

Institution: Manchester Metropolitan University

Unit of Assessment: D32 Art and Design: History, Practice and Theory

Title of case study: Arts for Health: increasing wellbeing through practice change,

representation and empowerment

Period when the underpinning research was undertaken: 2000–2020

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:
Lucy Burke	Principal Lecturer, English	2001-present
Clive Parkinson	Reader in Arts, Health & Social Justice	2004-present
Amanda Ravetz	Professor of Social and Visual Practice	2004-present
Stella Bullo	Senior Lecturer in Linguistics	2008-present

Period when the claimed impact occurred: 2014–2020

Is this case study continued from a case study submitted in 2014? No

1. Summary of the impact

The Arts for Health research group has impacted on the care provision for mental and physical health through the development of innovative arts-led and publicly-engaged methodologies, as well as creative modes of campaigning and activism. Delivered locally, nationally and globally, the impact of the group's co-created activity, which is geared to understanding and communicating experiences of physical and mental illness, disability and addiction, manifests itself in three ways: (1) addressing health inequalities by fostering greater inclusion through public engagement and advocacy; (2) creating the conditions for marginalised groups to represent themselves and give voice to the experience of their health conditions and care; and (3) changing health and care practice to engage and empower individuals and communities.

2. Underpinning research

Arts for Health at Manchester Met has been a global pioneer in researching the arts-and-health nexus. Originally founded as 'Hospital Arts' to humanise NHS environments, it evolved into 'Arts for Health' - the first centre of its kind internationally, for which the (then) lead, Peter Senior, was awarded both an MBE (1994) and the Chevalier des Arts et des Lettres (2001). Heading Arts for Health since 2004, Parkinson led the GBP385,000 HM Treasury-funded Invest to Save: Arts in Health (ISP) research project (2003-2007), which served to consolidate the evidence base for creativity, culture and the arts' direct impact on health and well-being. This project initiated the transition of Arts for Health from a focus on the clinical environment to a broader public health research agenda, as exemplified by a partnership set up between the University, the Department of Health and Arts Council England (ACE) that resulted in considerable public policy and wellbeing impacts, as reported in our REF 2014 case study. Since 2014, the Arts for Health research group has piloted a range of innovative arts-based public engagement methodologies to support people with physical and mental illness, disability and addiction in a better way. The group's shared ethos is to provide opportunities for otherwise marginalised demographics to represent themselves and gain agency within the often-disempowering contexts of the health and social care system. Their research seeks to illuminate and valorise a diversity of perspectives and experiences in order to challenge discriminatory attitudes and preconceptions. to improve care models and to address health inequalities with a particular focus on addiction, mental health, dementia and endometriosis.

Ravetz's and Parkinson's research has examined experiences of recovery from addiction. Parkinson's project, *I AM–Art as an Agent for Change* (2012-2014), involved over 200 people in recovery from substance use in the UK, Italy and Turkey. Examining addiction and recovery via conversation and narrative, with reference to civil rights concerns, his research set out to facilitate a more humanised representation, shaped by collective lived experience, resulting in *A*



Recoverist Manifesto (2014). This research was funded under the European Union's Life-Long Learning Programme, Grundtvig UK, which supports individuals and organisations involved in non-vocational adult education to participate in European training activities and projects. [1]. In Wonderland (2016), a collaborative artistic research project by, and for, people in recovery from substance use disorder and mental health issues, Ravetz employed artist Nunez's self-portrait methodology to explore how artistic practice can support the journey and experience of recovery. The aim was to understand the recovering person's emotional mind set and how art can strengthen the resilience of communities. The resulting body of work (self-portraits, artists' books, academic articles and online exhibition) was showcased at the Utopia Fair at Somerset House, London, in 2016. The film element of Wonderland won the AHRC's 'Research in Film' award (Utopia category). [2]. In UNSEEN: Simultaneous Realities (2017), co-produced with Manchester-based charity, Portraits of Recovery (PORe), Ravetz examined LGBT, South Asian and disabled communities in recovery from substance use, to document their journey to greater visibility and acknowledgement. The resulting film, My Recoverist Family (2017), was selected for the REELHEART International Film Festival, Toronto, and won Silver in the Best LGBT+ category. [3].

Burke is co-investigator on the D4D (Disability and Community: Dis/engagement, Dis/enfranchisement, Dis/parity and Dissent) project (2017-2020), an ongoing research programme that investigates the ways in which disabled people express, perform, experience and practise 'community'. Funded by the AHRC's Connected Communities stream, D4D comprises work packages exploring diverse areas, such as: robotics; the arts; education; employment; genetics; and gaming. Burke's work stream ('Now you see us') involves work with youth zones (Bolton Lads and Girls Club), a local high school (Parrenthorn High School in Prestwich/Manchester), and the New Vic Theatre in Stoke, using arts-based approaches to explore questions of community, identity, equality and inclusion. D4D is anchored in stakeholder co-production and involves close collaboration with ADWUK (Action on Disability and Work UK); DAO (Disability Arts Online); DaDaFest; DRUK (Disability Rights UK); Graeae Theatre Company; Mencap; Stroke support groups (Bristol and Cornwall); MS Society UK; and NDACA (National Disability Arts Collection and Archive), which is delivered by Shape Arts. Burke also worked closely with the artist and filmmaker, Liz Crow, resulting in a chapter on the role of social media in arts-based disability activism, which was inspired by Twitter responses to Crow's exhibition, 'Bedding Out' [4].

Another key concern of <u>Burke</u>'s and <u>Parkinson</u>'s research is the implementation of collaborative arts practice and arts-based co-production methodologies to promote patient agency, and to improve care provision for people with dementia. <u>Burke</u>'s work on the *Small Things* project 'The Island' (2017) introduced six artists to ten dementia patients from a care home in Wythenshawe, to mobilise Shakespeare's *The Tempest* as a tool for the residents to express themselves in creative ways conducive to articulating their personal values and unique life experiences [5]. As a co-investigator on the AHRC-funded project *Dementia and Imagination*, which brought together NHS staff, care homes, local government, the voluntary sector and various arts organisations, <u>Parkinson</u> investigated how visual arts engagement might contribute to the health and well-being of people with dementia. This research was collated into a handbook (2017), which includes a practical toolkit for artists interested in delivering arts-based activities with, and for, people affected by dementia [6].

Equally concerned with patient agency, <u>Bullo</u>'s work on the language of endometriosis uncovered communication barriers in healthcare leading to diagnosis delays of up to eight years. Visualising the endometriosis pain through co-created artworks, <u>Bullo</u> developed tools for improving communication and, together with a group of volunteers, compiled a terminological lexicon, including some 200 metaphorical pain descriptors for use by women, in consultation about their condition. Supported by a GBP50,000 Faculty-funded International Research Partnership Award, a Latin American branch of the project (Dr Pascual, Pontificia Universidad Católica de Santiago, Chile) was established in 2019 [7].

3. References to the research



- **1. Parkinson, C.** *A Recoverist Manifesto,* Arts for Health, Manchester Metropolitan University, 2014. ISBN 978-1-900756-76-1
- 2. Ravetz, A. Wonderland: The Art of Becoming Human film, produced in association with Portraits of Recovery (PORe), Manchester Metropolitan University, 2016. https://ahrc.ukri.org/research/readwatchlisten/features/wonderland-the-art-of-being-human/
- 3. Ravetz, A. My Recoverist Family, artist film, 2017. https://www.art.mmu.ac.uk/profile/aravetz/projectdetails/1033
- **Burke, L.** and Crow, L. 'Bedding Out: Art, Activism and Twitter', in Katie Ellis and Mike Kent's (eds) *Disability and Social Media: Global Perspectives* (London: Routledge, 2016), https://doi.org/10.4324/9781315577357
- **5. Burke, L.** and Zeilig, H. 'Privileging the Play: Creating Theatre with People Living with Dementia', book chapter in *Social Research Methods in Dementia Studies: Inclusion and Innovation*, pp. 205-21, Routledge, 2017. https://doi.org/10.4324/9781315517490
- **6. Parkinson, C.,** Taylor, K., Windle, G. *Dementia and Imagination: Research Informed Approaches to Visual Arts Programmes*, Manchester Metropolitan University, ISBN 9781842201527, 2017.
- 7. **Bullo, S.** 'Exploring disempowerment in women's accounts of endometriosis experiences', *Discourse and Communication*, 12(6), pp. 569-86, 2018. https://doi.org/10.1177/1750481318771430

Funding and Indicators of Research Quality:

- G1. A Recoverist Manifesto: European Commission, Grundtvig UK, GRP/12/167P, EUR20,000
- G2. Dementia and Imagination: AHRC, AH/K00333X/1, 2013-2017, GBP1,219,353
- G3. D4D: AHRC. AH/N004108/2. 2017-2020. GBP1.187.771
- 11. Wonderland AHRC 'Research in Film' award in the Utopia category
- 12. *My Recoverist Family* (2017) REELHEART International Film Festival, Toronto: Silver in the Best LGBT+ category

4. Details of the impact

Legacy impacts on the global discipline of arts and health

In the report by the All-Party Parliamentary Group on Arts, Health and Wellbeing on *Creative Health: The Arts for Health and Wellbeing* (2018), which was launched at Manchester Met to celebrate 30 years of its Arts for Health research group, Manchester is described as "the wellspring of the international Arts for Health movement" and the group is identified as being instrumental to the emergence of a global Arts for Health movement. **[A].** Demonstrating the group's ongoing influence on international policy, and recording the application of their research in arts and health practice in Ireland and other parts of the world, their work is cited by WHO in their scoping review: 'What is the evidence on the role of the arts in improving health and well-being?' (2019), which has been downloaded over 23,000 times. **[B].**

In 2015, Wellcome Collection acquired the Arts for Health archives as a major national resource, comprising 179 transfer boxes of paper records, approximately 100 artworks, and a large quantity of audio-visual and digital material. Jenny Haynes (Head of Collections and Research, Wellcome Collection) has attested to both the intrinsic research value of the collection and the effect of this unique acquisition on curatorial and organisational practice, stating that "on the back of this acquisition we were able to secure a significant amount of internal project funding to catalogue and conserve the collections [...] Acquiring these collections helped to mark a significant moment of change for us in terms of an expansion of our collecting focus into new areas which are in the same broad area of an intersection between art and health. We now having a growing collection of zines, artists books and art from therapeutic settings and have also begun to commission art for the collections. The material we acquired from MMU and the conversations we had with key contacts there during the process definitely helped us to build our confidence and push forward our thinking in these areas." [C].

De-stigmatising substance use and promoting recovery

The report by the All-Party Parliamentary Group on Arts, Health and Wellbeing acknowledges, in particular, the impact of <u>Parkinson</u>'s *A Recoverist Manifesto* (2014) on changing perceptions of



substance use and recovery, as well as the role of art as a vehicle for such change: through "building on ideas in the USA Bill of Recovery Rights, a shared statement – The Recoverist Manifesto – was developed, which attempted to dispel the myths associated with substance misuse, reframing addiction as a cultural issue and recovery as a civil rights concern." [A]. The film version of *A Recoverist Manifesto* (Part one) has been viewed more than 1,765 times. Testimonial from the national Scottish Recovery Consortium speaks to the value of 'Recoverism' as a conceptual framework, stating that the identification with being 'Recoverist' has "become part of the national discourse" and that "Clive's work has therefore had not only a huge impact on all we are doing in Scotland but the way that we do it." [D].

Ravetz's work on recovery as a political and human rights issue builds directly on Parkinson's, destigmatising perceptions of substance use, aiding recovery, and mobilising art as a medium for such change. Her projects: Wonderland (2016) and My Recoverist Family (2017), were developed in partnership with visual art charity, Portraits of Recovery (PORe). Participants in both projects attested to the positive emotional and behavioural impact the work had on them: "Wonderland was the first time we had looked at ourselves with anything other than society's eyes. It was about not being ashamed. When we looked at ourselves, we found we were not horrible, twisted monsters. It gave us the courage to do things we haven't done before." [E]. My Recoverist Family screened at REEL Recovery Film Festival, Los Angeles and New York; at Whitworth Art Gallery, with the panel including writer Will Self; at Islington Mill Art Academy; at the ESRC Social Science Festival, Manchester: and at the Niamos Centre in Hulme, Manchester. A participant said: "Wearing the costumes, getting to know one another, sharing true-life experience with each other and being that open, honest and trusting was amazing. It was very freeing"... "Looking at the film now, I've completely changed...the film was instrumental in that change. It was transformative." At the Whitworth premiere (audience of 150) Will Self commented: "One of the lovely things about the film was it showed that socialisation is at the core of recovery [...] The spontaneity and the involvement of the camera in it in a very nonjudgemental and non-narrative way. I found it very moving." [E]. Between 2016 and 2020 Wonderland was viewed over 5,682 times. In January 2020 My Recoverist Family was one of four films selected as part of Professor Ali Roy's inaugural lecture on 'Recovery Stories in Art and Social Research' at the University of Central Lancashire, attended by an audience of 80 people [E].

Increasing global understanding of dementia

Burke's cross-disciplinary work on dementia has influenced medical professionals, such as Dr Michael Chapman, director of palliative care at Canberra Hospital and Health Services, who notes that the "work of Dr Lucy Burke has helped me to understand, we have additional tools at our disposal, additional lights and lenses, that can aid in responding to the challenges posed by dementia." [F]. Burke's essay 'Imagining a future without dementia: fictions of regeneration and the crises of work and sustainability' is referenced in chapter 3.7 of the World Alzheimer's Report 2019. [G]. Parkinson's Dementia and Imagination handbook (2017) has shaped artists' practices across the UK and internationally. Parkinson has delivered training events for over 300 artists, educators and other participants in Australia, Lithuania, Japan and the USA. Three films produced by Parkinson, as part of the Dementia and Imagination project, which explore diverse shared experiences of dementia (The Grand Tour), and personal narratives of those living with the condition (On Beauty; On Belonging), were screened across a range of venues, including Wellcome Collection, the National Gallery of Lithuania, and MoMA, New York. Carrie McGee, Assistant Director, Community and Access Programs at MoMA, attested to their power: "The short films you have created so beautifully capture and illustrate what no research study ever could--that the emotional acuity and capacity for appreciating beauty that define the finest aspects of the human experience are alive and well in those living with dementia. I believe these films hold great potential in terms of helping society (policy makers, doctors, family members, care professionals) recognize the full humanity of individuals with dementia." [H].

Empowering the voices of disabled people

<u>Burke</u>'s expertise in community partnership-working resulted in her being commissioned as leader of Programme Development for the Disability strand of the Manchester-based Sick! Festival 2019, and the associated public art project *Graphic Encounters*. This project focused on



the role of the arts in disability activism, challenging exclusion and negative societal attitudes towards disability. Working with Heathlands Village (Federation of Jewish Services), the LGBT Foundation, and the self-advocacy group, Together All Are Able, Graphic Encounters explores the lives of four women living with disability, illness and long-term impairments. The women's stories were visualised by four international artists through a series of compelling posters that were shown across Greater Manchester's Metrolink network, and seen by an estimated 890,000 people across the region. [1]. Tim Harrison, Director of Sick! Festival states: "Since we formed, there have only been a handful of people who have had a major impact on SICK!Fest. Lucy is one of these. She has had an impact on how we think about things. She has introduced a nuance, subtlety and depth to how we approach issues. Her integrity and depth of understanding of the subject shaped our 2019 programme and has continued to inform our awareness." [1]. Burke has continued her work with Sick! Festival through the creation of '4OFUS': four videocast conversations about the impact of COVID-19 on the lives of people facing particular challenges with access to health and social care, dealing with isolation and loneliness, and providing support for the dying and bereaved. The opportunity to share experiences of lockdown through 40FUS was described as "incredibly cathartic" by Richard Currie, a disabled contributor. He noted that, "I feel that the project demonstrated how in times of social isolation we can use the platform of social media to bring people together to share their experiences. Taking part in this project it reinforces I am not alone." [J].

Changing the language of pain

<u>Bullo</u>'s project *Language of Endometriosis* has changed the diagnosis, discussion and treatment of the condition. 100% of women surveyed on the impact of the project's two art workshops said these had either "significantly" or "greatly" helped them to communicate their experience of endometriosis pain. Participants also asserted that the workshops had helped them to visualise their pain and translate it into a tangible, more articulate, format; that they now found themselves equipped with a better vocabulary to discuss physical discomfort; and that the workshops offered a "therapeutic release." **[K]**. <u>Bullo</u> was invited by theatre director and author, Kailey McGowan, to discuss the effects of endometriosis on relationships. She confirmed that <u>Bullo</u>'s research had informed the script of her play, particularly the theatrical representation of consultation scenes where patients described their symptoms to doctors **[K]**. <u>Bullo</u> was also interviewed by BBC Radio World Service Health Check Programme, and her work was recommended in The Guardian on 28/10/20 in a letter from University of Sheffield researchers in the field. **[K]**.

5. Sources to corroborate the impact

- **A.** Report, All Party Parliamentary Group on Arts, Health and Social Change, 2018. https://www.culturehealthandwellbeing.org.uk/appg-inquiry/
- **B.** World Health Organisation (WHO) reports containing citations.
- C. Email from Jenny Haynes (Head of Collections and Research, Wellcome Collection).
- **D.** Recoverist Manifesto PDF; https://www.youtube.com/watch?v=H7KKG89YVmA; testimonial to support impact of Recoverist Manifesto in recovery communities.
- **E.** Transcript of ESRC Social Science Festival screening of MRF and post-screening discussion; transcript of panel discussion Whitworth; Wonderland website; Email from Ali Roy and text of lecture; Portraits of Recovery testimonial; Article on *My Recoverist Family* including link to film: http://notebooks.drustvo-antropologov.si/Notebooks/article/view/91
- F. Michael Chapman, testimonial.
- G. World Alzheimer's Report 2019.
- H. Carrie Magee (MoMA), email testimonial.
- I. Tim Harrison (SICK!Fest), testimonial. Corroborating Burke's impact on Sick Festival.
- **J.** Richard Currie, testimonial. Corroborating Burke's impact within disabled community.
- **K.** *The Language of Endometriosis* evaluation survey data; Kailey McGowan testimonial; https://www.theguardian.com/society/2020/oct/28/the-vast-language-of-endometriosis-pain