Institution: The University of Edinburgh

Unit of Assessment: 34 Art and Design: History Practice and Theory

Title of case study: ‘I Am Breathing’: a film that raises awareness about, and lends a voice to, people with Motor Neurone Disease

1. Summary of the impact

I am Breathing, a feature-length documentary directed by Emma Davie (ECA) and Morag McKinnon (unaffiliated) and released in 2012, builds on experiments in co-creativity in film, and explores the ethics and the aesthetics of making a film with, rather than about a man dying of Motor Neurone Disease (MND). Neil Platt wanted to use the film to raise awareness about MND, and since his death, *I am Breathing* has not only been screened 242 times in thirty-four countries, but has been distributed in concert with the MND Association, raising awareness about the disease, contributing to increased sign-ups to the Association, and lending people with MND a new public voice.

2. Underpinning research

Neil Platt had six months left to live when he asked Emma Davie (Reader, ECA 2008-) and Morag McKinnon to film with him in 2008. Platt had been diagnosed with Motor Neurone Disease; and as his condition deteriorated he used a blog to lend himself online the articulacy he was losing in life and, in addition, to raise awareness about MND.

I Am Breathing was, therefore, made ‘with’ rather than about Neil Platt. For Davie the film was an experiment in the ethical and aesthetic issues of the relationship between subjects and objects in documentary film. The questions this experiment was designed to address were:

- How can text, fiction and documentary combine to make filmic narratives that empower their subjects?
- How can a documentary transcend its specific subject to convey universal messages?

This experiment began with discussions between Platt, his family, and the film crew about the ethical bases for the film during what would necessarily be an intimate and exposing process. These discussions subsequently informed the whole process, from filming to distribution.

The film concept was subjected to peer review and ‘pitched’ to several funders, receiving a total of £302k from Creative Scotland, Danish Film Institute, Channel 4, Wellcome Trust, Motor Neurone Disease Association, DR, the Danish Broadcasting Association YLE, The Finnish Broadcasting Association and the UK Film Council.

Once filming with Platt and his family was complete, the editing process was similarly driven by peer review. The Danish Editor Janus Billeskov Jensen acted as mentor throughout the edit, and drafts were repeatedly shown to collaborators from the Danish Film Institute. The questions they asked challenged the development of the narrative approach. For example, it became apparent that too many images of Platt’s suffering were alienating for audiences. By omitting them, and leaving more to the imagination, the film’s empathetic and universalising power was enhanced. In addition, ethical questions about the role of the observer drove the visual language and the narrative structure. For example, in order not just to look ‘at’ Neil but to attempt to engage 'with' him, Davie decided to use his words from his blog as text throughout, so they drove the story. Similarly, close-ups of Platt, and footage shot from his point of view, were used to see through his eyes, and to feel from his body.

The film premiered at the IDFA Festival in Amsterdam in November 2012. At this point, the second experimental phase of the research began, funded by the Scottish Documentary Institute (SDI), and a NESTA Digital R&D fund for Arts and Culture in Scotland Award. *I am Breathing* was distributed using experimental techniques unusual for documentary film, including:

Working with charities, notably the MND Association, so that the film could enhance their own fundraising plans; and encouraging MND/ALS associations worldwide to join in a screening day (21st June 2013).

Establishing a website, twitter account and a Facebook page in which stakeholders in MND could share their reactions to the film after these screenings.

Employing a Producer of Marketing and Distribution and Outreach Team to engage unusual and locally-based hosts and venues for screenings.

Using innovative technology: a sharing platform *Distrify*, was used to enable the film to be downloaded and screened, and a Customer Relationship Management tool called *Nationbuilder* to engage potential hosts and audiences for these screenings.

It is now possible to assess the impact of these experimental practices, as outlined below.

3. References to the research

3.1 Film: Davie, Emma and McKinnon, Morag *I am Breathing* 2012 (REF2 Output submitted)

3.2 Website: www.iambreathing.com

3.3 Pitch document (brochure): Davie, Emma and McKinnon, Morag *I am Breathin*g, available on request.

3.4 Q&A in London Open City Festival with Scientists Professor Chris Shaw (Professor of Neurology and Neurogenetics at the Institute of Psychiatry, King's College London), Vinod Nambisan (The Medical Ethics and Law Unit team, UCL), Andy Pape (Member of South London Group of MND Association), chaired by Jenny Horwell (DocHouse): https://vimeo.com/70121400

3.5 Application Document and award letter for funding from the Wellcome Trust, available on request.

3.6 Davie, Emma *An Irreducible Otherness: An Interview with Jean Perret,* DOX magazine 2009 (REF2 Output submitted)

4. Details of the impact

I am Breathing premiered at the International Documentary Film Amsterdam Festival in November 2012, where it was nominated for Best Documentary (5.5); and between that date and up to June 2013, it enjoyed festival screenings in fourteen countries, winning the Best Documentary Award at the River Run Festival in the USA, nominated The Best of Hot Docs in Canada, and for Best Documentary at the Tempo Festival in Sweden.

I am Breathing has also received critical plaudits, praised as one of the top ten films of 2012 by influential critic Tue Steen Müller of http://tinyurl.com/qyqpsxq (5.8). Trevor Johnston of Sight and Sound (5.6) called it 'Genuinely powerful film-making...an intimate portrait of heartbreaking courage - a haunting and inclusive encounter with...time, experience and mortality'. In reference to the original intentions of the film, the Hollywood reporter wrote:

As [Neil Platt] promises very early on, what we get is "a tale of fun and laughs with a smattering of upset and devastation." The former gives way to the latter only in the closing fifteen minutes or so, when the deterioration in Neil's condition results in his being relocated from his home to a hospice institution. His formidable powers of communication are by this stage ebbing away in a manner that nearly all viewers will find powerfully harrowing.

'Necessarily tough going, these sequences deliver what are in effect a series of knockout punches that leave us dazedly counting our blessings. But so firmly have Neil's particular wishes expressed – that he wants the film to promote awareness of MND and encourage fund-raising into the research of possible cures – that I am Breathing never feels in any way intrusive or exploitative. (5.7)

But the impact of *I am Breathing* was never intended to be confined to critical success. On MND Global Awareness Day in 21st June 2013 the film was shown at 242 screenings in thirty-four countries (5.2). Screenings were organised by people with MND, their relatives and friends, film-makers, charity workers and activists. Screenings were held in an old cinema in Kosovo, the Indian Medical Research Institute in Dehra Dun, parish halls, a Taoist temple in Beijing, a nightclub in Tallinn, and a taxi in the Home Counties.

The effects of this screening are partly documented on the *I am Breathing* website (www.iambreathing.com) (5.1) (4,107 'likes' since November 2012) via blog entries by hosts recording the event itself, their motivations for holding it, or their reactions to the film (5.9). A petition launched in June 2013 to screen the film in mainstream cinemas, with a target of 1000 signatures, collected that many within three days, and by July 2013 had collected 2300.

Scientists, medics and researchers working with MND reported changes in the way they found themselves thinking about the disease. After the screening at the Euan MacDonald Centre in Edinburgh, which is devoted to research into the care and cure of MND, one viewer wrote: '…our students spoke about the motivation it gave them with their studies and the pride they felt knowing they were in some small way helping to find a cure.' (5.9)

On 14 June 2013, Neil's wife, Louise Oswald was invited to talk about MND on ITV's *This Morning,* bringing awareness of the issue to around nine million viewers. (5.3)

Others who saw the film reported being moved to find new ways of raising funds for MND research. 'Tony' (MND fundraiser and host in the UK) wrote: 'Absolute silence after the film. It had an amazing effect and I have had people come forward asking how they can help.' (5.9)

'Debra' (UK) recorded: 'There was not a dry eye in the room after the event. Many people came up to me to thank me for sharing the film with them, and many have said they will help with other events that I do to raise money for Motor Neurone Disease Association.' (5.9)

The MNDA has reported the following changes in behaviour. A Facebook post on 21st June 2013 - MND Global Awareness Day - reached more than 68,000 people, an MNDA social media record; and their website received a 239% increase in visitors, compared to June 2012. As a result, more than 1800 people signed the MNDA Charter in Awareness Month. (5.4)

Sally Light, Association Chief Executive said: 'It [the advertising of the film] was a unique opportunity to reach out to thousands of people with no previous knowledge of the disease…Thanks to the film, the film-makers and, ultimately Neil and his family for sharing their story, we have spread the word to many thousands of people during our Awareness Month.' (5.4)

But particularly notable are the reactions of people with MND, who recorded that the film had not only helped them to raise awareness about their condition, but also, that being able to see and share Neil Platt's experience had lent them a sense of empowerment and community that they had previously lacked. Patrick O'Brien tweeted: 'Thrilled & inspired to see these films & heroes shining a light on #ALS / #MND. @Legacy_film @breathingfilm. Beautiful! We r in this 2gether' (5.10) while Siobhan Rock in Ottawa wrote: 'We are thankful that Neil has shared his personal journey so openly. It has inspired us. May it continue to inspire others around the globe. It is our hope, that our story, along with Neil's and others living with this horrible disease, generates the required awareness leading to the appropriate funding, support and eventually a cure.' (5.9)

5. Sources to corroborate the impact

Copies of these web page sources are available at https://www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+34

(5.1) Website pages describing screenings: http://tinyurl.com/kjmgbzm

(5.2) MNDA Awareness Month website, demonstrating collaboration with *I am Breathing* http://tinyurl.com/nejvtoo

(5.3) Site evidencing interview with Louise Oswald on ITV's *This Morning*: http://tinyurl.com/qe5porb

(5.4) Contact details for the MNDA, provided separately, to corroborate figures and impact of *I Am* Breathing on MNDA Awareness Month 2013

(5.5) IDFA website, recording plaudits for *I am Breathing*, http://tinyurl.com/k473hqn

(5.6) Trevor Johnston, review of *I Am Breathing* in *Sight and Sound*, July 2013 on *I Am Breathing* website. http://www.iambreathingfilm.com/tags/reviews

(5.7) Review of *I Am Breathing* in *Hollywood Reporter* http://tinyurl.com/pehzkeo

(5.8) Tue Steen Muller review of *I am Breathing* on http://tinyurl.com/qyqpsxq

(5.9) Blog posts about screenings of I am Breathing http://tinyurl.com/m97h131

(5.10) Tweet by Patrick O'Brien https://tinyurl.com/putfhsk