personal non-pecuniary interest - Current president of section on Lipids and Vascular risk at the RSM. Ex-chair of heart UK – current trustee. Have written editorials/papers. Editor of sections of current opinion in Lipidology. Writing committee of IBS-3. FHGIT group. All Wales FH group. In discussion re trials for new drugs – Genzyme/Sanofi and Novartis.
David Wald. - Personal non-pecuniary interest – Editorials and academic publications.
NCGC staff: - Angela Copper declared a personal non-pecuniary interest: Author on BMJ clinical evidence review secondary prevention of ischaemic cardiac events. Clinical Evidence 2011; 08-206.
NICE staff: None declared.

3. **The NCGC, overview and working practices**
   Silvia Rabar explained the role of the NCGC and who the technical team are.

4. **Role of the Guidelines Commissioning Manager/Equality scheme**
   Clifford Middleton gave details on the role of NICE, the guideline commissioning manager and the equality scheme.

5. **Patient and carer involvement**
   Emma Chambers detailed who the Patient and Public Involvement Programme are at NICE and the key role in ensuring patients'/carers' perspectives inform the work of the GDG.

6. **Searching the evidence**
   Alison Richards presented the role of information scientists in guideline development and discussed how to developing clinical questions using the PICO framework. She explained how searches are developed using the PICO, search parameters and databases.

7. **Evidence review process**
   Angela Cooper presented the evidence review process including all stages of systematic reviewing.

8. **Health economics process**
   Martin Harker gave an introduction to health economics in NICE guidelines and discussed cost-effectiveness, issues for the Lipid modification guideline and prioritising questions for economic modelling.

9. **Introduction to Lipid Modification: issues and scope**
   Anthony Wierzbicki introduced the remit, population to be covered and the need for this guideline update. The key clinical areas were introduced and areas not covered within the scope detailed.

10. **Clinical and cost effectiveness review question session**

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Angela Cooper introduced the draft protocols and explained the level of details and what information needed to be captured to allow the technical team search and review evidence to present to them at future meeting.

11. **Summary of next steps and any other business**
Silvia Rabar updated the GDG on how the protocols will be updated and highlighted future meeting dates.

Date, time and venue of the next meeting

24th October 2012, 10.00 – 16.30, at the Royal College of Physicians.