

Institution: Goldsmiths, University of London		
Unit of Assessment: 32, Art and Design: History, Practice and Theory		
Title of case study: The Iceberg: an award-winning artwork that gives voice to the emotional intensity of living with cancer and end of life care.		
Period when the underpinning research was undertaken: 2014		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Marion Coutts	Reader in Art	2001-
Period when the claimed impact occurred: 2014-2019		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>Written by Marion Coutts and conceived as an artwork, <i>The Iceberg</i> is a book that speaks to the emotional intensity of the lived experience of those who care for cancer sufferers. In 2015 <i>The Iceberg</i> won the Wellcome Book Prize in recognition of its ability “to excite public interest and encourage debate around medicine, health or illness”. It has received a large number of testimonials from cancer patients and their families that emphasise how the book’s unique and powerful language articulates the all-consuming and often unspoken emotional experience of caring for someone terminally ill with cancer. <i>The Iceberg</i> has been used by medical professionals to improve understanding of the experience of being a carer and a patient and in the medical humanities to open out debates about bereavement and the impact of cancer.</p>		
2. Underpinning research <p>In <i>The Iceberg</i>, Coutts was investigating a number of questions, specifically; how to use language to grant agency to the dying by writing against notions of unspeakability; the nature of temporality under chronic time, which led to ethical and linguistic decisions around tenses and endings; text as material, using visual and time-based tropes such as edit, surface, mass, syntax, pace, duration; how to use language to write about its loss [R1].</p> <p>The book grew out of notes made as individual Word documents during the illness and death of Coutts’ husband, the art critic Tom Lubbock, between September 2008 and January 2011. Each item – sometimes only a sentence - was formulated around paying close attention to the experience and texture of time as lived. Coutts had little interest in conventional ideas around memoir, and none at all in the grief memoir. Her proposition was to show rather than tell. The language of the book is highly visual; artworks are cited and encountered, but more often used as proxies through which to think. The visual world is presented as a major, highly unstable, player in experience. <i>The Iceberg</i> was conceived and developed as an artwork. The book was written entirely out of chronology and re-ordered during the edit. The proceeding of the time of illness as linear, towards a conclusion – death - was not a model which fitted Coutts’ conception of the experience.</p> <p>A great deal changed throughout the writing process. As the mass of sections mounted up, Coutts began to organise them into chains of text, on intuitive, non-chronological lines. This allowed Coutts to shift perspective from micro to macro. Certain subliminal, structuring principles arose as a result of this, for example, some sections are written from the premise of real or metaphorical high vantage points. The chains of text varied from 300 to approx. 3000</p>		

words and through the edit, these were drafted into three longer sections, divided into short, numbered subsections. This organisational principle – how parts related to the whole – was derived, in part, from Wittgenstein. Coutts was interested in his ideas on reality as a collection of facts that we can picture in language. Throughout Coutts became very focused on playing with syntax. Text as visual image and language as picturing were very important tropes in the writing. In addition, Coutts made extensive use of the blank scene or cut, derived from film editing. Chronology came back into the frame in later edits, when Coutts had to deal with complexities arising from the fact that some sections might cover an incident lasting five minutes, and others, six months. Actual time is noted indirectly: the only date markers in the book come from 22 emails quoted verbatim, sent out to a network of supporters.

The originality of Coutts' approach to writing about cancer as a form of writing against unspeakability and her innovative experiments with narration and time has led to Coutts being invited to contribute at multi-disciplinary Medical Humanities conferences and symposia, including *The Chronic: Temporality, Care and Health Research Symposium*, [March 2016], at Birkbeck College. This was a conference that drew on academics and specialists from the diverse fields of Psychosocial Studies, the Environmental Humanities, Psychiatry and Psychoanalysis, Geography, Literary History, the History of Medicine, Psychology and Gender Studies, to discuss the complex and contradictory experience of the chronic and 'chronic time' in illness.

3. References to the research

R1. Coutts, Marion. 2014. *The Iceberg: A Memoir*, London: Atlantic Books

ISBN 9781782393504

Paperback edition [2015]. US edition [2016]. Audio book [2016]

Translated into Mandarin [2015]; Spanish [2016]; Simplified Chinese [2017]. Korean [2019]

4. Details of the impact

The Iceberg has contributed to a greater understanding of the lived experience of cancer patients and their families amongst those affected by cancer, the public and medical professionals. The role of the book in the medical humanities has also informed practitioners thinking about chronic illness. Central to all of the responses to the book, whether by sufferers and carers, medical professionals, reviewers, or ordinary readers, is the emphasis on the emotional intensity of the book as an artwork - its language and poetic energy signify a fundamentally different approach to typical narratives written from the position of the carer and constitutes a new intervention in conversations with professionals and sufferers and carers.

Raising public awareness of the position those who care for cancer sufferers

The Iceberg has generated exceptional critical reception, winning awards, prizes, nominations and accolades in the UK and America, including shortlisting for the Samuel Johnson Prize for non-fiction 2014; the Costa Biography Award 2015; the Pol Roger Duff Cooper Award 2015. Longlisted for the Guardian First Book Award 2014: Finalist in the National Book Critics Circle Awards of America 2017.

In 2015, in recognition of the book's ability to extend our understanding of "what it means to

be human", *The Iceberg* won the Wellcome Book Prize [S1]. Awarded to novels that "excite public interest and public debate around medicine, health or illness", Simon Chaplin, Director of Culture and Society at the Wellcome Trust, said that it "is an immensely powerful book, written with astonishing candour and pulsing with raw emotion". Chaplin continued:

"The Iceberg" "shines a burning light on the devastating impact of illness and loss on those who surround and support someone in decline, while simultaneously celebrating the powerful bonds of family and love. It is tremendously difficult to read, but impossible not to become absorbed" [S1].

The uniqueness of Coutts's language is at the centre of the reviews to be found in the extensive press coverage in international newspapers, including; *The Guardian*, *The Observer*, *The Sunday Times*, *The Independent*, *The New York Times*, *The Los Angeles Times*, *The Irish Times*, *The Daily Telegraph* [samples provided in S2]. These reviews are also testament to the sustainability of the books reach and significance, as evidenced in this review in *The Irish Times* (2016):

"Since its publication, *The Iceberg* has been deservedly garnering gongs – the latest being from the Wellcome Book Prize; it has also garnered thousands of readers, flocking to experience Coutts's unflinching gaze at the terror – and the wonder – of "the period of dying that was also living" [S2c].

Coutts was in conversation with Martha Kearney, on *The World at One*, BBC Radio 4 on Tue 28 Oct 2014 and book reviewers writing for individual literary, book review and book interest blogs, like UTTERBIBLIO, have also commented on how *The Iceberg* speaks to the experience of those who have lost loved ones [S3].

Informing and Improving the lived experience of cancer patients and their families

The importance of *The Iceberg* as a book written from the position of a mother and carer is referenced and discussed in online cancer and terminal illness support platforms, such as *wellbeing.org*; *The MD Anderson Cancer Centre*, *University of Texas*, *Learning Centre* *Online Reading resource: The Brain Tumour Charity* Recommended books.

Evidence of the impact on cancer patients, their families and their carers can be found in the reviews of *The Iceberg* published on the *We are MacMillan* Cancer Support webpage under the heading "Read what people affected by cancer think about..." [S4]. As part of the larger MacMillan support network, the 21 reviews are offered as a resource by and for those who are directly affected by cancer - sufferers, the family of sufferers, and carers:

The reviews detail:

- "the power and brutal honesty of the book" and "impact of cancer on a young family"
- "the extraordinary poetic language Coutts uses"
- the value of the book in informing "medical professionals about the direct experience of suffering and caring"
- the way the book; "offers emotional support to those in a similar situation"; "is one of the very few memoirs that speaks from the position of the carer" and "uniquely articulates the sheer exhaustion and emotional despair that comes from caring."

The 180 reviews posted on the reader review website *goodreads* further serves to demonstrates how *The Iceberg* contributes to the public understanding of cancer [S5]. A number of these reviews are from members of the website who have experienced cancer as a carer, or family member, or who have lost a family member or a friend to cancer. In

affirming the “extraordinary narrative force and power” of the book, the *End of Life Wisdom* website, created in order to “assist those who have questions about how to proceed when confronted with the challenges presented at end of life”, lists *The Iceberg* on its page ‘Books on Death and Dying’ [S6].

Changing the way medical professionals relate to carers and family of patients with a cancer diagnosis

The effect of *The Iceberg* on the way in which medical professionals understand and relate to the experience of cancer is evidenced in reviews and discussions by specialist professionals in medical journals; in books on bereavement and the impact of cancer; on the websites of professional medical organisations; in Social Care Council Archives and on websites that support nephrology and mental health clinicians.

This reference to *The Iceberg* in a ‘Personal Development Plan’ of a social worker in an Oncology and Haematology social work team in a treatment and in-patient unit in a hospital in Northern Ireland is just one example of how the book helps professionals to connect with people in their care:

“*The Iceberg* by Marion Coutts...is a memoir by the wife of the art critic Tom Lubbock...Having worked for ‘too many’ years with cancer patients I am always concerned about potential burn out or dilution of empathy. I read this to remind myself of the patients/carers/families lives away from the clinical settings” [See p12. S7].

Other examples of how *The Iceberg* prompts medical professionals to reflect on their practice include a review in the *Practical Neurology* Journal ‘Bookclub’, in which Katherine Harding writes about how the bookclub members discussed the “the many practical clinical lessons” that can be derived from the book. A review published on ‘The Reading Room’ of the *British Medical Journal* blog ‘Medical Humanities’ draws attention the importance of the book as a counterpoint to recent philosophical accounts of brain damage and a book review in *The Journal of Psychoanalytic Psychotherapy* refers to *The Iceberg* in such a way that suggests that the book has become first-hand evidence about the personal experience of cancer and the extraordinary intensity and preoccupation of the sufferer. *The Iceberg* was also reviewed on *The Lancet Oncology* website ‘Cancer and Society’ and on *Psychonephrology.com*, a community of nephrology and mental health clinicians committed to understanding and helping patients cope with the psychosocial impact of chronic kidney disease [S8].

Participating in conversations at interdisciplinary Medical Humanities conferences and symposia

Coutts’ writing has found an important role in interdisciplinary conversations where creative insights from art, literature, dance, and poetry are positioned alongside research from academic and clinical fields to open up a space for new thinking and the pursuit of new questions. This interdisciplinary engagement is exemplified through the creation of a new workshop in the AHRC funded network ‘Modernism, Medicine and the Embodied Mind’ workshop entitled, *Modernism’s Chronic Conditions: Temporality, Medicine and Disorders of the Self* [The University of Exeter. April, 2015], where Coutts delivered a paper titled ‘Permanent Fires: Time, Language and Visual Experience in The Iceberg’.

Other examples of the effect of the book on opening up discussion with clinicians,

psychologists and philosophers and the public include Coutts' conversation with Professor Malcolm Reed, oncologist and Dean of Brighton and Sussex Medical School (BSMS); BSMS Professor of Ethics, Bobbie Farsides; BSMS Professor of Psycho Oncology, Lesley Fallowfield; Professor Peter Johnson, Chief Clinician, Cancer Research UK at *The Brighton and Sussex Medical Schools Debate, Facing Cancer* [Brighton Festival 2015] [S9].

5. Sources to corroborate the impact (indicative maximum of 10 references)

[S1] Press Release: Wellcome Book Prize 2015 winning statement for *The Iceberg*: [Wellcome Trust Press Release](#) (30 April 2015)

[S2] Select press reviews: a) Tessa Hadley, '[The Iceberg – A Memoir by Marion Coutts, review](#)' *The Guardian*, (July 2014); b) Dwight Garner, '[Review: A Widow Documents Her Loss in 'The Iceberg'](#)', *New York Times*, (January 2016); c) Rosita Sweetman, '[The Iceberg by Marion Coutts: a heart-scalding heart-warming book](#)' *Irish Times*, (July 2016) [Grouped Source]

[S3] Review (blog: book reviewer): UTTERBIBLIO: '[Review The Iceberg by Marion Coutts](#)' (8 September 2014)

[S4] Reviews (from people affected by cancer): Collated and published by Macmillan Cancer Support in 2014, [What people affected by cancer think of: The Iceberg](#) (October 2018).

[S5] Reviews (general public): Published online by Goodreads, [The Iceberg, by Marian Coutts](#) (June 2014-Dec 2020)

[S6] Reading List/Review: End of Life Wisdom, [Reading List - books on death and dying](#) (2014)

[S7] Reference: Social Care Personal Development Plan, Northern Ireland Social Care Council Archive, p12 (8 May 2017)

[S8] Reviews (medical professionals): a) Katherine Harding, 'Bookclub: *The Iceberg*', *Practical Neurology*, 16, 6 p. 502 (November 2016); b) Elizabeth Barry, 'Medical Humanities'. [The Reading Room: A review of Marion Coutts's The Iceberg](#), *BMJ blog* (January 2015); c) John Lawrence, '[The topic of cancer: new perspectives on the emotional experience of cancer](#)', *Psychoanalytic Psychotherapy*, 30,3, pp. 286-291 (May 2016); d) Katherine Russell, [The Iceberg](#) *The Lancet Oncology [Cancer and Society]* 15,13, pp.1430–1431 (December 2014) [Grouped Source]

[S9] Event (medical humanities): Brighton and Hove Medical School (BSMS), [Facing Cancer: The Brighton and Sussex Medical Schools Debate](#), Brighton Festival (May 2015)