

Marion McAllister

1. PERSONAL INFORMATION AND CAREER HISTORY

PERSONAL INFORMATION

Home address: 21, Whalley Rd Tel. 0161 226 4170
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Web profiles:

<http://www.geneticsforpatients.org.uk/biography.php>
<http://www.medicine.manchester.ac.uk/staff/151821>
http://www.nowgen.org.uk/stories/232-dr_marion_mcallister
<http://www.mrc.ac.uk/ResearchPortfolio/searchPortfolio/search.htm?search=1&select=AbsSummary&searchTerm=empowerment>

EDUCATION / QUALIFICATIONS

1999 PhD University of Cambridge, Faculty of Social and Political Sciences
1996 MSc course in Genetic Counselling, University of Manchester
1989 MSc in Biotechnology (by research), University College Dublin
1985 BA (Mod) Natural Science (Genetics), Trinity College Dublin; 2-1

SOCIETY MEMBERSHIP

- British Society for Human Genetics (BSHG)
 - Association for Genetic Nurses and Counsellors (AGNC)
 - Cancer Genetics Group

PRESENT APPOINTMENTS

- *MRC Research Fellow*, Medical Genetics Research Group, School of Biomedicine, The University of Manchester.
- *Honorary Registered Genetic Counsellor*, Genetic Medicine, Central Manchester University Hospitals NHS Foundation Trust (CMFT).

PREVIOUS APPOINTMENTS

- *Research fellow* (Genetic Counselling), Nowgen (North West Genetics Knowledge Park). Fixed-term contract, 2003 – 2007 (0.5WTE).
- *Registered Macmillan Genetic Counsellor*, Central Manchester University Hospitals NHS Foundation Trust. Substantive, 1999 – 2003 (1.0WTE); 2003 – 2007 (0.5WTE). GCRB Registration status: Recently re-registered until 2015.
- *Cancer Genetics Course Co-Ordinator*, Central Manchester Healthcare NHS Trust. Fixed term contract, Jun – Aug 1999.
- *PhD studentship* (Cancer Research UK), University of Cambridge Centre for Family Research, Faculty of Social and Political Sciences, 1996 – 1999.
- *Genetic Associate*. Central Manchester Healthcare NHS Trust. Fixed term contract, Jun – Oct 1996.
- *Management Consultant*. Andersen Consulting (now Accenture) London Office, 1990 – 1994.

KEY SKILLS

- Project Management
- Time Management
- Problem-solving
- Networking
- Commitment
- Good balance between working independently and as a team member

2. TEACHING AND TEACHING-RELATED ACTIVITIES

VISITING LECTURESHIP

- March 2011: 2-week Visiting Lectureship to South Africa. To visit the Universities of Cape Town and Witwatersrand MSc in Genetic Counselling courses and give some seminars and workshops, and to deliver a keynote address at the South African Society of Human Genetics biennial congress.

UNIVERSITY TEACHING

- 2007 – 2008: Attended New Academics Programme: A development programme for new academics, Faculty of Medical and Human Sciences and Staff Training and Development Unit, The University of Manchester.
- Module leadership: Developed and taught MSc module “Research Skills” to University of Manchester MSc in Genetic Counselling students 1999 - 2008.

- Appointed to Honorary Lecturer post at The University of Manchester in 1999.
- At University College Dublin, as a graduate student, I acted as tutor, practical class demonstrator and occasional lecturer to biology undergraduates.

RESEARCH SUPERVISION

- University of Manchester MSc in Genetic Counselling: Supervised 7 MSc research projects 2001 – 2008
- University of Manchester MSc in Clinical & Health Psychology: Supervised 2 MSc research projects 2009 – 2010

PROFESSIONAL TRAINING

- NHS: As Cancer Genetics Course Co-Ordinator, Central Manchester Healthcare NHS Trust (1999), I developed, delivered and evaluated a training course on breast cancer risk assessment and counselling to nurses working in Calman Breast units, who were setting up their own Breast Cancer Family History Clinics. This course continues to be delivered in the North West of England, co-ordinated by the Nowgen Professional Training team.
- Private sector: At Andersen Consulting (now Accenture) 1990 - 1994, I worked as a consultant in the firm's Change Management division. Work involved preparing the client workforce for implementation of strategic change, often involving new computer systems. Responsibilities included development and delivery of large-scale training and communications programmes, including training support and communications materials, client liaison, business process / job design & redesign.

3. RESEARCH

PREVIOUS AND CURRENT GRANT FUNDING

- 2010 – 2015: Funded by: *The Healing Foundation* (National Centre for Cleft Research) Applicants: Prof Bill Shaw (PI), Prof Michael Dixon, Prof Jill Clayton-Smith, Prof Kevin O'Brien, Prof Peter Callery, Prof Gunvor Semb, Prof Helen Worthington, Prof Paula Williamson, Dr Marion McAllister, Prof Katherine Payne, Ms Pauline Nelson. **Value: £2.5 million.**
- 2010 – 2015: Funded by: *Fight for Sight* (Programme grant). Title: "Improving healthcare provision for patients with inherited retinal diseases: an evidence-based approach". Applicants: Prof Graeme Black (PI), Dr Simon Ramsden, Ms Georgina Hall, Dr Katherine Payne, Dr Marion McAllister. **Value: £497,107.**
- 2007 – 2010: Funded by: *Medical Research Council* (Post-Doctoral Special Training Fellowship in Health Services Research). Title: "Empowerment: developing a robust instrument to measure patient benefits from clinical genetics services". Applicant: Dr Marion McAllister. Value: **£318,779**

GRANT APPLICATIONS UNDER REVIEW

- 2011 – 2014: Under review: *NIHR Research for Patient Benefit* "A Phase II pilot study to investigate acceptability and feasibility of a randomised trial to evaluate a patient-held record (PHR) to enhance patient self-management of Neurofibromatosis Type 1." Applicants: Dr Marion McAllister (PI), Prof Chris Todd, Prof Graham Dunn, Prof Linda Davies, Mrs Rosemary Abbott, Dr Bronwyn Kerr. Decision expected: November 2010. Value: **£241,071**

FELLOWSHIPS AND AWARDS

- 2007: Medical Research Council (MRC) Special Training Fellowship in Health Services Research (post-doctoral). Project: Empowerment: developing a robust instrument to measure patient benefits from clinical genetics services. **Value: £318,779**
- 2007: Health R&D North West Training and Mentoring (TRAM) scheme to support Health Services Research training and mentoring **Value: £4,500**
- 2006: UK Resource Centre for Women in Science, Engineering and Technology travel bursary to fund travel to Brisbane, Australia to present a paper at the International Congress of Human Genetics **Value: £990**
- 1984: Irish-American Foundation undergraduate award to a visit to the US to work in a research lab for Prof John Pringle, University of Michigan, investigating cell division cycle genes in the yeast *Saccharomyces cerevisiae*. **Value: £1,000**

COLLABORATIONS

I have personally initiated and developed the following collaborations that have contributed to the success of my MRC fellowship:

- *Prof Shoshana Shiloh* Professor of Psychology, University of Tel Aviv, Israel
- *Prof Chris Todd* Professor of Primary Care and Community Health, and Director of Research, School of Nursing, Midwifery & Social Work, The University of Manchester
- *Prof Graham Dunn* Professor of Biomedical Statistics, School of Community-Based Medicine, The University of Manchester
- *Dr Alex Wood* Lecturer in Applied Social Psychology, School of Psychological Sciences, The University of Manchester
- *Dr Bronwyn Kerr* Clinical Director and Consultant Clinical Geneticist, Genetic Medicine, Central Manchester University Hospitals NHS Foundation Trust and Honorary Senior Lecturer, Medical Genetics, The University of Manchester.

SELECTED RECENT RESEARCH TRAINING

- 2010 – ongoing: Research Team Leadership: A development programme for new and aspiring research group leaders, Faculty of Medical and Human Sciences and Staff Training and Development Unit, The University of Manchester.
- Mar 2010: Structural Equation Modelling using AMOS: 2-day course, Department of Mathematics and Statistics, University of Lancaster.
- Jan-Mar 2009: Advanced Online Research Methods module, University of Leicester (15 Masters level credits – Distinction awarded). Funded by ESRC Researcher Development Programme.
- Jan 2009: Structural Equation Modelling using M-Plus: 2-day course, Cathie Marsh Centre for Census and Survey Research, The University of Manchester.
- Apr–Jun 2008: Measurement: module, MSc Health Services Research, University of York.
- Jan–Mar 2008: Intervention studies (inc. RCT design): module, PhD student research training, School of Nursing, The University of Manchester.
- Jan–Mar 2008: Survey Design: module, PhD student research training, School of Nursing, The University of Manchester.
- Sep 2007– Jan 2008: Health Psychology: module, MSc Health Services Research, University of York.
- Apr 2007: Questionnaire design and analysis: 3 day course, University of Bristol, Dept Soc Med.

4. SERVICE AND LEADERSHIP

NATIONAL

- 2010 – 2013: Invited member of Advisory Group for Genetic Alliance UK's DH-funded project "Route Maps for Rare Conditions".
- 2007 – 2009: Contributed to the AGNC's successful application for regulation of the genetic counselling profession by the Health Professions Council.
- 2005: AGNC nominated representative to Health Technology Assessment (HTA).
- 2001 – 2006: Invited member of AGNC working group on Salaries and Career Structure for genetic counsellors. Contributed to developing a Career Structure for genetic counsellors, which was used by the Department of Health during implementation of Agenda for Change.

LOCAL

- 2009 – ongoing: Invited member of Central Manchester NHS Foundation Trust (CMFT) Multi-Professional Research Advisory Group, which drives the strategic development of research activities undertaken to deliver the CMFT Research Strategy for Nursing, Midwifery and Allied Health Professions.
- 2009 – ongoing: Invited member of Expert Panel for NIHR Research for Patient Benefit- funded project "Care of Ataxia Patients (COAP)" PI: Prof Katherine Payne.

- 2007 – ongoing: Invited member of Advisory Group for Rachel Belk’s NIHR PhD Studentship “Genetic and medical information in British Sign Language: terminology and its impact on access to services”.
- 2003 – ongoing: Co-ordinator of CMFT Genetic Medicine Genetic Counsellors’ Journal Club and internal Genetic Counsellor Professional Development training.

5. KNOWLEDGE TRANSFER AND PUBLIC ENGAGEMENT

KNOWLEDGE TRANSFER

- *Ehlers Danlos Support Group (EDS)* Invited book chapter “Genetic Counselling for EDS” for their booklet “The Management of Ehlers-Danlos Syndrome”. I asked my colleague Judy Tocher, who is part of the team delivering the National EDS Diagnostic Service in Sheffield, to co-write the chapter with me, which was submitted to the EDS Support Group in July 2010.

PUBLIC ENGAGEMENT

- *Genetic Alliance UK*: Invited presentation “Working together to improve clinical genetics services in the UK” at their annual conference “Giving patients a voice in the heart of debates”, London, 8 June 2010, which was attended by patients, the public and patient support group leaders.
- *Faces of Manchester*: As part of the first ever Manchester Science Festival, Nowgen ran a project entitled *Faces of Manchester* which was supported by a grant from The Wellcome Trust. The project aimed to stimulate interest in the genetic, social and cultural aspects of the human face and included a lunchtime lecture series. I was invited to give one of these public lectures, based on my published research, entitled “Family Faces: Appearances can be misleading”.

6. PUBLICATIONS AND RESEARCH CONTRIBUTIONS

PEER REVIEWED JOURNAL ARTICLES:

1. McAllister M, Dunn G, Todd C. Empowerment: Qualitative Underpinning of a New Patient Reported Outcome for Clinical Genetics Services. *Eur J Hum Genet* online publication 6 October 2010; doi: 10.1038/ejhg.2010.160.
2. McAllister M, Dunn G, Todd C. Patient Empowerment: A Measurable Patient-Reported Outcome for Chronic Conditions? *BMJ* (under review)

3. Myring J, Beckett W, Jassi R, Roberts T, Sayers R, Scotcher D, McAllister M. Shock, Adjust, Decide: Reproductive decision making in cystic fibrosis (CF) carrier couples - a qualitative study. *J Genetic Counseling* (under review)
4. McAllister M, Payne K, MacLeod R, Nicholls S, Donnai D, Davies L. What process attributes of clinical genetics services could maximize patient benefits? *Eur J Hum Genet* 2008;16, 1467–1476
5. McAllister M, Payne K, Nicholls S, MacLeod R, Donnai D, Davies L. Patient empowerment in clinical genetics services. *J Health Psychol* 2008;13(7):887-897
6. Payne K, Nicholls S, McAllister M, MacLeod R, Donnai D, Davies LM. Outcome measurement in clinical genetics services: a systematic review of validated measures. *Value in Health* 2008: 11(3):497-508
7. McAllister M, Payne K, Nicholls S, MacLeod R, Donnai D, Davies L. Improving service evaluation in clinical genetics: identifying effects of genetic diseases on individuals and families *J Genetic Counseling* 2007;16(1):71-83.
8. McAllister M, Payne K, Nicholls S, Donnai D, Davies L, MacLeod R. The emotional effects of genetic disease: implications for clinical genetics. *Am J Med Genet* 2007;143A(22):2651-2661
9. Payne K, Nicholls S, McAllister M, MacLeod R, Middleton-Price H, Ellis I, Donnai D, Davies LM. Outcome measures for clinical genetics services: a comparison of genetics healthcare professionals and patients' views. *Health Policy* 2007: 84(1):112-122.
10. McAllister M. Personal theories of inheritance, coping strategies, risk perception and engagement in Hereditary Non-polyposis Colon Cancer families offered genetic testing. *Clinical Genetics* 2003: **64**:179-89
11. McAllister M. Predictive genetic testing and beyond: A theory of engagement. *J Health Psychol*. 2002: **7**:491-508.
12. McAllister M, O'Malley K, Hopwood P, Kerr B, Howell A, Evans DGR. Management of women with a family history of breast cancer in the North West Region of England: training for implementing a vision of the future. *J Med Genet* 2002: **39**:531-5.
13. McAllister M. Grounded theory in genetic counseling research. *J Genetic Counseling* 2001: **10**:233-50
14. McAllister MF, Evans DGR, Ormiston W, Daly P. Men in breast cancer families: a preliminary qualitative study of awareness and experience. *J Med Genet* 1998: **35**:739-744
15. McAllister M, Kelly CT, Doyle E, Fogarty WM. The isomaltulose synthesising enzyme system of Serratia plymuthica. *Biotech Letts* 1990: **12**:667-672

EDITED WORKS: CONTRIBUTIONS

1. McAllister M. Outcome measures in clinical genetics services. In: eds. Kristofferson U, Cassiman JJ, Schmidtke J. *Quality Issues in Clinical Genetics Services*. Springer, 2010
2. McAllister M, Sabee C. Attributions and Personal Theories in: *Family Communication about Genetics: Theory and Practice*. In: eds. Gaff C, Bylund C. Oxford University Press, 2010

3. McAllister M. On the joys and sorrows of recruiting hospital patients. In: *Reflections on Research: The Realities of doing Research in the Social Sciences*, pp 67-69. Eds: Hallowell N, Lawton J, Gregory S. Open University Press, 2005.
4. McAllister M. On being used by research participants. In: *Reflections on Research: The Realities of doing Research in the Social Sciences*, pp111-114. Eds: Hallowell N, Lawton J, Gregory S. Open University Press, 2005.

INVITED SPEAKER: ALL EXPENSES PAID

1. "Patient empowerment in genetic counselling practice." Invited presentation, South African Society of Human Genetics Biennial Congress, South Africa, March 2011.
2. "Development of a coherent, multi-disciplinary research programme " Invited presentation, British Human Genetics Annual Conference, Warwick, 6 September 2010.
3. "Working together to improve clinical genetics services in the UK". Invited presentation, Genetic Alliance UK annual conference 2010 "Giving patients a voice in the heart of debates", London, 8 June 2010.
4. "Patient empowerment in clinical genetics services: Development of a new Patient Reported Outcome Measure". External departmental seminar, Department of Health Sciences, University of York, 10 March 2010.
5. "Patient empowerment in clinical genetics services." External departmental seminar, Institute of Medical Genetics, Cardiff University, 11 January 2007.
6. "Evaluating Genetics Services: Exploring the client perspective" Invited presentation, British Human Genetics Annual Conference, York, 13 September 2005.
7. "Towards Valuing Outcomes and Preferences for Genetic Services" Invited presentation, Association for Genetic Nurses and Counsellors Spring meeting, London, May 2004
8. "AGNC Career Survey" Invited presentation, Association for Genetic Nurses and Counsellors Spring meeting, London, May 2002.

SELECTED CONFERENCE ABSTRACTS:

1. McAllister M. Developing a coherent multidisciplinary research programme. *J Med Genet* 2010: 47: Suppl 1: S18
2. McAllister M, Wood AM, Dunn G, Todd C. Empowerment: Development and validation of a new outcome measure for evaluating genetic counselling interventions. *Eur J Hum Genet* 2010: 18 Suppl 1: EPL1.5.
3. McAllister M, Payne K, MacLeod R, Donnai D, Davies L. Patient empowerment in clinical genetics services: A new model developed from qualitative research. *Psychol & Hlth* 2008:23 Suppl 1: 179.
4. McAllister M, Payne K, MacLeod R, Donnai D, Davies L. Developing outcome measures for clinical genetics services: A triangulation approach. *Psychol & Hlth* 2008:23 Suppl 1: 179.

5. Myring J, Sayers R, Roberts T, Scotcher D, McAllister M Reproductive decision-making in CF carrier couples without an affected child. *Eur J Hum Genet* 2008: 16 Suppl 2: EP01.07.
6. McAllister M, Payne K, Nicholls S, Macleod R, Middleton-Price H, Donnai D, Davies L. Process and outcome in clinical genetics services: a new model developed from qualitative research. *J Med Genet* 2006: 43(1): Suppl 1: S62.
7. McAllister M, Payne K, Nicholls S, Macleod R, Middleton-Price H, Donnai D, Davies L. Evaluation of clinical genetics services – a qualitative study identifying outcome measures. *Eur J Hum Genet* 2006: 14: Suppl I EPL12.
8. McAllister M, Marks P. Attitudes and experiences of men at risk for BRCA1/2. *Eur J Hum Genet* 2006: 14: Suppl I EP55.
9. McAllister M, Payne K, Davies L, Nicholls S, Macleod R, Middleton-Price H, Donnai D: “How can we measure whether clinical genetic services are effective?” *J Med Genet* 2004: 41: Suppl 1: S47.
10. McAllister M, Payne K, Davies L, Macleod R, Nicholls S, Middleton-Price H. “Towards valuing outcomes and preferences for genetic services *Eur J Hum Genet* 2004:12 Suppl 1: EP38.

BOOK REVIEWS:

1. McAllister M. *Epidemics and history: Disease, Power and Imperialism* Sheldon Watts: Yale University Press, New Haven and London. 400pp. *Soc Sci Med* 1999;48:129
2. McAllister M. *The New Healers: The Problems and Promise of Molecular Medicine in the Twenty-First century*. 256pp. William R Clark: Oxford University Press, 1997. *New Genetics and Society* 2000;19(1):105-6
3. McAllister M. *Teach Yourself Genetics* M Jenkins: London, Hodder & Stoughton 1998. 154pp. *Instant Notes in Genetics* PC Winter, GI Hickey, HL Fletcher: Oxford, Bios 1998. 330pp. *New Genetics and Society* 2000;19(3):389-90

SELECTED PROFERRED PAPERS:

1. McAllister M, Payne K, Nicholls S, Macleod R, Middleton-Price H, Donnai D, Davies L. Towards measuring outcomes in clinical genetics services – a qualitative study identifying outcome measures. Oral presentation, International Congress of Human Genetics, Brisbane, Australia, August 2006.
2. McAllister M, Payne K, Davies L, Nicholls S, MacLeod R, Middleton-Price H, Donnai D. Poster presentation, American Society for Human Genetics Annual Conference, Toronto, October 2004: “How effective are clinical genetic services?”