

Institution: University of Edinburgh		
Unit of Assessment: UoA 21 Sociology		
Title of case study: Creating 'Everyday Cyborgs' – engaging clinicians, policy-makers, and publics about implantable medical devices		
Period when the underpinning research was undertaken: 2010 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Dr. Gill Haddow	Role(s) (e.g. job title): Senior Lecturer in Science, Technology and Innovation Studies	Period(s) employed by submitting HEI: 2002 - ongoing
Period when the claimed impact occurred: 2014 – 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <i>Your heart is failing and needs to be replaced. Would you prefer a human, animal, or a mechanical heart?</i> Haddow's quantitative and qualitative research into the effects of organ transplantation and body modification through the insertion of 'smart' medical devices has generated a new understanding of body-identity relationships at several levels: (1) Her collaborations with disadvantaged young people, patients and artists, resulting in several short films, radio programmes and podcasts, raised public awareness across the UK for the challenges and vulnerabilities of 'everyday cyborgs' (patients with implantable medical devices). (2) Through engagement with patient support groups, medical professionals and the Nuffield Council of Bioethics (NCoB), Haddow's work is informing medical practice and policy-making at UK government level on bioethical issues related to implantable medical devices and the oversight of emerging biotechnologies.		
2. Underpinning research With continuing technoscientific advances in biomedicine reaching old age without any bodily modifications is likely to become a rarity. But alterations to the integrity of the body can, as Haddow's cutting-edge research demonstrates, result in alterations to subjectivity and identity. These alterations will partly be determined by the type and kind of material that is used to repair, replace or regenerate the body. From 2013 to 2018, Haddow's Wellcome Trust project '<i>Animal, Mechanical and Me: The Search for Replaceable Hearts</i>' explored, from a sociological perspective and using both qualitative and quantitative methods, the following questions: 1. What do hypothetical preferences for replacement organs, i.e. whether they are human, animal or smart implantable mechanical ones, suggest about the relationship between bodies and identity (3.1)? 2. What do actual patient experiences and accounts of body modification through smart medical devices, such as implantable cardiac defibrillators (ICDs), or in-vivo biosensors mean for a patient's subjectivity, and how do they overcome vulnerabilities created by their new techno-organic hybrid identity (3.2)? 3. What can be learned from the findings about the relationships between technology, biomedicine and bioethics, also aiming to address regulatory concern related to smart implantable medical devices (3.3, 3.4, 3.5)? To explore the first question, Haddow conducted focus groups and a representative survey with young people in Scotland (age 11-17; n=1001). Young adults were selected because of		

their assumed lack of need for such technology as well as a familiarity with technoscience solutions to social and individual problems. Responses showed that human options were favoured most, with the majority expressing a strong preference for a 3-D bioprinted organ created from their own cells (3.1). Mechanical implants were not as popular as human options (3-D bioprinting or human organ donation), but not as unpopular as xenotransplantation (animal-to-human organ transplantation). Overall, results highlight the desirability of maintaining: (i) the boundaries between human beings and other animals; (ii) the boundary between the individual and other humans; and (iii) the integrity of the individual's own body (3.1). Findings also showed that whether implants were mechanical or organic impacted on the nature and content of young people's fears about them. Attitudes ranged from 'smart' technologies being perceived as safe to challenging what is considered as natural or 'normal' (3.2).

Haddow met with cardiologists at the Edinburgh Royal Infirmary who pointed to patient questionnaires frequently showing that ICDs (implantable cardiac defibrillators) cause distress, anger, depression, anxiety and social isolation. Through in-depth interviews with ICD patients, Haddow revealed that although these patients shared similar experiences with other cardiac patients, they faced additional challenges regarding device implantation and activation. In particular, the need to adjust to a body with a machine in it created specific, and increased, vulnerabilities (3.3). The automatic device activation to stop a sudden cardiac arrest causes physical pain created by shocks, but also feelings of autonomy loss and a lack of control. Nonetheless, Haddow's findings demonstrated how patients overcome these vulnerabilities in time through viewing the ICD as 'part of them,' becoming 'everyday cyborgs'.

The term 'everyday cyborg' first coined by Haddow describes patients who are characterised by increased vulnerability and lack of control caused by living with an implantable cybernetic device such as an ICD (3.4). The original use of the term 'cyborg' describes cybernetic adaptations to the body necessary to live in space but did not recognise any identity consequences for the astronaut (Clynes & Kline, 1960), whereas popular culture and literature has envisioned different forms of dehumanisation (e.g., 'Robocop'). In contrast, Haddow's research demonstrates that cybernetic technology does not cause dehumanisation: despite modifications to the human body making it less *human* in organic terms, it does **not** alter a person's subjectivity by making them less *humane* (3.4). Instead, Haddow's research tells an important story about how everyday cyborgs and their families need understanding and support through the adaptations required to the cybernetic changes in their bodies, subjectivities and wider social life. To promote this understanding and support, impact was built into the research from the outset by giving voice to disadvantaged and underrepresented members of the public and collaborations with artists, aiming to develop outputs that could raise awareness through their co-creative approach.

3. References to the research

3.1 **Haddow**, G. (June 2020) 'Animal, Mechanical and Me: Organ Transplantation and the Ambiguity of Embodiment' in Mason, K., and Boero, N. (eds.,) *The Oxford Handbook of the Sociology of the Body and Embodiment*, Oxford University Press, Oxford, pp. 165-181.
<https://web.archive.org/web/20210120122431/https://www.ncbi.nlm.nih.gov/books/NBK559943/>

3.2 **Haddow** G., Harmon, S., and Gilman L. (2016) 'Implantable Smart Technologies (IST): Defining the 'Sting' in Data and Device', *Health Care Anal*, 24, 210-227. (*This is a companion piece to 3.3. and reflects the interdisciplinary collaboration conceived of and led by Haddow as a sociologist and Harmon based in Law - Gilman, one of Haddow's PhD students was employed as the RA and collected the empirical elements and reviewed versions*).
 DOI: [10.1007/s10728-015-0309-8](https://doi.org/10.1007/s10728-015-0309-8)

3.3 Harmon, S., **Haddow**, G., and Gilman L. (2015) New risks inadequately managed: the case of smart implants and medical device regulation. *Law, Innovation and Technology*, 7:2, 231-252. DOI: [10.1080/17579961.2015.1106107](https://doi.org/10.1080/17579961.2015.1106107)

3.4 **Haddow**, G., King, E., Kunkler, I., and McLaren D. (2015b) 'Cyborgs in the Everyday: Masculinity and Biosensing Prostate Cancer', *Science as Culture*, 24:4, 484-506. (*This piece was written by Haddow who also collected data with the RA King. Kunkler and McLaren are both oncologists who actively contributed through reviewal and advice on the implantable biosensors*). DOI: [10.1080/09505431.2015.1063597](https://doi.org/10.1080/09505431.2015.1063597)

3.5 **Haddow**, G., Bruce, A., Calvert, J., Harmon, S., & Marsden, W. (2010). 'Not 'human' enough to be human but not 'animal' enough to be animal – the case of the HFEA, cybrids and xenotransplantation in the UK', *New Genetics and Society*, March, 29:1, 3-17. (*This piece was conceived, written and revised by Haddow with contributions by the authors listed in alphabetical order*). DOI: [10.1080/14636770903561182](https://doi.org/10.1080/14636770903561182)

4. Details of the impact

Haddow's research and collaborations led directly to a number of outputs (films, radio programmes and podcasts), which inspired media discussion and raised public awareness across the UK for the challenges and vulnerabilities of 'everyday cyborgs.' Further, her work informed medical practice and policy-making at UK government level on bioethical issues related to implantable medical devices and the oversight of emerging biotechnologies.

Raising public awareness for 'everyday cyborgs'

In 2014, Haddow collaborated with one of her ICD participants ('Maggie') and a film-maker to co-produce a short emotional film about Maggie's ICD implantation, which was called '*Maggie's ICD story*', viewed 412 times on YouTube and Vimeo (5.1) and included in the exhibition 'Medicine, What Now?' at the Wellcome Trust's Collection's permanent gallery 'Medicine Now' (2007-2019) (5.2) which attracts approximately 550,000 visitors a year. In 2015, driven by a desire to engage an audience rarely consulted with, Haddow undertook an 18-month film production project with six young people from a deprived area of Edinburgh. It aimed to target the ethical and social implications of new and emerging science and technologies, but the young people could choose the precise topic and content of the film. Through teaching them how to write, direct, film, animate and provide a musical score to their own gothic film '*Broken Wings*', they learned new skills and it allowed them to create their very own visions about xenotransplantation. The project involved Scotland's best animators, sound producers and creative artists (e.g., Screen Writing Edinburgh, Legs on Lens), but always with the young people in charge.

In order to capture the impact of these short films on the young people, professionals and artists involved in making them, these films along with two others in the project (*Electrifying Cyborg Heart* and *Everyday Cyborgs*) were joined together with 'talking head' sections of individuals discussing what they had learned from their involvement. This created a 45-minute documentary '*Everyday Cyborgs and Humanimals*', which has been viewed 566 times on YouTube (5.3). Its premiere took place at the Filmhouse, Edinburgh and was reviewed positively in the SciArt Center Magazine: "*At the intersection of art house cinema, medicine, and sociology, these films are unusual in their aesthetic treatment of difficult subjects. (...) The thoughtfulness of the film making cued through careful animation and an emphasis on the specificity of individual stories predisposes audiences to see into the lives of others without fear and with imaginative empathy (...) Taken together these films (...) offer new ways of thinking about bodies and the ways medical interventions change and do not change our sense of humanity*" (5.4). The overall project process was documented on the blog 'Animal, Mechanical and Me: The Search for Replaceable Hearts' and has had 2,034 unique visitors with 4,197 views (5.5).

Inspiring creative artists and media discussions

Additionally, Haddow's concept of everyday cyborgs has become a source of inspiration for creative artists and broadcasters, offering new ways to explore the daily routine of a techno-hybrid life. During 2018/2019, the award-winning playwright Carla Grauls was commissioned

by Audible Books to produce a short story, and she approached Haddow about a possible collaboration, describing their conversations later on as *“incredibly valuable in informing my work”* (5.6). The resulting audio play *‘Life Ever After’*, which deploys a “cyborg love story”, does not have exact listening figures but has had over 3,000 reviews since it was first aired in June 2019 in both UK and the US (5.6).

More recently, Haddow’s collaboration with the author Naomi Salman resulted in a fictional gay cyborg love affair story entitled *‘sur la comète’*, (‘on the comet’) in the anthology *‘Uncanny Bodies’* (2020). Salman wrote that Haddow’s *‘feedback and comments were greatly useful to the development of the story (...) As a result of this collaboration, I was able to develop a story based on real-life stakes and, I hope, asking real-life questions’* (5.7). An episode of BBC Scotland’s radio programme *‘Brainwaves’* (No 6: ‘Cyborgs’) was directly inspired by Haddow’s research, as stated by the programme’s presenter: *“It was indeed your work which set me off thinking about the whole subject (...) What has resulted has been an utterly fascinating journey into the world of transhumanism but also into the extraordinary work going on in Scotland developing cutting edge prosthetic technologies. It has been hugely thought provoking”* (5.8).

Informing ICD policy & medical practice

Haddow’s research has attracted the attention of practitioners and policy-makers, who have to “navigate” the intersections of technology, biomedicine and bioethics. The Nuffield Council on Bioethics (NCoB) sought Haddow’s assistance when drafting their 2019 Briefing Note (5.9). The Director, stated that the Briefing Note *“has generated positive responses, for example from Baroness Cumberlege who is currently leading an independent review of the safety of medicines and medical devices. It also led to meetings to discuss the note, including with Rob Orford, Chief Scientific Adviser (Health) to the Welsh Government [...] Dr Haddow’s research led us to use the term ‘smart devices’ to describe such devices in the briefing note and in the press release we published to accompany the launch of the briefing note.”* This press release, which focused on the security issues raised by smart devices, was picked up by 280 news sites (5.9).

Haddow’s research was conceived in collaboration with cardiologists in Edinburgh, and her findings are being well received in Scotland’s cardiology community and are said to have *“encouraged our (cardiology) department to take a more holistic approach to the management of our patients with implantable devices”* (5.10). Early indications are that the long-term impacts from this qualitative research will need additional time given COVID 19, e.g., Haddow’s presentation to the Cardiology Unit in Ninewells Hospital, Dundee has been postponed. In February 2020, Haddow accepted an invitation to present her findings about the need for additional support for ICD patients to Scotland’s Family Arrhythmia Network Support group (FANS) (5.11). Feedback described it as *“a fantastic presentation”*, offering a *“fascinating perspective.”* One mother emailing Haddow subsequently requesting details for ‘Maggie’s ICD Story’ said that the presentation had made *“a lasting impression”* on her and gave Haddow permission to use the photos of Annie her daughter who is an ‘everyday cyborg’ (5.12):



5. Sources to corroborate the impact

5.1 *Maggie's ICD story*; viewed 412 times on YouTube

<https://www.youtube.com/watch?v=B1SMZ4-Wxql>; <https://vimeo.com/146917739>

5.2 Email exchange with the Wellcome Collection's Visitor Experience team to use Maggie's Story in the 'Medicine What Now?' project and 'Medicine Now' exhibition.

5.3 *Everyday Cyborgs and Humanimals*' viewed 572 times on YouTube

<https://www.youtube.com/watch?v=7WiITY5FF5w>

5.4 SciArt Center Magazine

<https://web.archive.org/web/20201204130233/https://www.sciartmagazine.com/blog/event-everyday-cyborgs-and-humanimals-triple-short-film-screening-in-edinburgh>

5.5 Animal, Mechanical and Me: The Search for Replaceable Hearts.

- Wordpress webstatistics
- <https://web.archive.org/web/20201204130918/https://animalmechanicalandme.com/>

5.6 Carla Grauls' testimonial e-mail and an email with a number of the Audible reviews from the US.

5.7 Naomi Salman's testimonial.

5.8 Testimonial Senior Content Producer & Presenter, BBC Radio Scotland.

5.9 Testimonial from the Director of Nuffield Council on Bioethics and Briefing Note 2019 – Medical Implants.

5.10 Testimonial from cardiologist.

5.11 Email feedback on presentation at The Familial Arrhythmia Network for Scotland (FANS) support group and video upload on FANS website

5.12 Email feedback from member of audience of the presentation at the The Familial Arrhythmia Network for Scotland (FANS) support group and permission to use photographs.