

Impact case study (REF3b)

Institution: University of York
Unit of Assessment: 23, Sociology
Title of case study: Shaping policy and practice for those with, or at risk of sickle cell and thalassaemia disorders
<p>1. Summary of the impact</p> <p>Karl Atkin participated in a research programme that explored ways of best supporting those with or at-risk of sickle cell and thalassaemia from the perspective of patients, families, practitioners and policy makers. The findings have had an accumulated impact on: care standards for a range of health care professional and national policy bodies; public outreach; ante-natal care and screening policy; and have informed the training and education of doctors and nurses on how best to communicate with those at risk of inherited blood disorders. Findings have also contributed to the evidence base on social care and education, including providing practical guidance to teachers.</p>
<p>2. Underpinning research</p> <p>The case study is concerned with improving care and gaining recognition for those at risk of recessively inherited blood disorders, sickle cell and thalassaemia, which in the UK, predominantly affect ethnic minority populations. Over 17,000 have the conditions making them the most common recessive disorders in the UK. There are over 0.5m carriers.</p> <p>The research was undertaken between 2005 and 2013 by Atkin (Senior Lecturer/Professor) as either principal investigator (PI) or co-investigator (CI), whilst at the University of York. As PI he led projects investigating screening policies (and their implementation). As CI he was involved in projects that examined school education for people affected by sickle cell and thalassaemia. He contributed to the preparation of bids, analysis of research data, liaison with stakeholders, preparation of publications, and other dissemination materials and impact activities with practitioners and policy makers.</p> <p>A qualitative project, (2004-2006, Atkin PI, <i>Decision making and antenatal screening: to what extent do faith and religious identity mediate choice?</i>) interviewed young people, who were thinking about starting a family, to find out how faith would influence decisions about ante-natal screening (funder: National (NHS) Screening Committee)^a. The project began at the University of Leeds, with analysis and dissemination completed while Atkin was at York (2005/6). Faith is often assumed by policy makers and health practitioners to be a major factor in explaining why people refuse ante-natal screening. The research provided a more nuanced account^{1,2} whereby faith beliefs emerged as negotiable and did not determine choices. When making decisions, people used individually derived interpretations of their faith, alongside perceptions about the severity of the condition.</p> <p>Atkin was CI and was involved in all aspects of the research on, <i>Education for Minority Ethnic Pupils: Young People and Sickle Cell Disease (SCD)</i>, led by Simon Dyson (De Montfort University), 2005-2011 funded by the ESRC^c. The project sought the perspectives of children, their parents, teachers and policy makers on how best to improve the educational experience of those with SCD, by using questionnaires, interviews and focus group discussions. The findings demonstrated the difficulties faced by pupils and parents in convincing teachers (and Local Education Authorities) to take SCD seriously^{3,5}. Few schools had formal policies and good practice was the exception rather than the rule. This research concluded that pupils with SCD, faced disadvantage when at school, which affected their later life chances.</p> <p>A randomised control trial led by Theresa Marteau (Kings College, London; 2005-2010) explored the feasibility of offering ante-natal screening in primary care by comparing it to secondary care (<i>The SHIFT Trial</i>)^b. As CI Atkin (with Mike Calnan) was responsible for the qualitative component of the study, which explored the views of pregnant women and practitioners^{4,6}. The study showed how Department of Health ante-natal screening targets were not being met (27% of women were screened within 10 weeks of gestation, compared to the target of 90%), but established the effectiveness, acceptability and feasibility of offering screening in primary care, from the viewpoint of both practitioners and mothers.</p> <p>The SHIFT Trial suggested fathers were rarely screened during ante-natal screening. Little was known about why. In January 2011, Atkin (PI) secured NIHR funding to explore prospective fathers' attitudes to ante-natal screening (end date: April 2014)^d. Atkin (PI) also secured ESRC funding (Jan 2011 to April 2014)^e, to explore how people feel about being a 'healthy' trait carrier; an important area of research since screening policies are identifying more carriers than ever before. Preliminary findings from these projects have begun to inform policy (see below).</p>

3. References to the research

¹Atkin, K., Ahmed, S., Green, J., Hewison, J. (2008) 'Decision making and antenatal screening for sickle cell and thalassaemia disorders: to what extent do faith and religious identity mediate choice?' *Current Sociology*, 56 (1) pp 77-98. DOI: 10.1177/0011392107084380

²Atkin, K. (2009) 'Negotiating ethnic identities and health' in Graham, H (ed) *Understanding health inequalities* (2nd edition), Maidenhead, Open University Press, pp 125-140.

³Dyson, S, Atkin, K. Evans, H, Dyson, S, Culley, L and Rowley, D.T. (2010) 'Disclosure and sickle cell disorder: A mixed methods study of the young person with sickle cell at school', *Social Science & Medicine*, 70, pp 2036-2044. DOI: 10.1016/j.socscimed.2010.03.010

⁴Dormandy, E., Bryan, S., Gulliford, M.C., Roberts, T.E., Atkin, K et al (2010) 'Antenatal screening for haemoglobinopathies in primary care', *Health Technology Assessment* 14 (20) DOI: 10.3310/hta14200

⁵Dyson, SM; Atkin, K; Culley, LA; Dyson, SE; and Evans, H. (2011) 'Sickle cell, habitual dispositions and fragile dispositions: young people with sickle cell at school', *Sociology of Health & Illness*, 33 (3) pp 465-483. DOI: 10.1111/j.1467-9566.2010.01301.x

⁶Tsianakas, V., Atkin, K., Calnan, M., Dormandy, E and Marteau, T. (2011) Offering antenatal sickle cell and thalassaemia screening to pregnant women in primary care: a qualitative study of women's experiences and expectations of participation, *Health Expectations*, 15, pp 115-125. DOI: 10.1111/j.1369-7625.2011.00669.x

Grants associated with work (with quality indicators)

^aAtkin, K., (PI) Ahmed, S., Hewison, J., and Green, J., 2004-2006, 'Community engagement with haemoglobinopathy screening programmes: the role of faith and religion', National Screening Programme for Sickle Cell and Thalassaemia, £24,955. *Commissioned project, producing two peer review publications in Current Sociology¹ and Prenatal Diagnosis*

^bMarteau, T., (PI) Dormandy, K., Ades, T., Anionwu, E., Bryan, S., Calnan, M., Atkin, K., Roberts, T Davies, V., Dick, M., Gulliford, M., Harris, H., Johnson, T., Jones, P., Kavalier, F., Logan, J., and Wild, B., 2004-2008, 'Antenatal screening for haemoglobinopathies in primary care: a cluster randomised trial to inform a simulation model' (The SHIFT Trial), Health Technology Assessment Programme, £598,596. *Competitive, peer-review funded project producing ten peer reviewed papers^{4,6} (e.g. British Journal of General Practice and Health Expectations.)*

^cDyson, S., (PI) Atkin, K., Culley, L., Demanine, J and Dyson, S.E., 2006-2011, 'Education for Minority Ethnic Pupils: Young People with Sickle Cell Disease', Economic and Social Research Council, £208,000. *Competitive, peer-review funded project which to date project has produced, seven peer reviewed papers^{3,5} e.g. Social Science & Medicine, Sociology of Health & Illness, International Studies in Sociology of Education and British Educational Research Journal. The project was also graded outstanding, following peer review by the ESRC.*

^dAtkin, K., (PI) Dyson, S., Chu, C and Nortey P. 2011-2014, 'Involving fathers in ante-natal screening for sickle cell disorders: improving informed decision', NIHR Research for Patient Benefit, £239,000 *Competitive, peer-review funded project.*

^eAtkin, K., (PI) Dyson, Ahmad, W and Anionwu, E 2011-2014, 'Living with sickle cell or beta thalassaemia trait: implications for identity and social life', Economic and Social Research Council, £245,000. *Competitive, peer-review funded project.*

4. Details of the impact

The accumulated understanding and knowledge generated by the research has resulted in four broad areas of impact, with the overall aim of transforming and informing policy and practice, for a variety of different stakeholders, while stimulating an informed public debate.

A. Care standards and challenging neglect

An aim of these inter-related impacts – informed by the research projects on faith, on education and the SHIFT Trial^{a,b,c} - was to establish good, evidence-based practice, accessible to those working in health and social care; and to challenge the neglect of sickle cell and thalassaemia, while ensuring policy was connected with broader (theoretical) debates about choice, preference and identity.

- Several impacts challenged the neglect of sickle cell and thalassaemia among mainstream service providers working in health and social care, while encouraging practitioners to adapt evidence based practice. Impacts aimed at generating debate include a fact sheet for the Race Equality Foundation (1); an editorial for the National Institute of Health Library, in

celebration of National Sickle Cell month (2009); and an evidence based briefing paper for the National Children's Bureau (No: 246).

- Atkin was invited to produce a report for the All Party Parliamentary Committee on Sickle Cell and Thalassaemia Disorders (chaired by Diane Abbott, MP) on the care available to those with sickle cell and thalassaemia disorders (2). This informed several parliamentary questions and a debate in the House of Lords, initiated by Lady Benjamin on sickle cell disorders, in which Atkin was invited to contribute ideas to her speech (3). Such activities raised the public profile of the conditions.
- Atkin was invited by the Department of Health to become a contributing editor to the UK's Standards of Care of Adults with Sickle Cell Disorders (4). In addition to advising on the whole document, he specifically drafted the chapter on social care. The book offers evidence-based advice to health care professionals and commissioners, providing a benchmark against which NHS care for SCD and thalassaemia should be judged. This document was endorsed by the UK Forum on Haemoglobin Disorders, who recommended that it should inform standard operating practice for those professionals offering haematological care in the NHS.
- During September 2011, Atkin was invited to a closed workshop organised by the Dutch Ministry of Health to advise civil servants, senior service managers and policy makers on screening policy. This was followed up by a symposium, (Testen op HbP Dragerschap vor en tijdens de zwangerschap een kwestie van etniciteit) held at Radboud University (Nijmegen) in November 2012, to encourage debate among key health care managers on how best to offer ante-natal screening in multi-cultural societies. Atkin was invited to give the opening talk.

B. Public outreach and raising awareness

Informed reproductive choice relies on a well-informed 'at-risk' population. Using insights gained from his programme of research,^{a,b,d,e} Atkin has influenced and challenged national policy on screening, through his position as Chair of Public Outreach, for the (NHS) National Screening Committee for Sickle Cell and Thalassaemia; and as member of the advisory group for National NHS Audit of New-born Outcomes (5). Under his guidance, the Committee has: established 12 peer educators, working throughout England to raise awareness of sickle cell and thalassaemia among at-risk communities. To date these peer educators have provided face-to-face information to over 1000 people from at-risk communities, who in turn have cascaded information through their social networks. Other activities include production of a DVD (The Family Legacy) aimed at African communities (6), who had been previously neglected by screening policies. Community screening and repeated plays on local cable television in London (Ghana TV) suggest the DVD has reached 300,000 people (6). The Director of Communications of the NHS Screening Programme (Sickle Cell and Thalassaemia) Committee wrote: *'I would like to thank you in the warmest possible terms for everything you have done to support the outreach work. You have been an outstanding source of wisdom and knowledge and I cannot say how much I have appreciated this'*.

Since 2008, Atkin has been advising NHS Wales on the re-organising of screening services. His input, based on the research cited above^{a,b,d,e} has included ensuring any proposed changes in service provision are evidenced-based (e.g. the Health Impact Assessment of the proposed accommodation changes to the Cardiff Sickle Cell and Thalassaemia Centre by Susan Toner: March 2011, which Atkin helped draft). He also worked with 'Cardiff Friends of Sickle Cell and Thalassaemia' to ensure any changes to provision took account of the views of the local community. This included co-ordinating and participating in a community conference, *Community Spirit in Crisis* (November 2012), in which 60 lay participants along with representatives from commissioners debated proposed changes. An outcome was to prevent the closure of a community screening centre in Cardiff and its removal to a more impersonal local hospital, which was opposed by the community. The conference organiser and community development worker for the 'Cardiff Friends of Sickle Cell and Thalassaemia', said: *'Thank you so much for your support...[You have] inspired and motivated us, the support group to continue to strive for equity of services for Sickle Cell & Thalassaemia patients, carers, and at risk communities'*.

The Secretary of State for Health (December 2011) initiated a consultation exercise on the re-organisation of screening services in England. He requested advice from all the directors of specialist screening programmes (such as sickle cell and thalassaemia) on a confidential consultation document. The Sickle Cell and Thalassaemia Programme Director sought advice of Atkin and used part of his written response (informed by the research outlined above) in her

evidence to the Secretary of State for Health.

C. Government policy on screening and supporting informed choice

In 2012, as Chair of Public Outreach, Atkin has used his research on faith, involving fathers in ante-natal care and the social consequences of being a trait carrier to help draft nationally^{a,b,d,e} available, NHS published leaflets for informing 'at-risk' communities (7) including: an introduction to screening aimed at-risk parents; more detailed leaflets outlining the screening process to parents at risk of a range of haemoglobinopathies; and a leaflet providing advice to fathers on ante-natal screening. These leaflets have been circulated to all primary health care professionals in England, with a letter of recommendation from the Sickle cell and Thalassaemia Programme Director, explaining their use. Atkin's research^{a,b,d,e} informed the content and style of these leaflets. His research also provided evidence on how best to present accessible messages, consistent with how individuals make sense of their health, in a way that can help them make choices, commensurate with their own values and beliefs. The aim was to raise awareness among at-risk communities and practitioners, while providing reliable and accurate information, thereby facilitating informed choice.

The widely published SHIFT study^b was the first in the UK to provide evidence that current screening targets set by the Department of Health are not being met. This challenged policy thinking and informed the need for the leaflets outlined above. A letter written by the Sickle Cell and Thalassaemia Programme Director also drew the findings to the attention of commissioners. It initiated a more pro-active engagement with fathers on the part of the Public Outreach Committee, led by Atkin (see above). The research also led to the establishment of a national audit on newborn outcomes, which will run for three years (2012 to 2015). The findings aimed at national policy makers and local health care commissioners will inform policy by identifying bottlenecks in the screening process and suggesting solutions to overcome them. Atkin was invited to join the project steering group to provide independent advice on governance.

D. Educational support for children with SCD

Atkin was CI on an ESRC funded study, exploring the educational experience of those with a sickle cell disorder^c. One study impact has been the uptake of its guidance on how to manage sickle cell disease in the classroom by the Department for Education (DfE) on their web-site providing guidance to all schools and teachers in England on managing medical conditions in schools (8)

5. Sources to corroborate the impact

(1) Evidenced based fact sheet for Race Equality Foundation <http://www.darkredweb.net/REF-better-health/sites/default/files/briefings/downloads/health-brief17.pdf>

(2) Report to All Party Parliamentary Committee on Sickle Cell and Thalassaemia Disorders <http://www.dmu.ac.uk/documents/health-and-life-sciences-documents/sickle-cell/appgreportmarch2009.pdf>

(3) Evidence of parliamentary questions, <http://www.theyworkforyou.com/wrans/?id=2013-02-11b.142679.h&s=Sickle+cell#g142679.r0> and Lady Benjamin's speech <http://www.publications.parliament.uk/pa/ld201213/ldhansrd/text/130110-0002.htm>

(4) Standards of Care of Adults with Sickle Cell Disorders <http://sct.screening.nhs.uk/getdata.php?id=10991>

(5) Details of National NHS Audit of New-born Outcomes <http://sct.screening.nhs.uk/getdata.php?id=11558>

(6) Information on DVD <http://sct.screening.nhs.uk/cms.php?folder=2454> and distribution <http://sct.screening.nhs.uk/circulate> (edition 11, p6)

(7) Details of information leaflets <http://sct.screening.nhs.uk/news.php?id=12225> & <http://sct.screening.nhs.uk/circulate> (edition 11, p6)

(8) Guidance on managing sickle cell disorders in schools

<http://www.education.gov.uk/schools/pupilsupport/pastoralcare/b0013771/managing-medicines-in-schools>.

Corroboration of work on public outreach: Programme Director and Director of Communications, NHS Screening Programme (Sickle Cell and Thalassaemia), King's College London.

Corroboration of work in Wales: Public Health Wales, NHS Wales, Cardiff & Vale Public Health Team, Cardiff and Vale University Health Board