

# “Pasts, Presents and Futures of Medical Regeneration”

## Workshop 3: Cultures of Regeneration Research

### Report

The third and final project workshop took place at the Marks and Spencer Company Archive at the University of Leeds on 6<sup>th</sup> and 7<sup>th</sup> July 2016. Established in 1984 to celebrate the 100<sup>th</sup> birthday of the company, the archive comprises more than 70,000 items dating from 1884 to the present day and offers on-site and online events and workshops exploring the histories of science, art and design, technology and fashion.<sup>1</sup> Participants from previous workshops in the series were joined by new attendees with expertise in bioengineering, the social history of ageing and literary studies. Project Investigator Dr James Stark opened with a welcome and revisited the key topics and outcomes of Workshops 1 and 2. Following this, new participants were invited to introduce themselves and those from previous workshops offered updates on their research relating to the project themes.

Invited speaker Dr Lucy Burke (Manchester Metropolitan University) offered a summary of her co-produced research into cultural value and creativity and her work with people living with dementia and younger people with learning disabilities. Karen Jent (University of Cambridge) reported on *Unfolding Organogenesis*, an interactive drop-in exhibition at the Edinburgh International Science Festival, which enabled festival visitors to explore stem cell growth and organ development in conversation with scientists and artists.<sup>2</sup> Dr Jennifer Edwards, Postdoctoral Research Fellow at the Institute of Medical and Biological Engineering at the University of Leeds, described her work on acellular biological scaffolds in collaboration with NHS Blood and Transplant (NHSBT). Lucy Santos (Open University) gave an update on her doctoral research, including the compilation of a database of commercial beauty products containing radium produced and sold between the 1910s and 1930s in Britain and the United States. Dr Stark reported on the progress of his book on the history of anti-ageing and rejuvenation in the first half of the twentieth century, which encompasses diverse products and practices including: nutritional advice and dietary supplements, electrotherapy, hormone treatments and skincare. He also delivered news of his successful bid for an AHRC Leadership Fellows grant. This two-year project, titled “Endless Possibilities of Rejuvenation: Defining Youth, Defying Ageing in Britain, 1919-1948”, will examine the impact of the most widespread methods of rejuvenation on post-WWI Britain.<sup>3</sup> The project will include an international conference on anti-ageing and rejuvenation to be held in 2017.

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<sup>1</sup> “Marks in Time”, *Marks and Spencer*, [www.marksintime.marksandspencer.com/home](http://www.marksintime.marksandspencer.com/home)

<sup>2</sup> “Unfolding Organogenesis”, *Euro Stem Cell*, 23 June 2016, [www.eurostemcell.org/story/unfolding-organogenesis](http://www.eurostemcell.org/story/unfolding-organogenesis)

<sup>3</sup> “Endless Possibilities of Rejuvenation”, *University of Leeds*, <http://arts.leeds.ac.uk/medregen/>

The first presentation was from Pat Thane, Research Professor in Contemporary History at Kings College London, whose current work in the social sciences connects histories from the twentieth century with contemporary issues surrounding age, gender and class. Professor Thane began her paper, titled “Do Older People Need Regeneration?”, with the observation that age and ageing are not modern experiences. In Ancient Rome, Medieval Europe and across the seventeenth, eighteenth and nineteenth centuries, a percentage of the global population lived to the age of 65 and beyond. “Age” and “ageing” have not been fixed terms: rather, they have been culturally-defined across these historical periods and continue to be so. Turning her attention to the present day, Thane noted that life expectancy is increasing. There are now around 15,000 people over the age of 100 living in England and Wales, whilst Japan has the highest proportion of older people in the world. However, statistics on life expectancy often mask inequalities: the prospect of a longer life must be considered in tandem with questions surrounding quality of life. Thane drew on statistical evidence showing that in 2010, the socio-economic gap in life in disease-free life expectancy between rich and poor in the UK was 17 years.<sup>4</sup> According to Age UK, the UK’s largest charity working with older people, 16% of the country’s pensioners (1.8m) are living in poverty, with a further 1.2m deemed to be on the brink of poverty (where poverty is defined as less than 60% of median income). Since its introduction in 1908, the state pension has never provided enough for the recipient to live on: UK state pensions remain among the lowest in all high-income countries. Older people living in poverty, or close to it, are more likely to have health problems, but less likely to seek healthcare. In addition, the cultural diversity of older people is often overlooked: the risk of poverty amongst Pakistani and Bangladeshi pensioners, for example, is high.

Negative stereotypes of old age as a condition of decrepitude prevail, but the huge contributions of over-65s to their communities and the economies suggests a different story. Data from 2011 shows that 30% of this age group regularly volunteer in unpaid roles. The estimated value per annum for formal volunteering is £10bn; informal volunteering is thought to be worth £34bn. 49% percent of over-65s care for children or grandchildren. The overall contribution of this demographic group to the economy in taxes, volunteering, donations and spending is £40bn.<sup>5</sup>

Professor Thane noted that the growth of incentives to hide and/or reverse ageing are socially and culturally-informed, and emphasised the need for a distinction between these cosmetic practices and medical interventions which seek to improve or restore functionality. At the same time, it is important to consider that effective interventions are not necessarily medical: instead of modifying the body, environmental changes can be made to accommodate the physical and emotional needs of an ageing population. Thane emphasised the importance of new initiatives in this area through an overview of current healthcare policy. Cuts to the NHS mean that operations for treatments predominantly affecting older people – such as screening services, cataract operations and joint replacements – are low priority. Professor Thane’s presentation concluded with an emphasis on the need to investigate and address

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<sup>4</sup> *Fair Society, Healthy Lives: The Marmot Review*, 2010, <https://www.instituteofhealthequity.org/>

<sup>5</sup> *Gold-Age Pensioners*, Women’s Royal Voluntary Service, 2010, <http://www.royalvoluntaryservice.org.uk/our-impact/reports-and-reviews/gold-age-pensioners>

obstacles to effective medical regeneration whilst also placing the desirability of certain forms of regeneration – and the value attached to them – in historical and critical contexts.

Group discussion following Professor Thane's paper converged on urban planning, lifestyle and societal attitudes to ageing. Lucy Burke noted that recent interventions in dementia care have focused more on preventative measures and the importance of social activities, whilst Jennifer Edwards pointed out that patients with joint replacements are required to maintain certain levels of physical activity to restore use and prevent further degeneration. Project Research Assistant Catherine Oakley observed that the spectre of the normative body hangs over concepts and practices of age and regeneration. Professor Martin Willis pointed to the influence of the visual culture of medicine in this regard, noting that Greek sculpture has informed anatomical teaching and contributed to an idealized form of youthful vigour against which the human body is measured at all stages of the life-course. Dr David Pilgrim (University of Liverpool/University of Southampton) added that this idealisation applied not just to the ageing body, but to behaviour and conduct: the exemplary older woman, for example – married, motherly – is defined primarily by her relationship to men. Lucy Burke drew attention to the ableist assumptions inherent in some anti-ageing and regenerative thinking and suggested that we might draw on work in the field of Disability Studies to re-orient discussions about regeneration. Such an approach would analyse cultural anxieties about dependence and vulnerability, re-examine common indices of an individual's social value, and seek to learn from those with life-long impairments about what it means to live well.

After a short refreshment break, participants divided into cross-disciplinary groups to discuss the following questions concerning “Conceptual Cultures of Regeneration”:

- If regenerative medicine is “the application of scientific principles to repair, restore, supplement or replace the natural function of a biological system”, what is the role of society, culture and policy?
- If we think of the “Trinity” of regenerative medicine as the correct cells, material and stimuli, what implications does this have for perceptions of bodies?
- Is regeneration a “special problem”, biologically or socio-culturally?
- Where do humans fit into the wider biological realm of “regeneration”?
- Where do ideas of regeneration come from?
- How does regeneration appear in creative fictions?
- Should we manage expectation of what kinds of regeneration are possible?

Following a whole-group discussion on these topics, Dr Lucy Burke delivered the second presentation of the day, titled “Futures? Dementia and Human (Re)generation in Contemporary Culture”. In recent thinking about dementia, the biomedical paradigm predominates. Dementia is separated from “ageing”, although identifying and differentiating distinct pathologies remains a significant challenge. Dr Burke analysed the rhetoric of “crisis” applied in recent years to describe the prevalence of dementia. In the United States, Medicare has improved provisions for dementia treatment by identifying it as a disease. The biomedicalization of the condition has also, however, opened up the possibility that it can be “cured”. Discourses surrounding dementia are embedded within the rhetoric of “disaster

capitalism”, in which social “crises” also become opportunities for profit. Within this system, the individual must be vigilant, disciplinary and self-regulatory, taking active responsibility for an unknowable future. Such a logic governs the direction of policy and research in many areas, including ageing provisions in healthcare. It also justifies free-market commercial practices which are proffered as innovative – and necessary – solutions to the defined crisis. Former UK Prime Minister David Cameron’s “Dementia Challenge”, inviting new social investment in the dementia market, presents a case-in-point, operating alongside the neoliberal dismantling of the welfare state.

Having established the socio-economic and medical contexts for dementia, Dr Burke moved on to consider its representations within cultural outputs, exploring the ways in which dementia has emerged as an over-determined point of tangency upon which particular ideas about ageing, (im)mortality and human value are played out. The film *Deep Blue Sea* (dir. Renny Harlin) was released in 1999 at a time when the first successful experiments with human stem cells made global headlines. It follows a group of scientists at an underwater laboratory experimenting on the brains of sharks in their search for a cure for Alzheimer’s disease. After genetically engineering the animals, the scientists are faced with sharks of increased intelligence and aggression. The animals break free, kill the scientists and destroy the facilities. Dr Burke suggested that the film allegorises the eradication of the forces of capitalist speculation (embodied in the character of Russell Franklin, millionaire CEO and cannibal) and of scientific research (overcome by the elemental forces of fire and water). The film subverts a narrative of scientific progress in which human labour is displaced by the achievements of enterprising biomedical practice. Beginning with the prospect of regeneration, it concludes in a deracinated, deserted time of unemployment and social paralysis.

In Vernor Vinge’s 2006 speculative fiction novel *Rainbow’s End* set in San Diego in 2025, the protagonist Robert Gu recovers from late-stage Alzheimer’s disease following advances in medical technology. A former poet, he must adjust to a world of augmented reality in which all social interaction is technologically mediated and its commercial and medical dimensions. Dr Burke outlined the novel’s limitations with respect to the idea of regeneration. Medical technologies feature only implicitly, described without any reference to their histories or mechanisms. As such, they are abstracted from the conditions of production, including materials, processes and human labour. There is no critical exploration of the methods of regeneration in the novel that have facilitated Gu’s recovery and no examination of the socio-economic implications of capitalist investment in longevity. Concluding her analysis, Dr Burke emphasised the inseparability of corporeal regeneration and economic regeneration, reiterating the extent to which the contemporary meanings of dementia are tied to the logic of neoliberal marketisation. *Deep Blue Sea* and *Rainbow’s End* both entertain the possibility that investments in biotechnology will provide a solution to dementia as a crisis of ageing. Both cultural narratives testify, in different ways, to the ideological limits of this discourse. Difficult but important questions surrounding the possibility of living – and working – with a chronic condition, are occluded.

In the discussion following Dr Burke’s paper, Dr Stark observed the typically dystopic character of science fiction narratives featuring ageing and regeneration. More often than not, imaginative exploration of the possibilities, limitations and risks of scientific progress in this area envisage the worst outcomes, rather than the best. Stark suggested that such pessimistic narratives may represent a coming-to-terms with the difficulty – and potential impossibility –

of realising regenerative visions. Catherine Oakley drew attention to the parallels between contemporary “disaster capitalism” and the late nineteenth century “degeneration” crisis. Both periods are marked by significant economic changes: the second industrial revolution of the late nineteenth century and the neoliberal project of the 1970s onwards, respectively. In both instances, ideological attention converges on the health and functionality of human body, and forms of corporeal modification and exploitation facilitated by new technologies.

Day Two opened with a presentation from Martin Willis, Professor of English at Cardiff University. Professor Willis’ talk, titled “Histories of Seizures in Narrative and Image”, explored materials and approaches pertaining to Victorian catalepsy as a condition encompassing both degenerative and reparative elements. Willis examined the case-study of the “Soho Sleeper”, a French man with catalepsy living in London, whose extraordinarily lengthy cataleptic trance, extending over a period of three weeks, generated huge national interest in the popular press in 1887. Writing in *Popular Science Monthly*, the physician Armand de Watteville drew on coverage of the case in the *British Medical Journal* to discuss catalepsy, lethargy and somnambulism and their connection to questions surrounding national character and racial degeneration.<sup>6</sup> The Soho Sleeper became a medical test case without consent and a performative spectacle of pathological inactivity and eventual revivification. Professor Willis observed that cataleptic tropes of de- and re-generation such as this also appear across fiction in the nineteenth century, and offer fertile ground for literary analysis. British fictions from the late nineteenth century such as Arthur Conan Doyle’s “The Advent of the Resident Patient” and Richard Marsh’s *The Beetle*, and work by French writers such as Emile Zola and Guy de Maupassant, share a common concern with catalepsy as the loss of sensibility or consciousness, which is often also framed in economic terms as a loss of capital. In contrast to the objective observations in medical assessments and press coverage of the Soho Sleeper, such literary fictions offer first-person narrative accounts from the perspectives of cataleptic individuals. In these stories, catalepsy is configured as a reparative practice and the sufferer can regenerate to embrace a new kind of life.

Professor Willis then went on to examine visual images from British and French medical and scientific texts from the late nineteenth century, many of which documented hospital patients suffering from catalepsy or other types of seizure. In these photographic shots, the subjects are posed, and their violent contortions signified in performative terms: dance-like, or athletic. From here, Willis moved on to representations of seizure by contemporary artists. The Royal Academy artist Gus Cummins has used body-tracking technology to create artworks depicting his seizures.<sup>7</sup> The experimental filmmaker and printmaker Susan Aldworth has used X-ray and MRI scans of her body to create a visual commentary on her experience of epilepsy.<sup>8</sup> In 2010, the Los Angeles-based street artist Saber

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<sup>6</sup> A. De Watteville, “Sleep and its Counterfeits”, *Popular Science Monthly*, Vol. 31, September 1887, pp. 597-608. [en.wikisource.org/wiki/Popular\\_Science\\_Monthly/Volume\\_31/September\\_1887/Sleep\\_and\\_its\\_Counterfeits](http://en.wikisource.org/wiki/Popular_Science_Monthly/Volume_31/September_1887/Sleep_and_its_Counterfeits)

<sup>7</sup> “Interview: Gus Cummins Talks About His New Work Ictal”, *Disability Arts Online*, 11 August 2008, [www.disabilityartsonline.org.uk/Gus\\_Cummins\\_Interview](http://www.disabilityartsonline.org.uk/Gus_Cummins_Interview)

<sup>8</sup> “Susan Aldworth: The Portrait Anatomised”, *National Portrait Gallery*, 2013, [www.npg.org.uk/whatson/display/2013/susan-aldworth-the-portrait-anatomised.php](http://www.npg.org.uk/whatson/display/2013/susan-aldworth-the-portrait-anatomised.php)

posted a video in which he painted and then graffitied the American flag, as an expression of the challenges he faces trying to manage his epilepsy without adequate healthcare.<sup>9</sup>

Willis then turned to questions of methodology. How might researchers from the humanities and the sciences come together to think and talk about seizure? He suggested that the biologist E. O. Wilson's theory of consilience, as outlined in his 1998 book *Consilience: The Unity of Knowledge* (Vintage), offers negative instruction in this regard. In describing how knowledge might be synthesised from different specialized fields of human endeavour, Wilson suggested that the humanities are at an intellectual disadvantage and need to become "fully-fledged" to meet the sciences on their own terms. The humanities disciplines, Wilson argued, can only explore existing knowledge: they cannot produce new knowledge. More recently, the cognitive scientist Steven Pinker has echoed this scientism, suggesting that "a consilience with science offers the humanities countless possibilities for innovation in understanding". For Pinker, humanities disciplines are of value only in so far as they are subsumed by science: "Archaeology", he argues, "has grown from a branch of art history to a high-tech science. Linguistics and the philosophy of mind shade into cognitive science and neuroscience". The visual arts and literary scholarship, he insists, must follow suit.<sup>10</sup> Professor Willis concluded with the suggestion that the humanities, can work with the sciences through a variety of interdisciplinary critical approaches. Willis's own work on the "Soho Sleeper", integrating medical history and cultural studies, is a case-in-point. The "New Humanities" encompasses political and cultural perspectives on a wide range of materials, including art, television and literature.<sup>11</sup> We might therefore proceed by encouraging scientific researchers to recognise the value of this work, and to undertake it themselves, rather than the other way round.

Responding to Professor Willis's methodological "provocation" in the discussion session which followed, Lucy Burke observed that science can often seem monologic from the perspective of the humanities because it is convenient for it to be so: the same is true of the reverse. Dr Burke noted that the profound messiness of science – its irresolutions and (in)visible failures – are often of particular interest to humanities scholars. She emphasised the need for those in the humanities to recognise and engage with existing practices of self-reflection in the sciences. Dr Stark asked what a balanced, interdisciplinary project on catalepsy and epilepsy might look like, going forward. In response, Professor Willis suggested that a collaborative enquiry between literary scholars and neurologists, investigating possible sites of creativity in the brain, might represent a progressive, innovative and collaborative project that could not be undertaken in the same way by either the humanities or the sciences alone. Dr Stark remarked that a future large-scale project on medical regeneration might adopt a similar approach, combining research into the cultural and medical histories of regenerative practices with scientific investigations of regeneration as biological process.

In the "Soapbox" session which followed, participants were given the opportunity to lead group discussion on topics relating to regeneration arising from the project workshops so far. Several observations emerged from this dialogue. There is an inherent pluralism to regeneration: it has different meanings in different contexts and within different disciplines.

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<sup>9</sup> "Saber Speaks: Organizing For America Health Care Reform Video", *YouTube*, 18 October 2009, [www.youtube.com/watch?v=b5ZE8uQFM7o](http://www.youtube.com/watch?v=b5ZE8uQFM7o)

<sup>10</sup> Steven Pinker, "Science is Not Your Enemy", *New Republic*, 7 August 2013, [newrepublic.com/article/114127/science-not-enemy-humanities](http://newrepublic.com/article/114127/science-not-enemy-humanities)

<sup>11</sup> The Editors, "The New Humanities", *The Point*, <https://thepointmag.com/2014/criticism/the-new-humanities>

There is a widespread belief in the capability of science to solve key problems associated with ageing that is worthy of critical examination. The life-course has become marketized to such an extent that it is difficult to detach the desire for rejuvenation and regeneration from the commercial strategies which promote and profit from it. Lucy Burke reiterated that discussions surrounding regeneration apply only to OEDCs. Whilst interest and expectation of scientific progress in regeneration grows in these societies, LEDCs remain concerned primarily with basic access to healthcare. Given this socio-cultural divide, there is a risk that wide-scale practices of medical regeneration might come to rely on an underclass of donors drawn predominantly from poor populations. Dr Burke suggested the global political dimensions of a potential “black economy in medical regeneration”. She cited the Nigeria Pfizer Scandal in the 1990s, and reports of illegal organ harvesting from prisoners in China, and from street children in Guatemala, as examples of such dangers.

Catherine Oakley suggested the importance of questions surrounding research communication and “popular science” in discussions surrounding regeneration. The concepts of rejuvenation and regeneration have drawn interest since the beginning of human civilization. Scientific knowledge does not exist independently of other forms of knowledge, but is culturally produced and mediated. In managing expectations of regeneration, we must therefore pay close attention to the ways in which it is reported, represented, discussed and reimagined in the public sphere, where discourses of science and popular culture intersect. Professor Willis pointed out that recent scandals surrounding blood doping in sport represent a collective ethical engagement with regeneration: the unanimous verdict is that such performance enhancement should not be permissible, even in a hypothetical situation in which all athletes dope and therefore perform on an even playing field. Echoing conversations from the previous day, Cheryl Lancaster (Durham University) reiterated that a normative idea of the body – as western, white, athletic – underpins desire for regeneration. In this sense, regeneration is an elite pursuit. Dr William MacLehose (UCL) added that this normative model also applies not just to the body, but to the mind as well. Lucy Burke suggested that critical work on regeneration must therefore ask: what are our normative values? Where do they come from? And what are the alternatives?

Attention must also be paid to the potential social consequences of regeneration. The prospect of replacement organs, for example, may have implications for lifestyle, permitting reckless behaviours with serious consequences for personal identities (cf. the resurgence of “barebacking” in gay communities since the development of treatments for HIV). In addition, prospective visual differences between those who regenerate and those who do not may create a two-tier society of “superhumans”, “regenerates” or “posthumans” on the one hand, and “degenerates” or “disabled” groups, on the other. Alternatively, regeneration may have the capacity to disrupt the fiction of normativity. Burke underscored the importance of differentiating between “the norm” (i.e. that which is typical) and “normativity” (a social construct).

The closing session of the day, titled “Regeneration: Where Next? What Next?” invited participants to share ideas for the future evolution of the project beyond the workshop series and its funded duration. The group agreed that discussions surrounding regeneration are particularly meaningful when we think about ageing and disability in conjunction. Lucy Burke noted that Disability Studies scholars such as Lennard J. Davis and Tom Shakespeare have argued that people are only ever temporarily abled: impairment and dependency are the

rule, not the exception. Dr David Pilgrim suggested that regeneration might therefore be read as a technocratic attempt to hold more people, for longer, in a certain physical state of being human. The distinction between preventative and regenerative strategies for healthy ageing is also likely to prove useful to further enquiries. Bringing the discussion to a close, Dr Stark suggested that an initial project output might take the form of a series of papers to be published as a special journal issue or an edited book. Diverse contributions from participants might cover the definitional, conceptual, historical, methodological, personal, professional and philosophical dimensions of regeneration. It was decided that such a collection might be published under the title “New Critical Perspectives on Human Regeneration”. Unlike “medical regeneration”, the term “human regeneration” recognises the importance of cultural, social and economic discourses and practices, in addition to medical ones. Lesley Steinitz (University of Cambridge) suggested that a working schema with definitional clarifications be drawn up by the project organisers and collaboratively revised with contributors.

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