

Membership of the Familial hypercholesterolaemia clinical guideline updates standing committee

The Committee will operate as an advisory Committee to NICE’s Board, developing clinical guideline updates.

The terms of reference and standing orders for the Committee can be found in [appendix D of Developing NICE guidelines: the manual](#).

The Committee had 15 members (5 core members, 5 condition specific members and 5 topic expert members).

Membership list

Name	Job Title	Organisation
Chair		
Steve Pilling	Director	NCC Mental Health
Core members		
Jim Gray	Microbiologist	The Birmingham Children’s Hospital NHS Foundation Trust
Jo Josh	Lay member	Lay member
Grace Hampson (nee Marsden)	Economist	The Office of Health Economics
Julian Treadwell	General Practitioner/NIHR In-Practice Fellow	Hindon Surgery, Wiltshire/University of Oxford
Condition specific members		
Tarek Antonios	Senior Lecturer and Consultant Physician	St George’s University Hospital NHS Foundation Trust
Simon Corbett	Consultant Cardiologist	University Hospital Southampton
Nazish Khan	Principal Pharmacist Cardiac Services	Royal Wolverhampton Hospital
Jean MacLeod	Consultant Physician in Diabetes and General	University Hospital of North Tees

	Medicine	
Robert McNabb	Lay member	Lay member
Topic expert members		
Steve Forster	Lay member	Lay member
Lisa Gritzmacher	Nurse Specialist	Bristol Royal Infirmary
Steve Humphries	Emeritus Professor Cardiovascular Genetics	University College London School of Medicine
Nadeem Qureshi	Clinical Professor in Primary Care	University of Nottingham
Uma Ramaswami	Consultant Metabolic Paediatrician	Royal Free Hospital

Declaration of Interests

The effective management of conflicts of interests is an essential element in the development of the guidance and advice that NICE publishes. Please refer to the NICE website for the [Policy on Conflicts of Interest](#).

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Core members				
Steve Pilling	Director of British Psychological Society's Centre for Outcomes, Research and Effectiveness	A research group I jointly direct National Collaborating Centre for Mental Health (the NCCMH) receives funding from NICE to develop clinical guidelines. My research group is in receipt of funding from the Medical Research Council (MRC) and National Institute for Health Research to undertake research in mental health interventions and from the Department of Health and the Scottish Government to develop competence frameworks for psychological interventions. Declared - 07/04/14	Non-personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Associate Editor, International Journal of Antimicrobial Agents. Declared - 31/10/14	Personal Non-financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Associate Editor Journal of Paediatric Infectious Diseases. Declared - 31/10/14	Personal Non-financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Expert Advisor, British National Formulary for Children. Declared - 31/10/14	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	My Department is in receipt of an Educational Grant from Pfizer Ltd to develop improved diagnosis of invasive fungal infections in immunocompromised children Declared - 31/10/14	Non-personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Small shareholding (under £2000) in Glaxo Smith Kline. Sold in July 2016 Declared - 10/06/15	Personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Editor-in-Chief of Journal of Hospital Infection. Paid a fee Declared - 04/08/15	Personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Appointed a Member of the Cost (European Cooperation in Science and Technology) AMiCI Working Group. This is an EU-funded body that is developing standards for antimicrobial surfaces and cleaning methods in healthcare premises. I receive travel and accommodation expenses to attend up to two meetings per year in different European countries. Declared - 04/01/16	Non-personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Co-investigator in four major trials (3 HTA-funded; 1 British Council funded. Two trials are about antibiotic prophylaxis on obstetrics and gynaecology to prevent pelvic infections, one is comparing different suture materials and the fourth is a diagnostic test accuracy study for use in woman in labour). Declared 31/10/14	Non-personal Financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Co-investigator in study of antibiotic prescribing behaviour funded by Aston University, Birmingham Declared 09/06/17	Non-personal Financial Non-specific	Declare and Participate
Jim Gray	Microbiologist, The Birmingham Children's Hospital NHS Foundation Trust	Expert Advisor, Hearts Milk Bank. Unpaid role for this non-profit making organisation Declared 02/08/2017	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	Governor at Surrey and Sussex Healthcare NHS Trust: governor representing the voluntary sector. Declared - 07/01/15	Non-personal Financial Non-specific	Declare and Participate
Jo Josh	Lay Member	Steering Group Member at UK Community Advisory Board (UK-CAB) Declared - 07/01/15	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	Trustee at Surrey Community Action Declared - 07/01/15	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	Member of HIV ad hoc communications support Declared - 07/01/15	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	Mental health ad hoc communications support: member of ENRICH(A Toolkit For Care Home Research) panel Declared - 07/01/15	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	NHS East Surrey Clinical Commissioning Group: patient representative Declared - 07/01/15	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Jo Josh	Lay Member	British HIV Association (BHIVA) -Testing Guidelines committee Declared - 03/04/17	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	British HIV Association (BHIVA) - External Relations committee Declared - 04/04/17	Personal Non-financial Non-specific	Declare and Participate
Jo Josh	Lay Member	I am a member of the British Association for Sexual Health and HIV (BASHH) and Terrence Higgins Trust (THT) Lay Research Panel. My role is to advise on the structure, content and language of planned research from the patient perspective. Declared 07/08/2017	Non-personal Financial Non-specific	Declare and Participate
Grace Hampson	Economist, The Office of Health Economics	Employee of the Office of Health Economics, a registered charity, which receives funding from a variety of sources, including the Association of the British Pharmaceutical Industry. Declared - 29/02/16 (updated 16/06/2017)	Non- Personal Financial Non-specific	Declare and Participate
Grace Hampson	Economist, The Office of Health Economics	I was involved in some work that was published early this year that compared the different methodologies used by NICE's different HTA programmes. NICE were aware of this work, and a few of your colleagues participated in interviews with us. The study ("A Review of NICE Methods Across Health Technology Assessment Programmes) was published on OHE's website and the interviewees were notified about this. It's now been accepted for publication in Applied Health Economics and Health Policy. No payment received	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
		Declared - 29/11/2016		
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	Salaried NHS GP – Hindon Surgery, Wiltshire. Declared - 04/03/16	Personal Financial Non-specific	Declare and Participate
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	Editorial Board Member, Drugs and Therapeutics Bulletin (BMJ group). Annual retainer paid and travel expenses covered for the annual meeting Declared - 04/03/16	Personal Financial Non-specific	Declare and Participate
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	Vice-Chair Royal College of General Practitioners Standing Group on Over-diagnosis (no remuneration)	Personal Non-financial Non-specific	Declare and Participate
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	GP Appraiser – NHS England South Central. Paid Declared - 04/03/16	Personal Financial Non-specific	Declare and Participate
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	I undertake occasional educational work for GPs and GP trainees within the NHS. Declared - 04/03/16	Personal Financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Julian Treadwell	General Practitioner, Wiltshire and NIHR In-Practice Fellow, University of Oxford	NIHR in-Practice Fellowship, 5 sessions per week to undertake an MSc at the Nuffield Department of Primary Care in Oxford. The NIHR funding covers salary, tuition and conference fees Declared - 06/09/16	Personal Financial Non-specific	Declare and Participate
Condition specific members				
Tarek Antonios	Senior Lecturer and Consultant Physician, St George's University Hospital NHS Foundation Trust	None Declared - 29/03/16	Not applicable	Declare and Participate
Simon Corbett	Consultant Cardiologist, University Hospital Southampton	Network Service Adviser for the British Cardiovascular Society. This role incorporates the regional specialty adviser role for the Royal College of Physicians. No expenses are paid Declared - 21/05/14	Personal Non-financial Non-specific	Declare and Participate
Simon Corbett	Consultant Cardiologist, University Hospital Southampton	Director for Clinical Effectiveness for employer (University Hospital Southampton NHS Foundation Trust). Part of this role involves the dissemination and implementation of NICE guidance in the Trust. Declared - 21/05/14	Personal Non-financial Non-specific	Declare and Participate
Simon Corbett	Consultant Cardiologist, University Hospital Southampton	Independent cardiologist on the Trial Steering Committee of the randomised controlled AVATAR trial, a randomised trial of medical therapy vs ablation in patients with atrial fibrillation. The study is sponsored by Imperial College London and is part funded by Medtronic. Travel expenses are paid by Imperial. Declared - 02/04/14	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Simon Corbett	Consultant Cardiologist, University Hospital Southampton	Elected to the British Cardiovascular Society's Guidelines and Practice committee. The remit of this committee is to review, and where felt appropriate, endorse guidelines and to consider and respond to issues relating to the professional clinical practice of Society members. If I have been involved in drafting any of the guidelines under review I would not participate in the review. Travel expenses are paid. Declared - 25/05/16	Personal Financial Non-specific	Declare and Participate
Nazish Khan	Principal Pharmacist Cardiac Services , Royal Wolverhampton Hospital	Contributed to an advisory board hosted by Astra Zeneca (unpaid).No expenses paid Declared - 25/03/16	Personal Non-financial Non-specific	Declare and Participate
Robert McNabb	Condition Specific Lay Member	Member of all Wales Cardiac Rehabilitation & Heart Failure Working Group Declared - 31/03/16	Personal Non-financial Non-specific	Declare and Participate
Robert McNabb	Condition Specific Lay Member	Member of British Heart Foundation and Cancer Research UK Patient Data Reference Panel Declared - 31/03/16	Personal Non-financial Non-specific	Declare and Participate
Robert McNabb	Condition Specific Lay Member	Member of MHRA UK Stakeholder Platform for Reclassification of Non-Prescription Drugs Declared - 31/03/16	Personal Non-financial Non-specific	Declare and Participate
Robert McNabb	Condition Specific Lay Member	Member of MHRA Patient Group Consultative Forum Declared - 31/03/16	Personal Non-financial Non-specific	Declare and Participate
Robert McNabb	Condition Specific Lay Member	Daughter & son-in-law are NHS doctors Declared - 27/05/16	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Robert McNabb	Condition Specific Lay Member	Member of the Advisory Group for the REGenableMED research project looking at the regenerative medicine and medical innovation. As ESRC-funded project based at the University of York Declared - 27/05/16	Personal Non-financial Non-specific	Declare and Participate
Jean MacLeod	Consultant Physician in Diabetes and General Medicine	None	Not applicable	Declare and Participate
Topic experts				
Steve Forster	Lay member	Contributed to FH Awareness Raising Film sponsored by Amgen – Message From the Heart. Received small payment for contribution Declared – 25/01/16	Personal Financial Non-specific	Declare and Participate
Steve Forster	Lay member	I received expenses and payment for attending a NICE Appraisal committee for Evolocumab (20th October 2015) Declared – 26/02/16	Personal Financial Non-specific	Declare and Participate
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	Since May 15 I provide teaching sessions to primary care regarding FH and our service. Merck Sharp & Dohme Limited (MSD) is providing administrative support for my meetings. However, they have no influence over the session content and I am not getting any payment from them for this Declared – 12/02/16	Personal Non-financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	I have attended conference as an attendee as part of my learning and development in my role as a British Heart Foundation (BHF) funded FH nurse so their content included information about and related to FH (HEART UK 16/09/15 to 18/09/15) Declared – 26/02/16	Personal Non-financial Specific	Declare and Participate
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	I have presented at a conference (BCS,09/06/15) on the BHF day which was related to setting up my FH service. Travel costs only were paid by the BHF Declared – 26/02/16	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	I have presented a poster at HEART UK conference about VUS testing. I did win the runner up prize for the poster. VUS testing is different to cascade screening so it isn't directly to do with the review questions, but when we test people for FH sometimes we find gene alterations that we don't know enough about to classify them as either FH or not, so we call these variants of unknown significance (VUS).	Personal Financial Non-Specific	Declare and Participate
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	VUS poster submission to the European atherosclerosis society (EAS). I will present this at the EAS conference in April 2017 as a learning opportunity. Sanofi are sponsoring me to attend the conference (paying for economy flight, accommodation, meals and EAS registration) but have no say over content of the poster I have submitted, neither will they have any influence over the sessions I attend once at the conference. No payments made to me personally	Personal Financial Non-specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
		Declared 29/11/16		
Lisa Gritzmacher	Nurse Specialist, Bristol Royal Infirmary	Grant of £5,928.00 approved and received by Sanofi to provide administrative support to my Familial Hypercholesterolaemia service (FH) for 1 year. Grant: paid to departmental budget to fund bank admin hours of work to support FH service Declared - 06/04/17	Non-personal Financial Non-specific	Declare and Participate
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I have published 10 papers on FH over the last year and have an additional 3 in press and 5 that will be submitted in the next year. One of the papers is included in the update. Declared – 21/01/16	Personal Non-financial Specific	Declare and Leave during the recommendations for review questions 1 and 2 Declare and Participate for all of review question 3
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I am the Director of the Royal College of Physicians' Paediatric FH Register which started data collection in late 2012 and now has >350 registered patients. Current funding is from the BHF till August 2016. I have recently submitted a grant for continued funding to the International Atherosclerosis Society who are using funds from Pfizer to support this activity. Declared – 21/01/16	Personal Financial Non-specific	Declare and Participate
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I am the co-author of the 2013, 2014 and 2015 European Atherosclerosis Society (EAS) guidelines Development Group for management and treatment of FH in adults and children These reviews was supported by unrestricted educational grants to the EAS from Amgen, Aegerion, AstraZeneca, Genzyme, Hoffman-La Roche, Kowa	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
		<p>Europe, Novartis, and Sanofi-Aventis/Regeneron. These companies were not present at the Consensus Panel meetings, had no role in the design or content of the Consensus Statement, and had no right to approve or disapprove the final document.</p> <p>Costs for my travel to the EAS panel meetings were covered by the Society</p> <p>Declared – 21/01/16</p>		
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	<p>I am a committee member of the FH implementation group chaired by Prof Huon Grey to direct and monitor the >20 BHF funded FH Nurses (2013-now). Travel expenses paid</p> <p>Declared – 21/01/16</p>	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	<p>I chair the Steering Committee of the Southampton FH cascade testing implementation group. Travel expenses are paid</p> <p>Declared – 21/01/16</p>	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	<p>For the last 2 years I have been a committee member of a team convened by HEARTUK to implement electronic note searching in GP practice to identify FH patients. This activity has been sponsored by Sanofi. I received no funding or expenses for this attendance. Sanofi and HEARTUK have as of yesterday agreed to discontinue this activity.</p> <p>Declared – 09/03/16</p>	Non-personal Non-financial Specific	Declare and Participate

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	In September 2015 I gave a named lecture on FH at the HEARTUK annual conference, and my travel expenses were covered. HEARTUK receives sponsorship from several Pharmaceutical companies (including MSD, Pfizer, Amgen, Sanofi etc) Declared – 09/03/16	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I attended (December 2015) one meeting of a Panel convened on behalf of Sanofi to discuss implementation of NICE FH guidelines. I received no funding or expenses for this attendance. Given any potential conflict of interest I resigned from this panel in February 2016 Declared – 09/03/16	Personal Non-financial Specific	Declare and Participate
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I am organising and chairing a session at the HEARTUK conference in Edinburgh this June. The session is sponsored by Alexion. HEARTUK do not cover registration or travel costs of Chairs of such sessions and Alexion have agreed to cover these expenses. I will not be speaking or presenting any data and neither will any Alexion representative Declared - 08/06/16	Personal Financial Non-specific	Declare and Participate
Steve Humphries	Emeritus Professor Cardiovascular Genetics, University College London School of Medicine	I am the Medical Director of a UCL spin-out company called Storegene, which uses a 20 SNP genetic test, in combination with the classical risk factor profile, for estimating an individual's future risk of CVD. Up until now no genetic testing has been offered to patients with FH. Following requests from several clinicians, from 1 January 2017, Storegene	Personal Financial Specific	Declare and leave for recommendation making – review question 1

Name	Job title, organisation	Declarations of Interest, date declared	FH Classification	FH Decision
		will be offering a NGS test for the FH-causing genes, with service delivered through a UK accredited diagnostic laboratory. Declared - 14/12/16		
Nadeem Qureshi	Clinical Professor in Primary Care, University of Nottingham	Undertaking grant funded health service research on identification of familial hypercholesterolaemia and familial cancer in primary care. University has received grant funding for this research. Declared – 08/02/16	Non-personal Financial Specific	Declare and Participate
Nadeem Qureshi	Clinical Professor in Primary Care, University of Nottingham	Invited to a PCSK9 Education and Research Forum at Amsterdam Schiphol Airport on 22 May 2015. The Forum receives sponsorship from pharmaceutical companies. I paid my own travel but the Forum paid for 1 nights' accommodation Declared - 28/02/16	Personal Financial Specific	Declare and Participate (Personal costs were for travel / accommodation only in line with NICE's policy for travel and subsistence)
Nadeem Qureshi	Clinical Professor in Primary Care, University of Nottingham	Co-author of paper: Feasibility of improving identification of familial hypercholesterolaemia in general practice: intervention development study. Qureshi N, Weng S, Tranter J, et al. (2016) BMJ Open. 6: e011734. Paper included in the update. Declared 02/12/16	Personal Non-financial Specific	Declare and Leave for the recommendations on review questions 1 and 2 Declare and Participate for all of review question 3
Uma Ramaswami	Consultant Metabolic Paediatrician, Royal Free Hospital	None Declared – 03/02/16	Not applicable	Declare and Participate

Date last reviewed: 08/08/2017