

<p><b>Institution: De Montfort University</b></p>
<p><b>Unit of Assessment: 3 – Allied Health Professions, Dentistry, Nursing and Pharmacy</b></p>
<p><b>Title of case study: Ethnicity, Diversity, Inequality &amp; Sight Loss</b></p>
<p><b>1. Summary of the impact</b></p> <p>This case study describes the development of best practice guidelines about the issues facing people from black and minority ethnic (BME) communities with sight loss who would benefit from vision services (as well as suggesting ideas to improve BME access to vision services); contributions to the development of the UK’s Vision2020 strategy to transform the UK’s eye health, eye care and sight-loss services; and involvement in/evaluation of a major (£6million+) investment programme by RNIB for a series of ‘community engagement projects’ to address inequalities in eye health/care across the UK and affecting policy development in Wales &amp; Scotland.</p>
<p><b>2. Underpinning research</b></p> <p>The Mary Seacole Research Centre (MSRC) pioneered research in the nursing arena at DMU; however, in recent years research capacity and capability have increased significantly, and the MSRC has been subsumed into the Nursing and Midwifery Research Centre (NMRC).</p> <p>Prof Johnson [MRDJ], Director of Mary Seacole Research Centre (De Montfort University’s centre for research in diversity and health) has led the research field in issues around services for sight loss and ethnicity since his scoping review of the evidence in 1999 – Ethnic minorities and visual impairment: A research review (Johnson and Scase, 2000), commissioned by a major UK charity (now known as Thomas Pocklington Trust) and also published as ‘Visual impairment in ethnic minorities in the UK’ <i>International Congress Series</i> 1282 :438–442 (MO Scase, MRD Johnson) 2005. This research was undertaken at DMU by Johnson and Dr Mark Scase.</p> <p>Following on from the success of this review, a major development project was co-funded by Pocklington and the Housing Corporation, involving Johnson and Asesha Morjaria, [DMU, 2002–5] and a Big Lottery grant was awarded to a consortium of charities in Birmingham (Focus Birmingham, RNIB, Action for Blind People and various community-based groups) to run a three-year project to develop services in collaboration with the Mary Seacole Research Centre, the sole academic partners. Further research was undertaken by Johnson &amp; Dr Guo [DMU 2006–9].</p> <p>The research included literature review, development of a ‘participatory research’ approach with community groups, innovative action research including focus group interviewing, training community-based researchers, and evaluation studies as well as collaborative practice development and creation of a regional eye health forum bringing minority ethnic community groups and sight-loss service providers, statutory and voluntary, together for exchange of concerns and training in sight loss awareness/equality &amp; diversity issues.</p> <p>The research led to several major national workshops and conference presentations by Johnson, including: presenting to the Department of Health strategy group concerned; a series of national workshops organised by OPSIS (<a href="http://www.opsis.org.uk/">http://www.opsis.org.uk/</a> – an umbrella body of leading sight loss charities); a presentation to the Welsh Assembly Government, plus presentations to Vision2020 and RNIB international conferences.</p> <p>In 2010, the Department of Health funded another regional charity (Action for Blind People) to develop a similar project and encourage community development/volunteering in the East Midlands, with Johnson as a named researcher on the project [2010–12]. Action for Blind People has subsequently been awarded three-year Lottery Funding to develop this initiative (2013–15).</p>
<p><b>3. References to the research</b></p> <p><b>Key Outputs</b></p> <ul style="list-style-type: none"> <li>• Ethnic minorities and visual impairment: A research review (Johnson and Scase, 2000) commissioned by a major UK charity (now known as Thomas Pocklington Trust) and also published as Visual impairment in ethnic minorities the UK’ <i>International Congress Series</i> 1282 :438–442 (MO Scase, MRD Johnson) 2005</li> <li>• ‘Ethnicity, Sight Loss and Invisibility’ <i>British Journal of Visual Impairment</i> Vol 25,1 :23–33 (Johnson MRD, Morjaria-Keval A) 2006 (Peer reviewed)</li> <li>• Our Vision Too: Improving the access of ethnic minority visually impaired people to appropriate services; building a supported community referral system – Research Findings 8; Pocklington Trust/ De Montfort University June 2005 – ISBN 0-9550647-0-8 [Peer reviewed]</li> </ul>

## Impact case study (REF3b)

- Our Vision Too: improving the access of ethnic minority visually impaired people to appropriate services: building a supported community referral system - Occasional Paper 10; Pocklington Trust/ De Montfort University November 2006 – ISBN 0-9554465-0-3) [Peer reviewed]

**Funding**

- 2002: Thomas Pocklington Trust and Housing Corporation ~£92,361 (TPT) + £5,000 (HC) Development of a Community-Based referral system for visual impairment in black and Asian communities in Birmingham (PI: MRDJ) three years. Competitive, Peer reviewed funding
- 2006: Big Lottery/Birmingham Focus: MSRC was part of team obtaining funds to manage three-year development project 'Community View' – facilitating uptake of services for sight loss among BME groups in Birmingham. [Competitive tender to National Lottery Board] [MRDJ]
- 2010 Vision5: Review of Interventions to increase uptake and concordance/retention of marginalized at risk groups in relation to eye health screening to prevent avoidable sight loss £29,400 from RNIB (Royal National Institute of Blind People) (with Dr Mark Scase, DMU) [Peer reviewed, competitive tender]
- 2010 Vision4: BME Volunteering and self-help project, Action for Blind People/DH S64 grant £23,000 Evaluation and research support for DH-funded project in East Midlands [Peer reviewed, national government funding award] [MRDJ]

**4. Details of the impact**

Historically, there has been little significant research or service provision targeted at minority ethnic or other vulnerable groups while smaller early projects have been forgotten or were never formally written up to be included in the social policy evidence base. In the aftermath of inquiries into health inequalities (notably Acheson and Marmot) and Equalities legislation, and following significant lobbying, there has been pressure to address these issues and eye health has now been recognised as a significant public health issue following new QOF public health guidelines in 2012.

The national sight loss charity Pocklington Trust commissioned and published a 'Good Practice Guide' (Joule & Levenson 2008), which states explicitly that: "This good practice guide builds on an action research project and literature review by the Mary Seacole Centre, De Montfort University, and on developmental work and research in a range of national and local organisations. It is designed to provide information on issues facing people from black and minority ethnic (BME) communities with sight loss who would benefit from vision services, as well as suggest ideas to improve BME access to vision services." [Joule & Levenson 2008]. This is the only such guidance extant in Europe and is thus widely used and cited, as described in section 5.

The findings of Johnson *et al's* research (which highlighted exclusion/inequality of access for minority groups and worse outcomes) also fed into a major (£6million+) investment programme by RNIB in 'community engagement projects' to address inequalities in eye health/care across the UK. As a part of this programme, The Mary Seacole Research Centre were commissioned to undertake the evidence review that underpins this investment, now published by RNIB as RNIB report number CEP/01, 2011 (see section 5 for more information).

As a consequence of his research, Johnson was also asked to contribute to development of a training resource on 'ethnicity and optometry' for the General Optical Council's CPD agency DOCET in 2011. The DOCET training (CPD) resource has had wide distribution. The General Optical Council has distributed approximately 11,000 copies of the DOCET 'Optometry and Ethnicity' DVD to optometrists throughout the UK. Over 300 optometrists have submitted responses to the multiple choice questions on this programme to gain CET points. DOCET note that they expect this to increase. The programme is now also available online to UK registered optometrists, and they are in the process of developing the web site to incorporate more mechanisms for direct feedback on specific topics.

Finally, Johnson was invited to join the national strategy development group (Vision2020 UK) to advise on equality and (ethnic) diversity issues in the preparation of the national policy guidance ([www.vision2020uk.org.uk](http://www.vision2020uk.org.uk)) – leading to the national eye health strategy. Vision 2020 UK also supports the international initiative of the same name. Johnson has also been asked to join the new Low Vision policy subgroup looking at BME and equality issues to inform national policy in 2013.

*The following dissemination activities all contributed to the impact of this research:*

- Invited Presentation (MRDJ), UK Department of Health's Eye Care Strategy Group (May 2010)

- Prof Johnson delivered a workshop at the Vision2020 Annual Conference at QE Conference Centre London 16 June 2011 <http://www.vision2020uk.org.uk/UKVisionstrategy/>
- June 2011 MJ was interviewed by RNIB Radio and TV for the sight-impaired following presentations at Vision2020 Conference on ethnicity and sight loss.
- 'Ethnicity and Visual Impairment – Overcoming the Barriers' - Joint Conference by Gwent Association for the Blind & Welsh Assembly Government: "*Understanding the Needs of People with Sight Loss from Minority and Ethnic Communities*" Cardiff, Feb 2009 – over 500 attendees including two Cabinet Ministers of WAG.
- 2007 'Key Advisor' to the RNIB and UK Vision Strategy Group (an initiative of Vision2020 UK) on aspects of ethnicity in eye health.
- 2007 Supported Vision2020 & Low Vision Group with evidence to present to All-Party Parliamentary Group on Eye Health and Visual Impairment (with Birmingham Focus, our practitioner partners).
- 'Research regarding B&ME Groups, VI and take-up of Services' – Keynote address, OPSIS Conference: Focus on Needs of Vision Impaired People from Black and Minority Ethnic Groups, London 2007 (National Association for the Education, Training and Support of Blind and Partially Sighted People).
- 'Improving the Access of Ethnic Minority Visually Impaired People to Appropriate Services' – Keynote Speech, OPSIS/Queen Alexandra College World Vision Day workshop, Oct 2005.
- 'Improving the access of ethnic minority visually impaired people to appropriate services' – BME & Sight Loss Day, Henshaws Society for Blind People, Manchester, 18 February 2005.
- 'Ethnic Minorities and Visual Impairment' – Royal National Institute for the Blind, London, September 2001.

#### 5. Sources to corroborate the impact

For examples of lobbying and pressure to see eye-health recognised as a significant public health issue please see the following links:

- <http://www.vision2020uk.org.uk/ukvisionstrategy/commhome.asp?section=165&sectionTitle=Ey+e+care%3A+a+public+health+issue>
- <http://www.networks.nhs.uk/news/eye-health-professionals-welcome-the-first-ever-public-health-indicator-for-eye-health>
- <http://www.vision2020uk.org.uk/ukvisionstrategy/commhome.asp?section=221&sectionTitle=Briefing+on+Public+Health+Indicator&preview=1>
- [http://www.rnib.org.uk/professionals/Documents/Preventing\\_avoidable\\_sight\\_loss\\_August\\_2012.doc](http://www.rnib.org.uk/professionals/Documents/Preventing_avoidable_sight_loss_August_2012.doc)

The full citation for the Joule and Levenson good practice guide is Nikki Joule and Ros Levenson 2008 Good Practice Guide No 3: *People from Black and Minority Ethnic (BME) communities and vision services: a good practice guide* ISBN 978-1-906464-03-5. The report can be downloaded as the PDF via this hyperlink [PDF version \(286kb\)](#) (accessed 30/09/13) or a paper copy can be made available upon request. The third page of the document is where the cited statement about the underpinning research from DMU can be seen. For typical examples where this report has been cited please see the following links (all accessed 30/09/13):

- 'Achieving age equality NHS practice guide' (April 2010) <http://age-equality.southwest.nhs.uk/nhs-practice-guide.php> – this NHS practice guide lists Nikki Joule as one of its authors (see acknowledgements on pg 2) and cites the Joule and Levenson report as reference 233 on pg 100 where BME specific issues are discussed). A PDF of this report can be made available upon request.
- Social Care Online (from the Social Care Institute for Excellence) list the report on their site, see: <http://www.sciesocialcareonline.org/profile.asp?guid=51b1f17c-107f-490e-a1c0-15facef3c4db> Social care online is "the UK's largest database of information and research on all aspects of social care and social work. Updated daily resources include legislation, government documents, practice and guidance, systematic reviews, research briefings, reports, journal articles and websites. Every resource listed includes an abstract. Links to full text are also included where available. Social Care Online is a particularly useful resource for staff, students and researchers working in social work and social care" and thus provides a widespread non-academic dissemination pathway.

## Impact case study (REF3b)

- The Afiya Trust Manifesto provides an example of where the Joule and Levenson report has been taken up by the Third Sector: Achieving Equality in Health and Social Care. A Framework for Action – The Afiya Trust Manifesto 2010. This report can be downloaded from Academia.edu [http://www.academia.edu/1338377/Achieving\\_Equality\\_in\\_Health\\_and\\_Social\\_Care\\_A\\_framework\\_for\\_action\\_The\\_Afiya\\_Trust\\_Manifesto\\_2010](http://www.academia.edu/1338377/Achieving_Equality_in_Health_and_Social_Care_A_framework_for_action_The_Afiya_Trust_Manifesto_2010)
- The following link, from the Danish Centre for Visual Impairment, provides further evidence that the report, the only such guidance in Europe, has been taken up by an international audience: <http://netpubs.socialstyrelsen.dk/Nyhedsbreve/2009/NYH032009/html/chapter12.htm> – the report is listed under the 8<sup>th</sup> sub-heading (Etniske minoriteter – or 'ethnic minorities' in English) towards the bottom of this page, the bibliography for the site.
- The Welsh Eye Health Initiative also draws on Johnson's evidence in its deliberations: see presentation by Gillian Richardson (Director Public Health) for Public Health Wales, [http://www.vision2020uk.org.uk/ukvisionstrategy/core/core\\_picker/download.asp%3Fid%3D450&sa=U&ei=pYROUszaDoON7QaZn4GoAw&ved=0CDEQFjAF&usq=AFQjCNFI6OullwybCO4P\\_lwZJnfbPLCwuQ](http://www.vision2020uk.org.uk/ukvisionstrategy/core/core_picker/download.asp%3Fid%3D450&sa=U&ei=pYROUszaDoON7QaZn4GoAw&ved=0CDEQFjAF&usq=AFQjCNFI6OullwybCO4P_lwZJnfbPLCwuQ)

Johnson and his team were commissioned to evaluate the evidence underpinning the RNIB's £6million+ investment programme in 'community engagement projects' to address inequalities in eye health/care across the UK. The report they produced was *A review of evidence to evaluate effectiveness of intervention strategies to address inequalities in eye health care*. (Johnson MRD, Cross V, Scase MO, Szczepura A, Clay D, Hubbard W, Claringbull K, Simkiss P & Leamon S). (RNIB report number CEP/01, 2011). This can be seen on the RNIB website – [http://www.rnib.org.uk/aboutus/research/reports/2012/eye\\_intervention\\_report.doc](http://www.rnib.org.uk/aboutus/research/reports/2012/eye_intervention_report.doc)

The RNIB's link to the pilot eye health interventions can be seen via this link

<http://www.rnib.org.uk/professionals/health/research/interventions/Pages/pilot-interventions.aspx>

This page clearly states that Johnson et al from DMU were commissioned to undertake the evidence review. The research and investment programme were also profiled on the RNIB's page targeted at Health Professionals; see

[https://www.rnib.org.uk/professionals/health/Pages/health\\_professionals.aspx](https://www.rnib.org.uk/professionals/health/Pages/health_professionals.aspx) (RNIB links all accessed 30/09/13).

An interview with Johnson about his research and findings for RNIB Radio and TV for the sight-impaired was published in audio-newsletters circulated to all members of RNIB and other sight loss agencies June 2012. Copies can be made available upon request.

The General Optical Council's Directorate of Optometric Continuing Education and Training (DOCET – [www.docet.info](http://www.docet.info) accessed 30/09/13) training video, which features Prof Johnson, has been made available publicly to non-members through the video archive section of their website see <http://www.docet.info/cms/archive/index.cfm> (accessed 30/09/13). Johnson is listed as the third speaker. The website states that the "Optometry and Ethnicity" resource supports optometrists in improving their understanding of how ethnicity can impact clinically on the different types of eye conditions that may affect patients. It also looks at various cultural considerations that can affect patient examination and communication within your practice and provides guidance on developing 'cultural competence'. Copies of the training materials can be made available upon request, and the co-ordinator of the Directorate of Continuing Education and Training is happy to verify the claims in this case study about the number of copies of the material that have been distributed, the feedback received, and Johnson's role in the process.

Johnson's involvement in the Vision2020 programme can be seen via this link (which describes a presentation he gave to their conference in 2007):

<http://www.vision2020uk.org.uk/library.asp?libraryID=942&section> (accessed 30/09/13). Evidence for Johnson's involvement in the Low Vision policy subgroup is available through personal correspondence which can be made available upon request (or via, the co-ordinator of the Low Vision strategy).

Evidence for the dissemination strategy listed in section four can be provided by the author upon request (in the form of personal correspondence, papers and abstracts etc.).