

Institution: University of Westminster
Unit of Assessment: UoA 34; Art and Design: History, Practice and Theory
Title of case study: Sickle Cell Awareness
<p>1. Summary of the impact</p> <p>Jane Thorburn's research into Nigerian cinema and storytelling forms, together with her long-running practice-based research within documentary and experimental arts filmmaking, led to a NHS commission to produce a film on sickle cell disease (SCD). <i>The Family Legacy</i> project has had an impact on cultural values and health and wellbeing in civil society, and on public services and education in the UK and Nigeria. Making innovative use of the story-telling conventions of Nollywood home videos in order to engage its audience, the film successfully led an NHS campaign to educate - and enhance the public service offered to - people at risk of producing children with debilitating sickle cell disease, enabling them to make informed health choices before conception and during pregnancy. It also challenged taboos and myths that previously surrounded the disease. <i>The Family Legacy</i> has been widely disseminated, not only on television channels in UK, USA and West Africa, but also on genealogical websites and in ground-breaking outreach campaigns in barbers' shops, mosques, churches and doctors' surgeries in the UK. An estimated 12 million people have been reached by this campaign, with positive feedback of attitude change from the 3500+ people attending NHS awareness-raising sessions.</p>
<p>2. Underpinning research</p> <p>The research of Jane Thorburn, (Senior Lecturer/ Principal Lecturer 2001-present), has developed over the past 12 years, beginning with her background in documentary, music and experimental arts television production and moving on to her more recent engagement with West African cultural forms, story-telling modes and social and medical issues. Her NHS commission to research and produce a film on SCD arose directly out of the distinctive trajectory of her research career.</p> <p>One of her core interests lies in exploration of documentary and film form: she was an established professional filmmaker with a twenty-year track record in the television industry before joining the University of Westminster. Since 2001 she has become increasingly interested in pushing the boundaries of these forms where appropriate, from her experimental dance film <i>The Lift</i> (2001), which dealt with human behaviour and phobias, to <i>God Is Great</i> (2007), in which she approached the taboo topic of fistulas among West African women (holes between vagina and bladder caused by childbirth before the girl's pelvis is fully grown) through an unusually poetic and lyrical treatment. The film allowed women suffering from fistulas – and the attendant cultural prejudices – to tell their own stories in their own voices, as active agents, not passive victims.</p> <p>The second strand to Thorburn's recent research has been an engagement with West African cultural forms, including a particular interest in the Nigerian film industry (Nollywood) and its story-telling traditions. In 2007, at a time when little was known about Nollywood within the academy, and when the only documentaries about it were superficial and patronising, she travelled alone to Nigeria to research this industry and its history. This resulted in two documentaries, <i>Nollywood 1</i> (2008) and <i>Nollywood 2</i> (2010), both submitted to REF2. Thorburn's decision to conduct her core research through filming interviews enabled her to engage with the Nigerian filmmakers directly and establish a 'filmmaker to filmmaker' rapport on camera. She gained unparalleled access to her subjects and her resulting documentaries provide an intimate portrait of Nollywood filmmaking, on its own terms and without patronising it. Her research established who the key players were, which were the most successful films, and what were the economic and legal problems facing this industry. It also challenged previous assumptions about the industry that had negatively compared Nollywood's output with cinema from Europe and the USA. She allowed the filmmakers' own voices to explain how the industry's innovative low-tech production and distribution methods operated and how these dramas drew on African story-telling traditions. She argued that the major output of Nollywood was diverse and that the dramas that circulated on VCD were more akin to television soap opera than Hollywood or art cinema. Her research for these two projects also established that Nigerian mainstream audiences liked family dramas, with moral stories, that were informative as well as entertaining. Comedy and spectacularly opulent settings were popular ingredients. Audiences mostly watched these VCDs at home or in small groups where viewers</p>

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would discuss the characters' behaviour. Thorburn's own production process innovatively echoed Nollywood's production and distribution methods: she made both films on DVCAM on minimal budgets and used informal distribution channels to reach large audiences, leading to wide dissemination of the work, including through piracy around the world.

The success of Thorburn's 2007 film *God Is Great* in educating medical professionals and mainstream audiences about fistulas (the BMA screened the film for doctors at their conference in 2008), combined with her knowledge of the West African diaspora, led to an invitation from the NHS (via the charity Womanbeing Concern) to develop an innovative outreach programme to inform the UK-based African and Caribbean diaspora about SCD and the genes that cause it.

Drawing on her knowledge of what films appeal to Nigerian audiences, and following research into the disease itself, Thorburn convinced an initially reluctant NHS to fund production of a drama that drew on Nigerian home video conventions. *The Family Legacy* (2009) was researched, produced, directed and edited by Thorburn, who also devised the storyline and commissioned Nigerian/UK writer Ade Solanke to write the full dialogue script. The plot unfolds around dramas within a wealthy extended family, whose members unknowingly possess different combinations of gene status, with tragic consequences for a new baby. The birth has serious repercussions on family relationships, when all have to reassess their past fears and prejudices. The key research focus of this project was to establish how best to engage with hard-to-reach audiences of West African cultural backgrounds, without alienating the sensitivities of men or of various religious groups, and without patronising or haranguing its audience. Script and format ideas were based on detailed case study research by Thorburn and tested on audiences as the film developed. The final format that Thorburn devised was a drama entertainment that echoes the storylines, opulent settings and comedy of Nollywood soaps, whilst educating audiences with accurate medical information.

3. References to the research

1. *The Lift*, (2001), 9 mins. Directed and Produced by Jane Thorburn. £50,000 from Arts Council and BBC2 for the series 'Dance on Camera'. Broadcast on BBC2 (31 Dec 2001), BBC Knowledge (2002), and on channels in Australia and Europe. Selected for Cannes HD Film Festival 2001. DVD available from HEI, also online in Arts on Film Archive: <http://artsonfilm.wmin.ac.uk/films.php>
2. *God is Great: but what can I do with my life?* (2007), a 22 minute documentary made in Northern Nigeria, that explored in poetic form the stories behind the medical problems caused by fistulas occurring in young women forced into childbirth too young. Screened on TV in Nigeria and UK, including The Community Channel and HiTV. Researched/produced/directed/camera/edited by Jane Thorburn. Evidence of screenings and DVD available on request from HEI.
- 3: *Nollywood: Just Doing It*, (2008), a 30 minute documentary on the history of the Nigerian film industry, researched/produced/directed/camera/edited by Jane Thorburn. Widely screened in festivals and on Nigerian TV and Sky UK. Part-funded by UOW (£3000). Submitted in REF 2; DVD available in portfolio. See also: <http://www.janethorburn.co.uk/nollywoodJustDoingIt.html>
4. *The Family Legacy*, (2009), a 23 minute drama on sickle cell disease, researched/produced/directed/edited by Jane Thorburn, who also wrote the story on which the script was based. She also produced factual extras for the DVD and NHS website (filmed case studies and a counseling session). Multiple screenings in festivals and on TV in UK and Nigeria. Submitted in REF 2; DVD available in REF 2 portfolio. Funding from NHS (£75,000).
5. *Nollywood 2: Doing It Right*, (2010), a 25 minute documentary portrait of the Nigerian film industry in 2009 and the crisis it then faced, researched/produced/directed/camera/edited by Jane Thorburn. Screened in festivals and on Nigerian TV and Sky UK. Part-funded by UOW (£3000). DVD available in REF 2 portfolio. <http://www.janethorburn.co.uk/nollywood2DoingItRight.html>
6. 'Love and Madness: Reading *Araromire* and *Love in the Time of Cholera*' in *Journal of African Media Studies*, Vol. 3, No. 1, April 2011. A journal article written by Jane Thorburn on the narrative strategies of the Nigerian film *Araromire*, the production of which was filmed for *Nollywood 2*.

4. Details of the impact

Impact on Public Services and Education

Within the UK, the film has changed attitudes to Sickle Cell Disease (SCD). One in four West Africans carries the sickle cell gene: most of them, including in the UK, do not know their gene status. Where both partners in a couple carry the gene, they have a 25% chance of giving birth to a

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child with SCD. Male cultural attitudes in these communities often mean men refuse gene testing and disown their own babies with SCD. Cultural prejudice, ignorance and taboos surround the disease in the UK and Africa. People suffering from SCD need support with education, work and housing due to the impact of health crises on working life, but health professionals and others who do not fully understand the disease may discriminate against SCD sufferers. The NHS believed earlier pamphlet and documentary campaigns had largely failed to reach the relevant audiences.

The NHS reports that *The Family Legacy* film has met its objectives in raising awareness of the disease. According to the NHS, the Family Legacy project (the film in the context of the Sickle Cell Society outreach work) “was the most successful outreach activity that we delivered” and “it had high visibility within the NHS and has been influential in informing approaches to public health information”. Significant numbers of viewers agree that the film has encouraged them to test their gene status and to care more sensitively for those suffering with SCD. Public presentations by the SCS on the film’s dissemination, as well as the independent evaluator’s report, confirm this.

The Family Legacy film was originally intended for facilitated small-group community screenings in the UK, including Q & A sessions by the Sickle Cell Society. Since the project began in 2009, the film has been viewed in facilitated screenings in London and Manchester by more than 3,000 people of African and Caribbean descent, via 87 events at community groups, barber shops, Black History Month events, churches, mosques and schools. Participants in the facilitated screenings completed evaluation forms after community sessions. At February 2012, of 1059 respondents: 78% said they had learnt something new from the screening; 84% agreed the film captured the key issues and gave useful information on caring for someone with SCD; 50% didn’t know if they were carriers; of these 53% said that the film made them want to find out; 90% agreed that the screening should be offered to both men and women before starting a family (i.e. pre-conception screening). Several men stood up to admit that they had rejected their child with SCD as “not mine”, as is portrayed in the drama. 76% of respondents were Black African, Black Caribbean or Black British. The majority were aged 16-49 years; 31% male, 62% female. (‘SCS Presentation’ PDF, page 3).

In addition, the film has been used to educate medical practitioners through presentations at: (1) Second National Conference of Blood Disorders in Public Health, 12 - 14 March 2012, Atlanta USA; (2) Conference of the Global Sickle Cell Disease, 14 - 15 March 2012, Atlanta, USA; (3) Second Meeting of the Worldwide Initiative in Social Studies on Haemoglobinopathies, 16 March 2012, London UK.

The Family Legacy DVD also includes additional interviews with people who formed part of the original case studies on whose experiences the drama is based. These have been uploaded to YouTube by the NHS and have substantial viewings in their own right, in addition to the 5000+ views on YouTube for the film itself. <http://www.youtube.com/watch?v=JAv1Ja2AYhw> Junior Kebbay, **2109 views**, <http://www.youtube.com/watch?v=HHpZcJRu5s8> Oliver & Hannah, **1135 views**, http://www.youtube.com/watch?v=V2q2_ygbTqM Reconstructed Counselling Session, **1,758 views**, <http://www.youtube.com/watch?v=ZfbAomuplsA> Iyamide Thomas, Sickle Cell Society, **1,324 views** <http://www.youtube.com/watch?v=D4NI7-FhGI>

Impact on Civil Society and Cultural Life

Audiences: Although the film was originally conceived in order to reach West Africans living in the London Borough of Southwark, its success has far outstripped initial expectations, both in the quality of response to the film and in the scale of the film’s penetration with ‘hard-to-reach’ audiences. Extensive media coverage (see below) has led to the film being seen far beyond its original target audience, both in the UK and abroad, on all media, including numerous websites and even pirated copies on Nigerian media. Iyamide Thomas, Regional Care Advisor of the Sickle Cell Society, estimates that more than 12 million people have potentially been reached via:

- more than 28 TV screenings in the UK including multiple screenings on the Community Channel in October 2010 and several Nigerian channels transmitting in the UK (e.g. Nollywood Movies TV, Hi-Nolly, BEN TV, HiTV, OHTV); TV broadcasts in Nigeria and Sierra Leone (both official and pirated); 11 radio interviews, community and on-line (e.g. *Vox Africa* with Henry Bonsu, *Colourful Radio*); 18 press articles (e.g. *The Voice*, *African Voice* newspapers); 4,820 views (to 30 July 2013) via the dedicated NHS website www.familylegacy.org.uk; film trailer showing in GP surgeries; 6,326 views to September 2013 of the ‘Special Extras’ featured on the DVD (see links

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above); 5,000 reached via joint events with NHS Blood & Transplant and the Seventh-Day Adventist Church (which also included thalassaemia awareness); 33,000 reached via *Seventh Day Adventist Messenger Newsletter* and *Adventist News Network*; clip of the film (in context of scene of a barber's shop screening) on BBC2, 5 July 2011, <http://www.bbc.co.uk/programmes/b012g0cc>

Film Festivals: As a short drama, the film has been shown in film festivals, including the bfm international film festival at the ICA (20 Nov 2009) and the British Urban Film Festival, London (3 October 2009); at the Africa Centre, London, with Q&A (4 July 2011) and at the Africa Centre hosted by '100 Black Men of London' organisation (7 February 2012). It was screened on Sierra Leone Broadcasting Corporation (national TV) as part of a human rights film festival, followed by panel discussion on human rights issues raised, and texted questions from viewers (2010).

Websites: The film has also been adopted by a number of popular websites concerned with family issues and gene abnormalities, including Human Genetics Disorders website, as well as those of '100 Black Men of London'; 'Vibe and Vegas'; and 'Cool Great Stuff' and others. (*Although these sites are no longer active screen grabs are available: hard copies of these available on request*).

Future Spin-Offs: The film has generated considerable interest including an invitation to Thorburn to make a mini-series based around The Family Legacy's fictional family for HiTV (at the time Nigeria's most popular cable channel), and requests for similar dramatic films dealing with other genetic blood abnormalities and health issues involving different ethnic minority groups by bodies such as the Thalassaemia Society. Due to time constraints Thorburn has so far refused all these. The film has also inspired celebrated top Nigerian film director Tunde Kelani to make Nollywood's first feature film on sickle cell disease. He has hired Ade Solanke, the script-writer that Thorburn hired to write *The Family Legacy* based on her own original idea and research, to write it for him.

5. Sources to corroborate the impact

Impact on Public Services and Education

1. NHS website: www.familylegacy.org.uk
2. Summary details of 96 facilitated sessions of the DVD outreach programme in communities, barber shops and mosques. <http://www.janethorburn.co.uk/theFamilyLegacy.html> From this link, scroll to bottom of page for downloads of 'Sickle Cell Society Presentation' (PDF); 'DVD Facilitated Grass Root Sessions' (word doc); 'Family Legacy coverage' (Power Point Doc); and 'Independent Evaluator's Report' (PDF).
3. Video documentation of outreach programme made by the NHS. <https://vimeo.com/61159609> The video starts and concludes with *The Family Legacy*, with audience Vox Pops at the end (video also includes a section on thalassaemia, which runs from three minutes in for around two minutes).
4. Letter from (former) Communication Consultant, NHS Sickle Cell and Thalassaemia Screening Programme, confirming the success of the Family Legacy project from the NHS point of view.
5. Presentation of the film's dissemination and the independent evaluators' report prepared by the Sickle Cell Society at: http://www.janethorburn.co.uk/pdf/Sickle_Cell_Society_Presentation.pdf

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6. Letter from Regional Care Officer, Sickle Cell Society, confirming target audiences' engagement with the film and its success in educational campaigns for both these and medical practitioners.
7. Dossier of evidence of all screenings, including tv screenings, scans of articles about screenings at Africa Centre and Black Men of London (from *The Voice*, *African Voice*, etc), film festivals and related websites. The most important are documented within REF2 submission: see Thorburn, Output 4, portfolio and 'supplementary material' DVD. Full dossier available on request from HEI.
8. Letter from (former) business manager of HiTV confirming the film's popularity and multiple screenings on a commercially-driven channel that does not show 'public information' films.
9. Top Nigerian director /producer confirms that his new feature film on Sickle Cell Disease, (arguably Nollywood's first cinema film on SCD) is inspired in part by *The Family Legacy* in a filmed endorsement in which he holds the DVD of Thorburn's film up to underline the point. <http://www.youtube.com/watch?v=kxSvuxnQ9lk#t=40>. 3000+ views.