MEDHUMS 101:
What is medical humanities?

the polyphony

Durham University
Institute for Medical Humanities

wellcome

Medical humanities is a vibrant field that is growing in scope, scholarly breadth and positive global impact.

This brochure will introduce you to some of its core ideas and ways of working – particularly the area known as the 'critical medical humanities' – welcoming you to a field of research that includes diverse perspectives from academia, people with lived experience, healthcare and public health.

What is medical humanities? is produced by *The Polyphony*, a web platform that stimulates, provokes, and expands conversations in the critical medical humanities. Supported by Durham University and funded by Wellcome since 2018, it is based in the UK but publishes contributions from researchers across the globe, reaching readers in more than 150 countries.

The brochure is part of the 'MedHums 101' series, led by Associate Editor Aly Fixter. You can scan the QR code at the end of each section to read relevant articles from *The Polyphony* and explore each topic further. We hope this sparks your curiosity, inspires your imagination, and encourages you to engage with the critical medical humanities.

Medical humanities...

01 Uses the arts, humanities and social sciences to improve our understanding of health and human experience.

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10 Makes vital contributions to questions of public health.

Medical students respond to the *Traces* exhibition featuring work by young disabled artists, as part of a pilot study run by the Stoneygate Centre for Empathic Healthcare. Source: Marianne Scahill-Pape, Creative Medicine Arts Associate.

01

Uses the arts, humanities, and social sciences to improve our understanding of health and human experience

The medical humanities developed in the mid-20th century, initially in connection with medical education. Humanities subjects like art, literature, history, theology, philosophy, and ethics were incorporated into clinical training programmes in response to the highly technical and specialised nature of medicine and healthcare.

Medical students were encouraged to study paintings and poems about illness, think about the ethical dilemmas doctors face, and analyse historical medical practices. Educators thought this would help them acquire the tools they needed to better understand and empathise with their patients, reflect on their biases when making decisions about treatment, and develop more compassionate ways of communicating in the consulting room.

Fast-forward to the 21st century and the critical medical humanities is not a sub-field of medical education but a discipline in its own right. Researchers in this field recognise that biomedical models of health and illness do not tell the whole story. They draw on the methods and source materials of the arts, humanities, sciences, and social sciences to shed light on people's experiences of health and illness and explore how concepts of disease and wellness are constructed, change, and vary across cultures.

Medical humanities researchers increasingly collaborate with people with lived experience and healthcare professionals who share an interest in the social, economic, and environmental factors that influence health and wellbeing for individuals, groups and communities. They want their research to help improve health policy and practice, and advocate for societal change as well as transformations in scholarly understanding.

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02

Embraces ‘radical interdisciplinarity’

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One of the great strengths of the medical humanities is its interdisciplinary approach. A medical humanities research team might deepen our understanding of breathlessness, for example, by bringing together specialists in philosophy, anthropology, dance, literature and respiratory medicine.[1]

Medical humanities research also increasingly engages partners from outside academia, including health and voluntary sector professionals, people living with health conditions, their families and carers, as well as artists, writers, activists and policy makers.

Large scale research projects have been particularly important to the development of this way of working. In the UK, Wellcome, a global charitable foundation, has funded medical humanities research teams working on a wide variety of subjects, including shame and medicine,[2] voice-hearing,[3] histories of maternal mental health,[4] health and social care assessments,[5] and disability and technology.[6]

This kind of interdisciplinarity is ‘radical’ in that it seeks to establish new ways of doing health research that cut across traditional boundaries between disciplines, sectors, and areas of expertise.[7] It challenges established beliefs about authority and knowledge, values a diversity of people and perspectives, and can involve ‘entanglements’,[8] intellectual tensions, and frictions that ultimately lead to new insights. There is also a strong emphasis on process within the medical humanities, with attention to ethical practices and how collaborators work together often as highly valued as the resulting knowledge.

Artwork used to illustrate *Threshold Worlds* (thresholdworlds.org.uk) – an interdisciplinary study of dreams and dreaming which brought together narrative theorists, psychologists, artists and literary scholars. Image: Lucie Treacher, *Light Sleeper*. Reproduced with kind permission of the artist.

Artwork from the website for *Waiting Times* (waitingtimes.exeter.ac.uk) – a multi-stranded research project on the temporalities of healthcare supported by Wellcome (2017–2023).

03

Extends what counts as evidence in health research

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Clinical trial results and statistical data are often viewed as the most valid forms of evidence in health research. For example, the randomised controlled trial (RCT), which measures the impact of treatments under carefully established and monitored conditions, is commonly regarded as the 'gold standard' of evidence in medicine. However, researchers have also pointed out the limitations of clinical trials in producing information about health.[9]

Quantitative approaches can take a mechanistic view of the human body as a collection of separate parts that can be understood through purely numerical measurement. They also assume the best treatment decisions and guidelines can be made by generalising from populations to individuals, ignoring the way health and illness emerge from an interplay between our bodies and social, cultural, economic, and environmental factors over time. Focusing on quantitative data can also exclude or invalidate knowledge about health that comes from traditional medicine and indigenous communities.

Medical humanities researchers propose a more inclusive view of evidence that incorporates qualitative (non-numbers-based), narrative and artistic sources such as interviews, people's stories, films and visual art. These approaches explore people's experiences of health and illness and provide insight into the personal and social dimensions of health that statistical methods cannot always capture. In this view, numerical data and RCT evidence is not irrelevant to our understanding of health and human experience – it is just one form of knowledge among many others.

Zines can be both forms of evidence and knowledge production in medical humanities research. Image: *In the Zine House* by Lea Cooper (zinejam.com). Reproduced with kind permission of the artist.

04

Puts lived experience at the centre of health research

Lived experience is the insight and understanding that you get when you have personally lived through something.[10] In the medical humanities, it refers to the knowledge and expertise that comes from living with a life-impacting health condition, disability, or culturally recognised form of 'difference' such as neurodivergence.

It can also include knowledge arising from experiences of poverty, neglect, abuse, trauma, and other forms of prejudice or discrimination like racism and ableism.[11] It is a unique form of knowledge that is just as valuable as knowledge acquired through education, research, and clinical practice.

The phrase 'Nothing about us without us' emerged from disability activism in the 1990s.[12] It captures a core principle of much medical humanities research – namely, that it should be led by, or incorporate the views of, those communities potentially affected by it. This involvement can take different forms, ranging from consultation and engagement through to co-production, participatory action, and user-led research. What unites these approaches is the belief that the stories and perspectives of people with lived experience yield insights that academics and practitioners without lived experience would otherwise miss. Centring lived experience in the production of knowledge about health and illness aims to promote inclusion, rebalance power, and address issues related to social justice, ensuring research is informed by real world concerns.

Photo by Vince Fleming on *Unsplash*.

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05

Sees health as shaped by deep inequalities in society

People experience health and illness differently depending on a range of factors, including gender, age, class, sexuality, disability and race.

For example, in the UK, people living in the most affluent areas can expect to live around 10 years longer than those in the most deprived regions.[13] Maternal death rates are three times higher for women from Black ethnic minority backgrounds compared to white women.[14] And 52 per cent of people who identify as LGBTQI+ have experienced depression, compared with 16 per cent of the general population.[15]

The medical humanities is concerned with why this happens and what needs to change. It rejects the idea that poor health is entirely determined by individual choices or genetics, and highlights the role of poverty, unequal access to health services, housing, education and employment opportunities, as well as the influence of racism, discrimination and other forms of prejudice. Medical humanities researchers working with decolonial, queer theory and disability studies approaches also work to build more inclusive research cultures which centre the lived experience of marginalised and minoritised groups.

Photo by Jonathan Kho on *Unsplash*.

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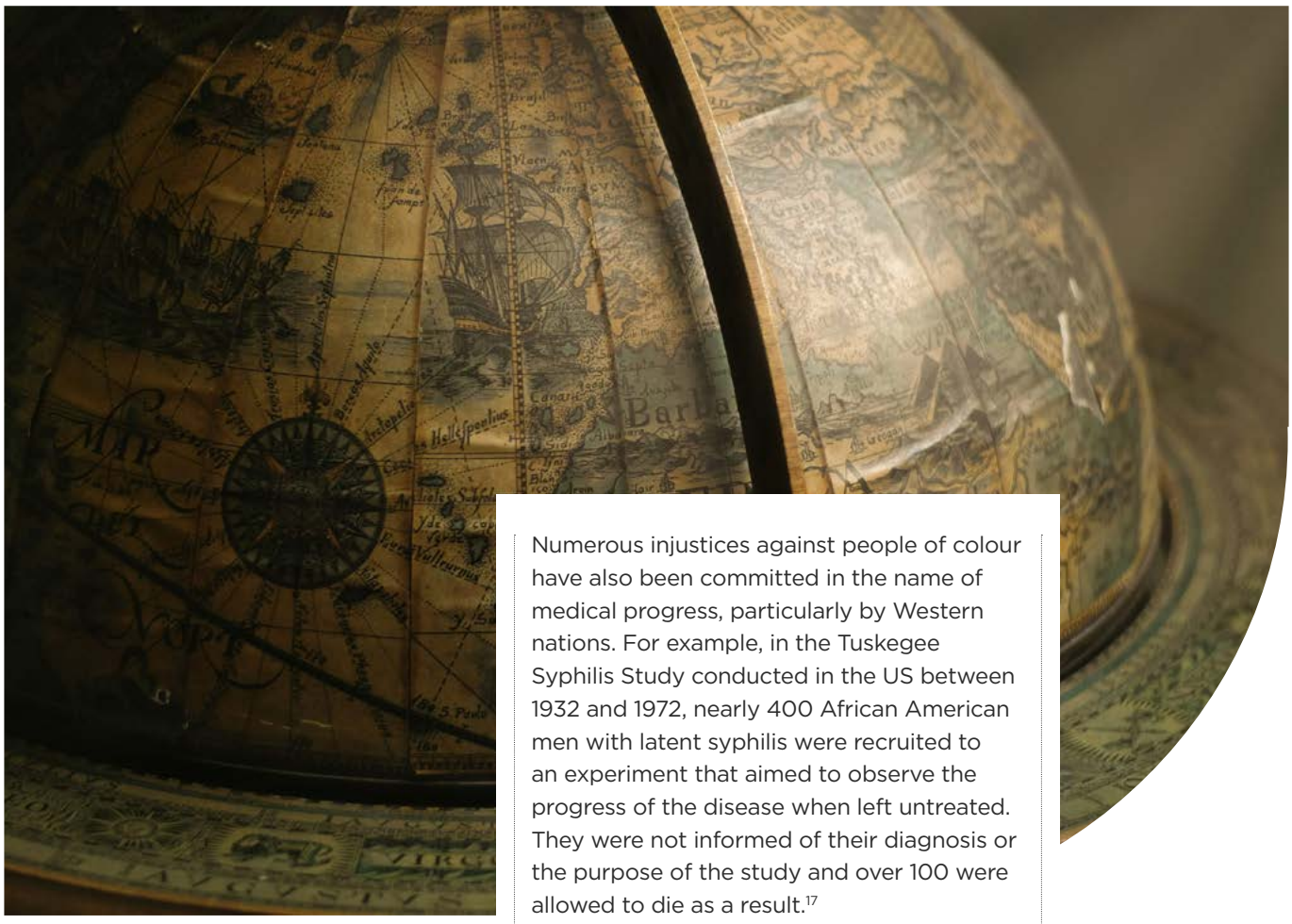

Photo by Viktor Forgacs on *Unsplash*.

06

Unpacks the legacy of colonialism and the impact of racism in healthcare

From enlisting native peoples into hard labour to usurping ancient cultures and traditional healing methods, colonial practices have had enduring negative impacts on the health of indigenous populations.[16]

Numerous injustices against people of colour have also been committed in the name of medical progress, particularly by Western nations. For example, in the Tuskegee Syphilis Study conducted in the US between 1932 and 1972, nearly 400 African American men with latent syphilis were recruited to an experiment that aimed to observe the progress of the disease when left untreated. They were not informed of their diagnosis or the purpose of the study and over 100 were allowed to die as a result.[17]

Racism in Western medicine persists today. In the UK, Black African or Caribbean men are five times more likely than their white counterparts to receive a schizophrenia diagnosis due to racist stereotypes of violence.[18] In the US, mental distress in African Americans regularly leads to incarceration in prison rather than treatment by mental health services, due to similar racial prejudices.[19]

The medical humanities unpacks the legacy of colonial violence, racism and medical experimentation, and explores its impact on the health of minoritised communities today. This reflects a shift in medical education towards forces that influence health outcomes beyond the level of doctor-patient interactions.[20] Seeking to challenge the dominance of Western institutions and knowledge systems by amplifying the voices of those who have historically been excluded from healthcare research, medical humanities researchers may use literature and creative arts like music, dance and drama to engage ethically with knowledges and practices about health and wellness from non-Western perspectives.

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07

Explores and critiques the role of stories and storytelling in our understanding of health and illness

Stories and storytelling practices around health and illness are an important area of focus in the medical humanities. Illness memoirs gained popularity in the 1980s–90s, as patients who had been left feeling silenced and objectified by health care services sought to share their experiences.

Narrative was championed as a means of making clinicians more empathic, providing insight into the way in which medical treatment could be traumatising and dehumanising. Patients were encouraged to reclaim their voices and to produce their own knowledge about the illnesses they lived with.[21]

More recently, academics have questioned the role of narrative within the medical humanities. Critics argue that not everyone experiences life in narrative form,[22] and that traditional illness narratives, which often portray an individual's positive journey from illness to recovery, can exclude those with chronic or terminal conditions or those whose experiences of ill-health are fragmentary or episodic.[23 24] Many medical humanities researchers now call for more attention to stories of health and illness that are ambiguous or ambivalent,[25] as well as for space for alternative forms of expression, such as music, visual arts, dance and yoga.[26] Awareness has also developed that the use of patient narratives can be made into a 'box-ticking' exercise by health organisations, a process which may cause distress when difficult experiences are recounted, and often draws unfairly on free labour from those with lived experience.

Documentary film *in the real* (dir. Conor McCormack, 2015; produced by Hearing the Voice) provides powerful examples of alternatives to traditional illness narratives.

FIND OUT MORE

Happen (2012) by Jayne Wilton. Photographed on display in the *Catch Your Breath* exhibition at Palace Green Library, Durham, 2018–19.

08

Champions arts-based and creative approaches

Creativity is central to the medical humanities, in a sense that goes well beyond the idea that engagement with the arts promotes health and wellbeing. Visual art, films, creative writing, dance, theatre and music can provide people with novel ways of sharing their experiences and help to change public conversations about health, illness and disability.

Crucially, collaborating with visual artists and working with objects and images can generate new questions, perspectives, and methods in health research.[27 28] The 'visual medical humanities' increasingly looks towards this form of knowledge production, in part as an alternative to the dominance of narrative approaches in the field.

The medical humanities also champions creativity within interdisciplinary and cross-sector research collaborations. For example, Durham University is known internationally for pioneering the use of arts-based and experimental techniques in medical humanities research to help collaborating partners understand each others' disciplinary perspectives, diverse backgrounds, and ways of thinking.[29] Creative facilitation creates safe and inclusive spaces in which academics, clinicians, activists, and people with lived experience can come together to share ideas, establish meaningful connections, and identify new research priorities and opportunities for real-world change.

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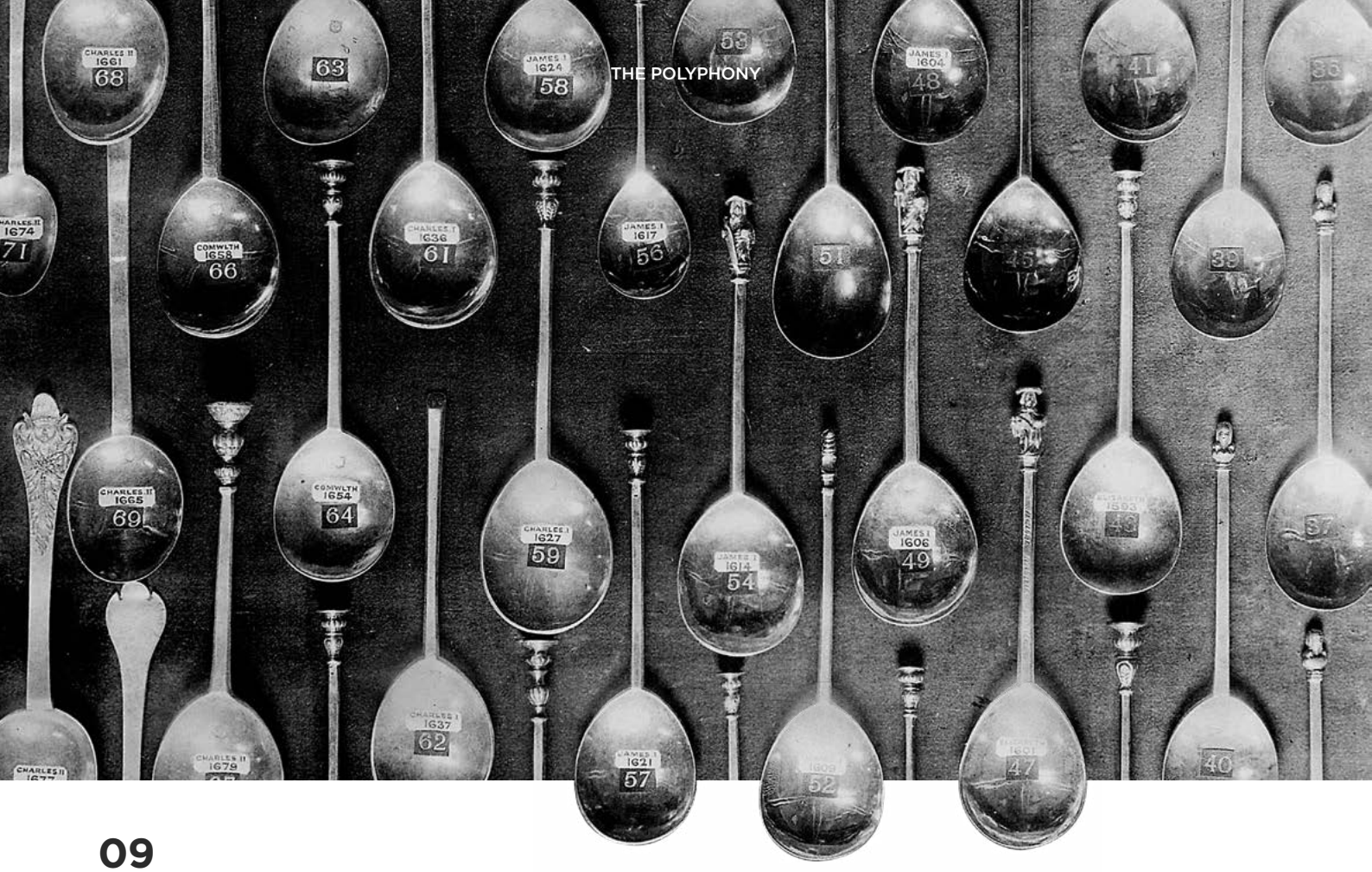

09

Questions what it means for bodies and minds to be 'normal'

Spoons from the Burlington Fine Arts Club. Source: Wellcome Collection. Invented by Christine Miserandino, spoon theory is an introduction to the way in which people living with long-term illness or disability have a limited amount of energy (represented by spoons) to spend on tasks on any given day.

Medical practice often rests on the idea that bodies and minds can be returned to 'normal' functioning. When a doctor checks someone's heart rate, they are checking whether it falls inside a statistically normal range. If it falls outside this range, they will try to bring it within these parameters.

Similarly, if a child is developing at a slower rate than the 'normal' rate for their age, they are diagnosed as having a 'developmental disorder'. Interventions will then often seek to enhance their mental or physical development, bringing them back towards the 'norm'.

The medical humanities draw from theories that question the assumption of normal as healthy, natural, and objective (free from bias). When it comes to disability, the 'social model of disability'[30] views disability as caused not by any inherent 'abnormality' in an individual, but by barriers created by society which prevent people with atypical bodies and/or minds from fully participating in everyday life. For example, buildings that are not wheelchair accessible will disable people with mobility impairments. Neurodiversity scholars build on this by suggesting that there are diverse ways of communicating, perceiving, and experiencing the world, and that it is perfectly possible to be atypical but healthy.[31 32]

The critical medical humanities advocate for approaches within healthcare that restore the subjectivity and agency of people whose bodies are, or have in the past been, considered 'abnormal'. These approaches give us additional ways of viewing and researching body-mind difference that can positively affect medical practice as well as how we understand each other and ourselves.

FIND OUT MORE

10

Makes vital contributions to questions of public health

A glass sculpture of the coronavirus (COVID-19) by Bristol-based artist Luke Jerram.

Public health is the science and art of protecting and improving the health of populations, from neighbourhoods and cities to countries and world regions. This work takes place through education, the promotion of healthy lifestyles, research towards the prevention of disease and injury, and detecting, preventing and responding to infectious diseases.

Medical humanities increasingly moves beyond a focus on individual experiences of health and illness to thinking about the health of communities and populations in ways that can make important contributions to this field.

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Recent medical humanities research on Long Covid, for example, shows how patient-led research and activism was critical to achieving clinical and wider cultural recognition of the condition.[33] Durham's Institute for Medical Humanities is collaborating with Linköping University on a study that is pioneering in its approach to Long Covid as a biomedical, clinical, embodied, social and political phenomenon.[34] Other researchers have shown how narrative, visual and autoethnographic methods can illuminate the lived experience of post-viral illness in ways that directly address health inequalities. Together, this work has implications not just for our understanding of Long Covid and the care needs of patients, but for the contribution of medical humanities to the study of emerging illness and of pandemic responses more broadly.

Medical humanities researchers also work closely with community and other organisations to raise awareness of public health issues. In South Africa, *Eh!woza* – a collaboration between an infectious disease research institute, artists and a youth-based educational charity – used film to improve public understandings of tuberculosis.[35] Research from the University of Cape Town drew on perspectives from a children's hospital, anthropology and fine art to shed light on the complexities of childhood poisonings caused by the use of illegal street pesticides in urban townships.[36]

Street art entitled 'Super Nurse' by FAKE on 21 April 2020 in Amsterdam, Netherlands.

Glossary of terms

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An introductory course on, or overview of, a subject.

Ableism

A set of beliefs or practices that devalue or discriminate against disabled people.

Activism / activists

Efforts or individuals aiming to bring about social change.

Agency

A person's capacity to act independently and make choices.

Arts in Health

A movement that uses arts-based interventions to improve health and wellbeing, often in clinical contexts.

Biomedicine

A branch of medicine focused on the biological (biochemical, molecular, genetic and cellular) aspects of health and disease.

Clinical

Relating to the treatment of patients in healthcare settings.

Clinical trial

A research study conducted with patients with the goal of determining whether a treatment works and is safe.

Co-production

An approach in which people work together in equal partnership, sharing power and responsibility from the start to the end of a project.

Colonialism

The practice of one country establishing control over another territory and its population, often leading to exploitation and cultural erasure.

Decolonial

A perspective that seeks to dismantle colonial legacies and power dynamics in knowledge production.

Developmental disorder

A group of diagnoses (e.g. autism, ADHD) that are conventionally considered to result from atypical or delayed mental or physical development.

Disability Studies

An academic field based in the humanities and social sciences that views disability in the context of society, culture, and politics.

Disciplines

Branches of knowledge or fields of study, such as medicine, sociology, and philosophy.

Entanglement

A theoretical term originating in quantum physics that in the medical humanities is used to encourage researchers to set aside their usual allegiances and identifications and think more experimentally.

Epidemiology

The study of the causes, distribution, control, and prevention of disease in different groups of people.

Global South

A term used to refer to countries in Africa, Latin America, Asia, and Oceania that are low-income and often politically or culturally marginalised.

Humanities

Academic disciplines that study human culture, including literature, philosophy, history, and the arts.

Indigenous communities

Original inhabitants of a region, often possessing distinct cultural practices and languages, and facing historical marginalisation.

Long Covid

The World Health Organisation defines Long Covid as the continuation or development of new symptoms three months after an initial SARS-CoV-2 infection, with these symptoms lasting for at least two months with no other explanation.

Marginalised

Excluded from mainstream social, economic, and political life.

Mechanistic

Relating to theories that describe social or natural phenomena as though they are machines operating due to purely physical factors.

Minoritised

Marginalised or made into a minority due to systemic discrimination.

Mobility impairment

A condition that affects an individual's ability to move in a typical manner, for example an inability to walk.

Narrative

A story; a spoken or written account of connected events.

Neurodivergence

To be neurologically different from the established typical.

Neurodiversity

Refers to the natural diversity of human minds.

Participatory action research

A research approach to social issues that involves the participation and leadership of those people affected, who take action to produce positive change.

Qualitative data

Non-numerical information that provides insights into people's attitudes, beliefs, and experiences.

Quantitative data

Numerical information that can be measured and analysed statistically.

Queer Theory

A way of thinking that aims to dismantle traditional assumptions about gender and sexuality, as well as fighting against social inequality and challenging conventional academic approaches.

Randomised Controlled Trial (RCT)

A study design that randomly assigns participants to either a group that receives treatment or a control group that does not, to compare outcomes.

Sector

A distinct part of society or economy, such as healthcare, education, or industry.

Social justice

The pursuit of equality and fairness in social policy, distribution of resources, and the protection of rights.

Social sciences

Academic disciplines that study human society and social relationships, including sociology, psychology, and anthropology.

Subjectivity

An individual's personal point of view or perspective.

Syphilis

A sexually transmitted infection caused by the bacterium *Treponema pallidum*.

Traditional medicine

Healing practices and beliefs that are rooted in the cultural traditions of a particular community or society.

Tuberculosis

An infectious disease that primarily affects the lungs, caused by the bacterium *Mycobacterium tuberculosis*.

User-led research

Research that is directed or conducted by people with lived experience of the issues being studied.

Visual medical humanities

A sub-field that analyses visual and material culture in order to contribute to understanding health, illness, and the body.

Voice-hearing

The experience of hearing voices that others don't, often associated with mental health conditions like schizophrenia and psychosis.

Endnotes

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About *The Polyphony*

The Polyphony publishes some of the most exciting work in the critical medical humanities: its aim is to capture, celebrate and extend the diversity of voices which together make up this interdisciplinary field of research and creative and clinical practice.

A dynamic and talented editorial team of early career researchers produce *The Polyphony*, publishing more than 100 articles per year and reaching a readership of over 10,000 people. The platform provides a space for health professionals, arts-in-health practitioners, people living with complex health conditions, and researchers at different career stages, to connect with each other, experiment with new ideas, and share work in progress.

The Polyphony is produced by the Institute for Medical Humanities at Durham University. It reflects the Institute's commitment to providing a platform for marginalised voices, and to diversifying and widening the perspectives that contribute to dominant debates in the medical humanities through engagement with the Global South.

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Visit our website to find out how you can join the conversation.

thepolyphony.org

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