

## Impact case study (REF3b)

<b>Institution:</b> University of the West of England (UWE), Bristol
<b>Unit of Assessment:</b> 32 – Philosophy
<p><b>Title of case study:</b></p> <p>Changing preconceptions among the public and healthcare professionals on the meaning of illness and the human body.</p>
<p><b>1. Summary of the impact</b></p> <p>Havi Carel's work on the experience of illness has had wide-ranging and significant impact on health professionals, patients and their families, policy makers and health researchers throughout the world. Her influential book, <i>Illness</i>, sparked a public debate on the importance of the first-person experience of illness. Consequently, through presentations, media coverage, public debates, academic-practitioner networks, educational activities and public workshops, Carel's influence on many people's perceptions of illness has been profound.</p>
<p><b>2. Underpinning research</b></p> <p>Research by Dr Havi Carel (Senior Lecturer in Philosophy at UWE until 2012) explored the experience of illness. It consisted of four main strands: 1. A philosophical examination of how illness is experienced by patients; 2. The development of a phenomenological analysis of this experience; 3. An application of this analysis to healthcare provision; and 4. An examination of the effects of ill health on wellbeing.</p> <p>Building on Carel's earlier research which examined happiness (or wellbeing) and its relationship to health [R1] and the concept of death [R2], the project began by identifying a deficiency in the naturalistic approach to illness and proposing to augment naturalism with a phenomenological perspective. It then developed this phenomenological approach in two monographs and a series of papers.</p> <p>Carel's main claims are that medicine and healthcare as practised in the West overlook the lived experience of illness, and that phenomenology provides a useful framework to explore this experience and communicate it to health professionals [R3, R4, R5]. In these publications, Carel identified several problems that arise from this oversight, notably: the hampering of patient-physician communication; a limited understanding of noncompliance; medical interventions that are not amply informed by patient needs and preferences; a feeling of alienation among patients from healthcare provision and healthcare institutions; and patients not being supported in trying to make sense of their illness [R3, R4].</p> <p>The research was first presented in a book, <i>Illness</i> [R3]. The ideas were then worked out in detail and published as academic research publications (8 articles in peer reviewed journals, 5 book chapters and 3 edited collections) with the support of AHRC, Leverhulme Trust and British Academy research fellowships and grants. Given the focus of the work, some of the underpinning research was also published in prestigious medical journals such as the <i>Lancet</i> [R6] and the <i>British Medical Journal</i>, (2010), as well as in leading philosophy of medicine journals [R4, R5]. It also featured in two journal special issues (<i>Studies in History and Philosophy of Biological and Biomedical Sciences</i> 41(4) (2010) and <i>Philosophy</i> 67 (2012)), and an edited collection (<i>Health, Illness and Disease</i>, Acumen, 2012).</p> <p>Emerging from this research, Carel developed a phenomenological toolkit for patients aimed at exploring their personal experiences of illness and changes to their lives caused by illness. The toolkit also communicates aspects of patient experience that are not well understood [R4]. The toolkit has been (and continues to be) presented to patient groups and groups of medical staff and has been a key means of influencing people's perception of illness and enhancing professional healthcare practice.</p>
<p><b>3. References to the research</b></p> <p>R1. Carel H (2007) "Can I be Ill and Happy?" <i>Philosophia</i> 35(2):95-110. <a href="https://doi.org/10.1007/s11406-007-9085-5">DOI: 10.1007/s11406-007-9085-5</a></p> <p>R2. Carel H (2006) <i>Life and Death in Freud and Heidegger</i>, New York &amp; Amsterdam: Rodopi,</p>

## Impact case study (REF3b)

ISBN 90-420-1659-0 (217pp.).

- R3. Carel H (2008), *Illness: The Art of Living*. Acumen Publishing Limited, Stocksfield. ISBN 1844651525
- R4. Carel H (2012) "Phenomenology as a Resource for Patients". *Journal of Medicine and Philosophy* 37(2): 96-113 [DOI:10.1093/jmp/JHS008](https://doi.org/10.1093/jmp/JHS008).
- R5. Carel H (2011) "Phenomenology and its Application in Medicine". *Theoretical Medicine and Bioethics* 32(1): 33-46. [DOI:10.1007/s11017-010-9161-x](https://doi.org/10.1007/s11017-010-9161-x)
- R6. [Carel H](#) & [Macnaughton J](#) (2012) "How do you feel?": oscillating perspectives in the clinic *Lancet* 379(9834): 2334-2335 (23 June). [DOI:10.1016/S0140-6736\(12\)61007-1](https://doi.org/10.1016/S0140-6736(12)61007-1)

**Key grants**

Havi Carel (PI) and Rachel Cooper (Co-I), *Concepts of health illness and disease*, AHRC, (01/01/2009 - 31/12/2010), £25K.

Havi Carel, *The Lived Experience of Illness* Leverhulme Trust, (01/05/2011 - 30/04/2012), £22K

Havi Carel, *The lived experience of illness: a philosophical analysis of the ill first-person*, British Academy, (01/10/2012 - 30/09/2013) – 12-month Research Fellowship, £73K

**4. Details of the impact**

Carel has employed a variety of means to ensure public and professional engagement with her research, resulting in widespread influence and uptake among a diverse range of people and stakeholders. Particular emphasis has been placed on maximising knowledge exchange through interaction with health practitioners.

Carel's book, *Illness*, received an enthusiastic reception. It was shortlisted for the Wellcome Trust Book Prize 2009 and was swiftly translated into several languages. A doctor at Cheltenham Royal Hospital wrote that "as a doctor who tries and regularly fails to get things right, it has already informed my practice and views" [S1]. The AHRC, in its annual report 2009/10, highlighted the exemplary nature of its influence on health professionals and policy makers [S2]. Patients also valued the book as helping them understand and articulate their own perspective of illness [S3]. The book is currently used in the teaching of medical students in numerous universities including Cambridge, Cornell, Duke, Temple, Bristol, Durham, Lancaster, Central Lancashire, Aberdeen and Kings College London [S4]. Its impact has spread well beyond the health professional arena, for example inspiring the work of artist Kamina Walton who quoted from Carel's book in her touring exhibition 'Heavy Words, stories from the cervix: a visual exploration of cervical cancer' [S5].

*Illness* triggered an international debate on the experience and understanding of illness through widespread media coverage and internet discussions. For example, an interview on Australia's ABC Radio's The Philosopher's Zone [S5] and a video debate on the meaning of pain for iai.tv (philosophy for our times: cutting edge debates and talks from the world's leading thinkers) [S7]. Among the many blogs that discuss the book, an example [S8] from New Zealand commented that it is "a book I would recommend for anyone – healthy and non-philosophically inclined included – because inevitably, directly or indirectly, sooner or later, the way you yourself and society around you thinks about illness will have a major impact on your life."

As a consequence of the widespread interest in her work, Carel participated in book festivals, such as the Dartington Literary Festival (2009), the Durham Book Festival (2010) and 'How the Light Gets In' (the philosophy and music festival at Hay on Wye) (2012). She appeared on Radio 3's Free Thinking Festival (2010) and discussed the book and its practical application in the medical arena with numerous groups of physicians and nurses at events such as Medfest (2011), Medicine Unboxed (2011) and the 'Schwartz Center Rounds' in Gloucester and Cheltenham Hospitals (supported by the Kings' Fund and designed to help healthcare staff provide compassionate care). Carel's work was at the core of a multidisciplinary research network supported by AHRC on 'Concepts of Health, Illness and Disease'. The book's reach has even extended into prisons; in a pilot project at Erlestoke Prison, Wiltshire, inmates were able to relate the book's discussion of a

## Impact case study (REF3b)

changed geography and a new relationship to space brought about through illness to their own experience of dislocation as prisoners.

In a podcast interview with Carel and a feature article in the AHRC research magazine Carel's two-year network grant was flagged up by the AHRC as promoting innovative high-impact research [S2]. It also resulted in a multidisciplinary and accessible volume (*Health, Illness and Disease*, Acumen, 2012)

The AHRC project included public events that were free, open to all, and widely advertised. Each event was attended by more than 100 members of the public, health professionals and other practitioners. For example, an event on "Addiction: should we penalise or treat?" held at the Watershed, Bristol (2010) received widespread coverage in local media and attracted many health and social care practitioners. Analysis of more than 50 feedback forms showed that around two thirds of practitioners believed that the event had provided them with new ways of thinking about their professional practice which would continue to influence their work. One participant wrote that "the event impacted on my practice in understanding that how we frame our attitudes to the client affects their ideas of agency" [S10]. At a similar event on 'Organ Donation' more than three quarters of participants said that it had provided new ways of thinking about their practice and many said, on a personal level, that it had made them re-think the need for an open discussion about organ donation with family members [S10]. The events were made available as freely accessible podcasts.

Carel's publications have engaged the medical profession in particular; for example, her *British Medical Journal* article has been downloaded nearly 3,000 times. Her work with health professionals has also included invitations to speak at high profile meetings such as keynotes to the British Medical Acupuncture Society Annual Conference 2010 and the British Pain Society Annual Conference 2011. Not content with simply disseminating her research, Carel has sought to engage health professional directly by designing and running bespoke workshops. Piloted on nurses and physiotherapists, the workshops have since been used with groups of psychiatry trainees, respiratory registrars and respiratory nurses. These workshops enable participants to reflect on their professional practice, making them aware of and influencing, their underlying thinking about the human body.

Proactive engagement with the media has brought Carel's work to a wider public audience. She has written for the *Independent* and *The Daily Telegraph* [S8] and been interviewed on BBC Radio 3, BBC Radio Bristol, Y-net, Israel and ABC Radio, Australia [S6]. She has received many responses and reactions to her public engagement work and continues to exert influence in key policy areas and in cognate fields. For example, she has been invited to act as an advisor to the King's Fund on the benefit to patients of the 'Schwartz Center Rounds' (2013) and her work as been commended by Sir Tom Shakespeare, Disability Advisor to the WHO at an event at the Sage, Gateshead as part of the Free Thinking Festival (BBC Radio 3, 2010).

##### 5. Sources to corroborate the impact

- S1. Clinician at Cheltenham Royal Hospital in an email of 29.09.10 (corroborating statement no. 1 on REF system; available from UWE, Bristol).
- S2. AHRC Annual Report & Accounts AHRC 2009-10, available at <http://www.ahrc.ac.uk/News-and-Events/Publications/Documents/Annual-Report-2009-10.pdf> (page 36)
- S3. A member of the patients' group Cavernoma Alliance UK highlights the value of Carel's work: <http://www.cavernoma.org.uk/opus253/ConceptsofHealthAndIllness.pdf>
- S4. **Testimonials** (available from UWE) of the usefulness of the book *Illness* in teaching students in subjects other than philosophy, such as medicine:
  - Associate Professor, Cornell University [2 on REF system]
  - Professor, Temple University [3 on REF system]
  - Teaching academic at University of Durham [4 on REF system]

**Impact case study (REF3b)**

- S5. <http://www.kaminawalton.co.uk/heavy.html>
- S6. Interview with Carel on Australian radio:  
<http://www.abc.net.au/radionational/programs/philosopherszone/the-philosophy-of-illness---havi-carel/3103840>
- S7. Video at: <http://iai.tv/video/the-agony-and-the-ecstasy>.
- S8. <http://books.scoop.co.nz/2009/02/09/driving-out-the-suffering-of-the-soul/>
- S9. <http://www.independent.co.uk/news/people/profiles/havi-carel-my-10year-death-sentence-440805.html> and <http://www.telegraph.co.uk/health/3356402/Can-I-be-ill-and-happy.html>
- S10. Analysis of event feedback forms (available from UWE, Bristol)