OVERCOMING BARRIERS TO PROGRESS IN MEDICAL HUMANITIES RESEARCH

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EXECUTIVE SUMMARY

Medical humanities is a growing and evolving research field. The Institute for Medical Humanities at Durham University has commissioned this report as part of a process of reflecting on this growth and looking to the future. It is particularly written for those with an interest in medical humanities and how it might develop in the future such as research leaders, institution leaders, stakeholders, and funders

The report explores:

- challenges and barriers to progress in the field;
- successes and opportunities in the field; and
- where change or adaptation might be needed to allow medical humanities and the people who work within and around it to thrive.

The issues and opinions presented in this report were gathered between January and July 2022 from discussions at events, one-to-one interviews, and an online survey. The contributors all have professional interests in medical humanities and are from a wide range of disciplines, career stages, and countries.

SUMMARY OF MAIN FINDINGS

RESEARCH CULTURE

Challenges

- Narrow definitions of success
- Access to funding and other resources
- Lack of time and institutional support

Opportunities for Change

- Developing relationships with key funders and lobbying for change
- Providing support to develop more fundable projects and stronger applications
- Developing case studies based on exemplary projects
- Working with senior colleagues to ensure that research time is protected
- Resisting compromise on interdisciplinary approaches and prioritising deep collaboration
- Employing professional staff to relieve some of the administrative burden on researchers

DEVELOPING PEOPLE

Challenges

- Job availability and job precarity
- Interdisciplinary research is seen as a risky career choice
- A need for training and development opportunities at all career stages
- Researchers often feel isolated lacking like-minded peers

Opportunities for Change

- Ensuring that job contracts are as long as possible and substantive enough to live on
- Creating more entry level, less independent, teaching, and hybrid posts
- Providing researchers at all levels with training, mentoring, and development opportunities, including support to identify and develop transferable skills
- Emphasising the value of interdisciplinary research skills
- Creating and supporting more networking opportunities

DOING MEDICAL HUMANITIES RESEARCH

Challenges

- Articulating what it means to do medical humanities research (particularly to 'outsiders')
- Navigating interdisciplinary research and publishing
- Navigating the relationship with medicine and biomedical approaches

Opportunities for Change

- Agreeing and articulating the core pillars of a medical humanities approach
- Sharing good examples of interdisciplinary research processes
- Developing more collaborative relationships with key publishers
- Consider focusing collective effort on a narrower range of themes to increase impact
- Seeking out opportunities to get researchers into medical spaces
- Consider partnering more with public health

ENGAGEMENT

Challenges

- Lack of understanding, skills, and confidence
- Accessing funding and other resources to support engaged research
- Finding collaborators and navigating relationships with them
- Managing the boundaries between researcher and participant

Opportunities for Change

- Employing specialist professional staff
- Building relationships with communities of interest as early as possible
- Providing training, coaching, mentoring, and other financial and non-financial support
- Acknowledging that everyone is learning and allowing for experimentation and reflection
- Developing mentoring and support for researchers in a challenging or vulnerable position

EQUALITY AND DIVERSITY

Challenges

- European culture and the English language dominate medical humanities
- People working in medical humanities are disproportionately white and female
- Perceived lack of representation and poor job prospects are likely dissuading students from more diverse backgrounds

Opportunities for Change

- Deliberately working to draw in more diverse perspectives and source materials
- Using positive action, financial support, and mentoring to encourage promising scholars
- Collaborating more with medicine, biomedicine, and allied professions
- Doing more outreach with school age children

INTRODUCTION

Medical humanities is a growing and evolving research field. The Institute for Medical Humanities at Durham University has commissioned this report as part of a process of reflecting on this growth and looking to the future. It delves into the challenges and barriers to progress as well as the successes and opportunities in the field. It considers where change or adaptation might be needed to allow medical humanities and the people who work within and around it to thrive. It is particularly written for those with an interest in medical humanities and how it might develop in the future such as research leaders, institution leaders, stakeholders, and funders.

The issues and opinions presented in this report were gathered during the first half of 2022 from discussions at two events in Durham, 13 one-to-one interviews, and an online survey completed by 102 people. Neither the interviews nor the survey can claim to be comprehensive and there will be a bias towards people already connected to Durham University. However, the contributors represent a wide range of disciplines and career stages, and hail from countries around the globe. All have existing professional interests in medical humanities approaches and a desire to see them flourish. Full details of the contributors can be found in Appendix 1. Although the issues reported here were generally held to be common, they are not experienced with the same intensity by all. For example, job precarity disproportionately affects early career researchers and workforce diversity throws up different challenges in Africa and the UK.

Where possible evidence was sought, in published literature and elsewhere, to support the statements made. In many cases this was challenging. Often these issues are being raised tentatively and perhaps, where they relate to quite personal concerns, being vocalised for the first time. Given these sensitivities any comments are included anonymously. Many of the challenges identified relate to matters like research processes, inter-personal relationships, or career development which are rarely the subject of research outputs in the medical humanities. Therefore, less formal outputs like media reports and podcasts have provided valuable insights.

Contributors were also asked to suggest actions which might help to overcome or mitigate the barriers identified. Thus, this report seeks to present not just problems, but also potential solutions to some of the key challenges which are currently facing medical humanities. Hopefully implementing some of these actions might enable medical humanities to flourish and achieve even greater impact in the future.

The report is presented in five sections: Research Culture, Developing People, Doing Medical Humanities Research, Engagement, and Equality and Diversity.

- **Research Culture** explores issues which relate to the ways medical humanities research is funded, organised, and evaluated.
- **Developing People** shifts the focus to the medical humanities workforce considering employment matters, training and development, and inter-personal relationships.
- **Doing Medical Humanities Research** looks more closely at some of the unique challenges of undertaking and publishing interdisciplinary and collaborative research in this field.
- **Engagement** considers the increasing importance of working with communities of interest outside of academia and the issues this raises.
- **Equality and Diversity** reflects on the dominance of the English language, European culture, and white voices in medical humanities, and what might be done to address this.

RESEARCH CULTURE

"Collaboration is an environment as much as a behaviour."[1]

Challenges

- Narrow definitions of success, particularly in terms of outputs and whose expertise is valued, which disadvantages slower, interdisciplinary, more creative, and engaged research
- Access to funding and other resources to carry out interdisciplinary medical humanities research is difficult
- Even when funding is obtained it can be hard to access the time and institutional support needed to carry out the research, and administrative processes and bureaucracy can also be a significant barrier

Opportunities for Change

- Developing relationships with key funders/change-makers and lobbying for change
- Providing support to develop partnerships and projects which are more fundable and to craft stronger funding applications
- Using exemplary projects as case studies to demonstrate the value of different approaches and different kinds of outputs
- Research leaders developing relationships with senior university colleagues to ensure that research time is protected
- Resisting compromise on interdisciplinary approaches that have been proven to work and prioritising relationship building and deep collaboration
- Employing professional staff who can help with processes, relationships, and organisation to relieve some of the burden on researchers

Challenge: Narrow Definitions of Success

The prevailing culture of research across academia is in crisis. Damning reports have highlighted the stress-fueled, ultra-competitive environment faced by most researchers[2-5]. A culture of measuring worth by productivity and metrics has created a system which privileges certain kinds of knowledge and outputs (quantitative subjects and peer-reviewed publications) and devalues less quantifiable achievements. Deviation from this norm is almost actively discouraged and rarely rewarded. This 'publish or perish' mentality also has meant that there has been less focus on the processes of doing research leading to some unscrupulous practices and high-pressure environments.

Medical humanities is not immune to these cultural struggles. Conversations at the Durham University event on 25 February 2022 emphasised that the prevailing definitions of academic excellence and success are narrow and leave little room for collaboration, creativity, experimentation, and innovation. These are the very things that interdisciplinary medical humanities research thrives on.

The survey also revealed considerable frustration at the types of outputs which are considered valid and as well as the kind of expertise which is prized. Getting recognition for non-conventional outputs was ranked as the fourth most significant barrier, just behind access to funding and resources. As the exemplary projects featured in this report demonstrate, some of the most impactful outputs including patient-focused interventions, films and other creative projects, and enduring partnerships don't 'count' for conventional university processes like recruitment, promotion, or assessment exercises like REF.

Opportunity: Modelling a different kind of success and lobbying for change

The research examples featured in this report (see Fig 2, p17) have been objectively judged as excellent, receiving high levels of funding, awards, and other commendations. They have also embraced a slower, more engaged, and more experimental approach, resisting being defined by current norms. Therefore, medical humanities is well placed to provide examples of what excellence might

look like in the context of research design or process, and to use these to lobby funders and universities for change. Indeed, funders also want change. The new UKRI strategy states *"Many essential skills, capabilities and talents are undervalued, and measures of success and excellence can be too narrow."* There is an opportunity for medical humanities to lead the way rather than conforming to the norm. Senior academics also have a part to play in learning about and modelling what a kinder, values-led, more compassionate, and more ethical research culture might look like.[2,3]

Challenge: It is difficult to access funding to support interdisciplinary medical humanities research

Access to funding was rated as the most significant barrier to research progress in the survey. Although this is a common challenge in academia, the problem does seem to be particularly acute for medical humanities. In the UK the Wellcome Trust are the only major funder to explicitly support health-related humanities and social sciences research. The National Institute for Health Research (NIHR) are increasingly open to humanities and social science perspectives, but they tend towards a science model, expecting projects to have defined research questions from the outset and quantifiable health outcomes. This presents challenges for interdisciplinary and engaged research approaches which start by defining these questions together. The main public funder, UKRI, currently organises most of its funding into disciplinary research councils e.g., Arts and Humanities Research Council (AHRC), Medical Research Council (MRC) and Economic and Social Research Council (ESRC). Although UKRI are beginning to move towards supporting more interdisciplinary research, current supported projects tend to include less radical collaborations such as incorporating social sciences insights into a primarily biological project.

However, UKRI have recently published a new 5-year research strategy which explicitly states greater support for collaboration, new disciplines, engagement, and creativity.[5] Furthermore, an unexpected benefit of the pandemic is that the pace of change seems to be accelerating. Lockdowns gave everyone, including senior policy makers, acute experience of being deprived of social contact, with limited access to culture and nature, and restricted resources. This has sharply highlighted the importance of these things in our lives. The data on COVID severity and deaths has also emphasised the stark differences between rich and poor, and the far-reaching consequences of living with underlying health conditions.[6] A senior academic, influential in policy and funding circles, disclosed that politicians and medical professionals are actively seeking out different ways of dealing with the unprecedented challenges they are facing. They also shared that, where once MRC were not even open to discussion with AHRC, they are now initiating discussions. Another example of change is the recently established AHRC 'Health Disparities' fund[7] which explicitly seeks to use arts and humanities approaches to deal with health challenges. Social prescribing is also becoming mainstream.[8] The door has opened a crack and there is a real opportunity for medical humanities researchers to get a foot in the door.

Opportunity: Collaborate and engage to create more fundable projects and stronger applications

To take advantage of some of the opportunities that are presenting themselves, medical humanities researchers will need to seek out opportunities to engage and collaborate. The interdisciplinary nature of medical humanities means that being open to different perspectives and ways of working is a core principle of the field. However, medical humanities scholars could more often look a little further to find these different perspectives. A senior researcher in psychology felt that medical humanities could be more open to learning from the working practices of the sciences. A survey contributor felt the relationship with arts practice could be much more collaborative. Other contributors from outside academia felt there was much for researchers to learn from practicing healthcare professionals, charities, and community organisations. As further discussed in the engagement section, pivoting the medical humanities gaze from the academic world to the people it seeks to serve could be transformational. Rather than seeing this as compromise or dilution, it can be approached with curiosity and a genuine desire to connect and learn, while remaining true to its medical humanities roots.

There are also practical steps that could be taken to increase the likelihood of funding applications succeeding, for example training in crafting applications, collaborative bid writing teams, and professional support. Often applications are shared for comment and contribution when it is too late to make any meaningful changes. Collaborators or engagement activities are sometimes added as an afterthought rather than being embedded from the start. Brokering and seedcorn funding could help establish suitable collaborations and allow space for those relationships to develop well before the application deadline.

Challenge: Finding the time and space to do interdisciplinary research

The expected pace of academia also creates challenges for the medical humanities. When it comes to interdisciplinary work, excellent research processes are open and collaborative with opportunities for developing relationships and learning from others. Projects like Hearing the Voice have demonstrated the power of regular meetings as a way of 'thinking together'.[9] Excellent interdisciplinary research also needs time and space which can be hard things to find in a pressured academic life. Furthermore, this need for extra time is often not recognised by funders. Survey respondents repeatedly said that their biggest challenges were lack of time and conflicting priorities.

Opportunity: Working with senior leaders to ensure research time is protected

Time away from teaching and administrative duties to focus on research is essential for making significant progress. Thus, many contracts allow academics to accrue research leave and grants often include a funding allocation to provide teaching backfill. However, negotiating these periods of leave can be slow and difficult. Project and research institute leads can help by taking a proactive approach to working with heads of department and other senior leaders and planning ahead to ensure that research time is protected while keeping workloads manageable.

Challenge: Collaboration needs connection

COVID has also created significant challenges for doing interdisciplinary research well. Online events have proliferated and there has been a real boost to connectivity around the world and the accessibility of research. However, this has often come at the expense of deep collaboration, engagement, relationship building, creative and innovative thinking.[10] Participants at the February event expressed some concern over the balance of online and face-to-face events – facing challenges of quantity over quality. Another interviewee discussed a project which floundered due to a lack of interpersonal connection between the collaborators.

Opportunity: Making time and space for face to face

Humans are social creatures, and it is much easier to really connect in person than via Zoom. It has been particularly hard to build or maintain relationships with new or non-academic partners. However, the growth of video conferencing has uncovered what can be achieved online and, particularly, how much it enhances accessibility. Going forwards it will be necessary to find a balance and think carefully about the best model for events and meetings depending on their purpose. Where the goal is relationship building and genuine interdisciplinary collaboration, regular face-to-face interactions must be prioritised.

Challenge: Excessive admin and bureaucracy is slowing progress

The burden of paperwork and bureaucracy involved in applying for, setting up and running an interdisciplinary research grant is a significant barrier. It was rated 5th overall by survey respondents but ranked 1st for senior and 4th for mid-career researchers.

In some cases, the sheer administrative burden of funding applications becomes prohibitive. The paperwork required is often wildly disproportionate to the amount of funding on offer, increasing the pressure to try and make every application perfect, and further increasing the burden of drafting, proof-reading, and checking. It is a vicious circle. Not to mention then the time required to read and judge these applications, largely unpaid work which academics undertake on top of their day jobs.

> *"Early Career Academia is filling out tons of forms, chasing it up over months, filling out loads more forms, chasing it again, months and months pass, all for a measly £100"*[11]

The system also entrenches existing inequalities. Already successful researchers are more likely to achieve additional funding, scholars with effective institutional grant development support are more likely to achieve funding, and those with secure jobs are more likely to achieve funding.

Further challenges emerge when it comes to running grants. Contributors reported difficulties with ethics procedures, contracts and collaboration agreements, staff recruitment, compensating collaborators, not to mention planning for meetings and events which enable that crucial relationship building.

"The 'informed consent' process required felt intrusive and obstructive. I thought it put off potential participants, especially people without English as a first language, and also from working-class, non-university educated & lower income communities, and people who have reasons to distrust authorities (e.g., refugees/asylum seekers, people of colour, people with mental health difficulties, etc.). A real shame, and it clearly reinforces the social science research bias toward white, middle-class, neurotypical communities."[12]

Opportunity: Campaign to change the system

The current system is outdated, unfair, and elitist. Although funding policies and processes are largely out of the control of individual researchers, their collective voice is powerful, and funders are beginning to reconsider their policies[5]. Different application models such as ultra-short applications, lotteries, narrative CVs, and participatory grant making are being mooted. All researchers are urged to join in these discussions to help create a fairer system. Seeking opportunities to sit on funding review panels or charity boards is also a great way to have more influence on decision making as well as learning about how these organisations operate.

Opportunity: Invest in professional support

Professional staff have a key role to play here as well. Although everyone has their own interests and aptitudes, academics' core competencies are likely around research and teaching. It is unreasonable to also expect them to be experts at relationship building, engagement, communication, organising events, finance, or project planning. It is also a disservice to people who have built their careers based on skills like facilitation or event management to treat these skills as things that everyone can do. Anyone who has experienced a flawlessly organised meeting or marveled at a beautiful website knows what a difference dedicated professionals can make. Unexceptional funding applications can also be salvaged in the hands of someone who understands budgets, can write in plain English, or knows how to embed engagement.

Like academics these professionals need good jobs, development opportunities and support. They also need to be treated as integral parts of research teams and acknowledged as such. Too often professional staff, like research partners, are excluded from grant applications, unacknowledged in case studies and unrecognised in publications despite often being the glue that holds the project together.[4,13]

DEVELOPING PEOPLE

"I worry about our junior colleagues."[12]

Challenges

- Job availability and job precarity are a constant worry for those not on open-ended contracts
- Pursuing interdisciplinary work is seen as a risky choice for less-established researchers
- This is a growing field with people entering at all career stages so there is a need for training and development particularly in relation to interdisciplinary methods, collaboration and engaged research
- Some researchers find themselves isolated within departments, institutions or even countries, lacking like-minded peers and opportunities to network and collaborate

Opportunities for Change

- Wherever possible ensuring that job contracts are as long as possible and substantive enough to live on
- Creating more entry level, less independent, teaching, and hybrid posts
- Supporting researchers at all levels with training, mentoring, and development opportunities, as well as support to identify and develop transferable skills which may help them transition to non-academic or hybrid roles
- Emphasising the value of interdisciplinary research skills to institutions, funders, and employers
- Creating and supporting more networking opportunities

Challenge: Job security is a constant worry for those not on open-ended contracts

Job availability and security were highlighted as a major challenge by several early career researchers (ECRs) who contributed to this report. In our survey, it was ranked as the 5th most significant barrier for ECRs and 6th for PhD students. It has long been true that not everyone who completes a PhD will be able to pursue a career in academia. There are simply not enough jobs. Although available studies are patchy, research suggests that, although around 70% of students want to continue in academia post-PhD, in reality less than half will actually achieve that goal.[14,15] The numbers achieving a full-time open-ended position are even lower. Research conducted by Vitae in 2008 and 2010 showed that although arts, humanities and social sciences graduates are more likely to be working in HE than other disciplines, they are predominantly teaching (A&H 37%, SS 44%) rather than conducting research. Only 9% of arts and humanities and 15% of social sciences PhD graduates were working in HE-based research, compared to 27% for biological sciences and 19% for physics and engineering. [16]

Furthermore, when surveyed 3-4 years after completion, arts and humanities doctoral graduates were the least likely to be in full time work (59%, compared to 80% for science graduates) and most likely to have had multiple different jobs in that time. Arts and humanities respondents were also more likely to be engaged in portfolio working (multiple jobs) out of necessity rather than choice, because they could not find a full-time position in their preferred vocation.[16] Thus, even 10+ years ago it seems that the perception of increased job precarity for arts and humanities graduates is genuine. Even between 2008 and 2010 there was a drop in the numbers of graduates on open ended or longer fixed term contracts and a rise in shorter term and casual contracts.[16] The situation has undoubtedly worsened since then. Job precarity is increasing with early career researchers struggling to get a foot on any career ladder, with short-term or casual contracts increasingly normalised.

"I worry about our junior colleagues, who are facing pretty bleak career prospects and years of being exploited."[12]

"Lack of mentorship is now the biggest barrier to me having confidence in publishing or creating new project. But without some kind of grant / fellowship I can't access a reliable, long term mentorship relationship with academic staff anymore."[12]

Challenge: Interdisciplinary research is seen as a risky career choice

Furthermore, contributing ECRs also believed that choosing to move into an innovative interdisciplinary research field is risky. Most academic contracts, even research-focused ones, tend to include some teaching. That teaching is usually of undergraduates, and undergraduate teaching tends to be split along disciplinary lines with fairly conventional subject matter. There is genuine fear that to become specialised in a very new or very interdisciplinary area would mean losing that disciplinary 'home' and so being seen as unemployable. There is further concern that working on large project teams and contributing to multi-author papers can also lead to a loss of identity which would harm future prospects.[17] It is clear that, although all graduates face some challenges on entering the workforce, these challenges are more acute for those drawn to medical humanities.

Opportunity: Mentoring, training, and support

When asked what had or might have made a difference to their career, ECRs highlighted training, capacity building and mentoring programmes to help them identify and develop transferable skills and learn about other career paths which might suit them. One ECR felt that quality mentoring was invaluable in helping them tread the line between being disciplinary enough to get a teaching job, while still contributing to medical humanities scholarship. The need to support ECRs at this transitional stage is not unique to medical humanities and other schemes are emerging which may provide valuable insights or development models. For example, the Prosper programme, a partnership between Liverpool, Manchester, and Lancaster Universities, is piloting approaches to help unlock postdocs' potential to thrive in multiple career pathways.[18]

Opportunity: Framing interdisciplinary skills as a virtue

As the field develops, so too will medical humanities undergraduate modules and Masters programmes. These also offer teaching opportunities which may help to embed interdisciplinary scholars in their institutions. It is also clear that interdisciplinary research is the future and researchers with these skills will become increasingly in demand both in academia and in the wider world.[19] Being a pioneer can be a challenging path, but it seems likely that time will improve the prospects for today's students. Again, support to frame their interdisciplinary skills as a virtue will serve researchers well now and in the future.

Opportunity: More responsible recruitment

Institutions also have a responsibility to ensure that they are offering real jobs which are substantial enough for people to live on. Fixed term contracts are not a bad thing in and of themselves. Open-ended contracts are becoming rarer in all forms of employment, and it is normal for entry-level employees to move around to some degree as they find the right work for them. However, fixed term contracts should be as long as possible within the bounds of the funding available and the scope of the project.[17] This benefits employers as well as employees - contracts which are less than 1 year inevitably mean that the employee will be preoccupied with looking for their next job, and perhaps won't be giving their full attention to the current role.

"Difficult to craft experience when people will only offer jobs to those already with the experience. Funding periods/jobs are so short-term that you're constantly having to think about the next move"[12]

"What is good work?

Good quality work is characterised by features including job security; adequate pay for a healthy life; strong working relationships and social support; promotion of health, safety and psychosocial wellbeing; support for employee voice and representation; inclusion of varied and interesting work; a fair workplace; promotion of learning development and skills use; a good effort–reward balance; support for autonomy, control and task discretion; and good work–life balance." [20]

Opportunity: More entry level and less independent posts

In the current employment climate, an unexpected disadvantage of offering longer or more substantial contracts is that the candidates coming forwards are often very experienced. This makes getting that foot on the ladder even more challenging for fresh graduates, particularly if their personal circumstances mean they can't afford to wait for opportunities to arise, to work unpaid on developing their CV, or relocate to take up a job. There is an emerging gap in the career ladder for more entry-level research positions which might allow for both directed and independent research.

Given the perception that much of the most effective medical humanities research being done in projects (see 'Doing Medical Humanities Research' section), rather than by lone scholars, perhaps it is worth looking at how other disciplines structure their project research teams. For example, in the sciences a common post-doctoral entry-level position is a research assistant for a project or a more senior researcher. Here researchers only look to become independent and direct their own projects after several years.

At present in medical humanities research assistant roles tend to be very short and focused on, for example, literature reviews to underpin funding applications. These are exactly the kind of precarious short-term roles that need to be phased out. However, stringing these short projects together to create one role could be very beneficial. It would be better for the employer, avoiding repeated recruitment processes, and better for the employee who would get a more substantial job and the career-enhancing opportunity to work with many different researchers and see how academic life works.

Challenge: Development opportunities and support usually target junior researchers

Not everyone who finds themselves drawn towards medical humanities is a PhD student or post-doc. Mid-career and senior researchers interviewed often described how they found themselves gradually turning towards medical humanities later in their working life. Many are attracted by the collaborative, interdisciplinary and engaged ways of working, but depending on their career path, they may have little experience of actually working in these ways. Interestingly, in our survey senior researchers ranked 'Identifying alternative career paths and transferable skills' as their 5th most significant barrier – the highest placing of all career stages. However, senior respondents ranked access to training as 22 of 30 suggesting that what is currently on offer is not serving them.

Opportunity: Tailored development opportunities for all career stages

It is essential that there are ongoing opportunities for developing interdisciplinary skills which are not just targeted at junior colleagues. Topics suggested by contributors included interdisciplinary working, collaboration, communication, engagement, crafting funding applications, and writing retreats. A number of survey respondents also wanted exchange programmes (particularly internationally) and visiting fellowships to help develop personal relationships as well as skills.

Collaborations with non-academic partners are also opportunities to learn. Schemes like residencies and placements, which either bring partners into the university or, even better, provide opportunities for researchers to go and experience a different working environment can be hugely beneficial, particularly for those who have never worked outside of academia.

Of course, it is easy for these opportunities to be interpreted as asking people to do more. Academics are already working too hard. As discussed in the Research Culture section, the teaching and administrative burden inherent in academic roles is squeezing out the time needed for research and thought work, with many staff on 'workload models' that well exceed 100%. It is also notable that job satisfaction amongst academics has plummeted in recent years.[2,21] Opportunities for collaboration and personal development are exactly the sort of things which are proven to improve job satisfaction, but only when they don't feel like an additional burden.[2]

"Many of us are the sole person at our institution and therefore do not have easily available collaborators. Also, it means traditional disciplines often do not understand us and have little desire to do so"[12]

Challenge: Feeling isolated

Collaboration and connection are easier for some than others. Although some have the privilege of working in large research centres or clusters, others may be trailblazers within their institutions. Interviewees in countries or institutions where medical humanities is just emerging reported finding themselves isolated at times and lacking peers with similar interests. In the survey feeling isolated was ranked 8th most significant barrier overall and a top 10 concern for almost all groups. Networking and sharing research through conferences and meetings has always been a core tenet of academic life, but for these isolated scholars it is even more important.

Opportunity: Networks and support groups

Websites, online meetings, and conferences are an excellent way to reach a large audience and increase awareness of research, but deeper exchanges are needed too. To meet this need medical humanities networks are developing around the world and should be encouraged and supported. Other initiatives already mentioned, e.g., exchanges or fellowships, could also be very valuable for developing nourishing relationships.

DOING MEDICAL HUMANITIES RESEARCH

"Medical humanities leans into difficult questions."[22]

Challenges

- Articulating what it means to do medical humanities research and the value of this approach (particularly to those 'outside' the field)
- Navigating interdisciplinary research and publishing
- Navigating the relationship with medicine and biomedical approaches

Opportunities for Change

- Agreeing and articulating the core pillars and benefits of a medical humanities approach
- Sharing examples of interdisciplinary research processes
- Developing more collaborative relationships with key publishers
- Consider focusing collective effort on a narrower range of themes to increase impact
- Seeking out opportunities to bring medical humanities approaches and people into medical spaces (e.g., hospitals or conferences) to develop relationships
- Consider partnering more with public health

Challenge: 'Outsiders' don't understand what it means to do medical humanities research

Many of the contributors talked about feeling that medical humanities approaches were not accepted as valid or appreciated within their institutions or professional communities. This was particularly an issue when trying to explain their work to those outside the field, in contexts such as justifying their research to heads of department, gaining credibility from partners, or framing a project for a funding application. It connects to other high-ranking barriers like the pressure to demonstrate real world impact (ranked 7th) and feelings of isolation (ranked 8th) reported in the survey suggesting that many researchers feel that those around them don't understand or appreciate what they do. Furthermore, the relationship between practical medicine and medical humanities research is an ongoing source of tension.

Challenge: Different terminologies abound

Even the name 'medical humanities' is a topic of debate with many feeling it doesn't truly encapsulate their research approach. Of those surveyed 42% most closely identify with 'medical humanities', with 36% opting for 'health humanities' and a further 9% choosing 'medical health humanities'. Some researchers reported feeling more affiliated to their home discipline despite being strongly identified as medical humanities by others. Meanwhile others had exactly the opposite experience – feeling more affiliated to medical humanities than their original subject specialism. Of those who responded to our survey 46% reported feeling more strongly aligned to their home disciplines(s) than medical humanities (with 21% choosing medical humanities and the rest answering 'both equally').

It is of course understandable that there are numerous different perspectives on this question of identity. Debate is a necessary part of imagining and experimenting with new ways of doing things. And medical humanities is a relatively new field, having emerged as a discrete field of study around the turn of the 21st Century. What is perhaps surprising is how much this debate continues to dominate people's thoughts, their conversations, and their conceptions of themselves and their work. The only people interviewed who seemed fully secure in their understanding of and place within medical humanities were senior academics.

Challenge: Researchers want more recognition for their approach

One thing was clear from all contributors – they believe in the potential of their approach and want it to be more widely recognised. So much so that 'knowing how to engage with change-makers' was ranked the 6th biggest barrier in our survey. They believe that medical humanities can make a difference to real world problems. They want to be able to explain what they do to stakeholders, research partners, colleagues, supervisors, and funders, and be taken seriously.

Opportunity: Articulating the core pillars and benefits of a medical humanities approach

Multiple papers have attempted to define the field, but many of the most accomplished scholars in medical humanities now actively resist any attempts to define it, feeling that rigid boundaries hinder innovation and stop the field evolving organically. So, perhaps it is more useful to ask not what the field of medical humanities 'is', but what does it mean to 'do' medical humanities? And what might this medical humanities approach have to offer thinking and practice within academia, healthcare, support services, and everyday life.[23] Several contributors asserted that, above all, medical humanities is a field that leans into complexity and difficult questions, providing a framework for thinking about them. A framework that, compared to a biomedical model, uses different methods, and draws on different sources.

So, whilst resisting rigid classifications and inflexible boundaries which might stifle the hallmark creativity of the field, there might be value in agreeing a loose working definition of medical humanities. In researching and writing this report, four elements have emerged which seem to be common to all the exemplary medical humanities projects (see Fig 1). If this framework seems to be acceptable to most medical humanities scholars and stakeholders, then it could be used to inform communications and frame projects in a more impactful way. Using these four pillars can help researchers to answer crucial questions relating to their research - what, how and, perhaps most importantly for non-specialists, why.

Fig 1: Proposed core pillars of a medical humanities research framework

1. **Methodology**: Using the research approaches and source materials prevalent in the arts, humanities, and social sciences
2. **Topic:** Studying health and medicine-related issues
3. **Engaged and/or interdisciplinary:** Involving partners in the research, whether from other academic disciplines or from outside academia such as healthcare professionals, people living with health conditions, carers, activists, advocates, and creative practitioners.
4. **Change-focused:** Seeking to challenge the status quo or make progress in some way, with the ultimate goal of improving health, healthcare, policy, or practice.

Challenge: Navigating interdisciplinarity in medical humanities research

Many contributors commented that the truly interdisciplinary approach of medical humanities was a defining strength. This was particularly notable within large projects which might draw together perspectives not just from the arts and humanities, social sciences, and human sciences, but also from more applied disciplines like engineering, law, or education. Medical humanities research also typically includes insights from outside academia such as healthcare professionals, people living with health conditions, carers, activists, advocates, and creative practitioners. The way that these voices come together varies, but the most impactful work is often being done in large 'crucible' projects which meld together many different perspectives. (See Fig 2)

The success of these projects and the emphasis on interdisciplinarity led some (generally senior) researchers to raise questions of whether it is desirable or even possible to be a 'lone researcher' in medical humanities (by 'lone researcher' they mean someone who does their research alone without formal collaborators either within or without academia). They felt that research at the interface of one humanities discipline and health could valuably contribute to academic scholarship but was unlikely to achieve significant impact beyond this. This shift may make it increasingly challenging for people from traditionally lone disciplines to break into the field, and to do effective medical humanities work without the funding, support, and skills to bring people together. This could also inadvertently increase the pressure on funding and resources which has already been identified as the number one barrier.

Contributors also reported other challenges relating to interdisciplinary working. Finding collaborators, navigating interpersonal relationships, publishing conventions, the career impact (both positive and negative) of being part of an interdisciplinary team. Accessing training on interdisciplinary methods and approaches and finding avenues to publish interdisciplinary work were both top 10 challenges in the survey.

Opportunity: Share research processes not just outcomes

As discussed in the Research Culture section, more sharing of, not just outcomes, but also research processes could help bridge this gap. This would help demystify the black box of interdisciplinarity and understand exactly how it is done. The Durham University Working Knowledge series[24], a spin off from the Hearing the Voice project, is an attempt to do this. It includes short downloadable reports on topics such as 'Interdisciplinary Authorship' and 'Transferable Methodology'. Expanding on this series and developing guidance and training could be very valuable. Case studies of award-winning or high-profile projects such as those listed (Fig 2) which focused on practicalities such as processes, team roles, project plans and budgets could be very beneficial.

Opportunity: Seek out journals that want to publish interdisciplinary work

An interviewee who edits a journal also described frustration at the current trends in publishing and the difficulties of publishing interdisciplinary research. Their approach has been to subvert the current publishing paradigm of simply waiting for papers to be submitted and then critiquing them. Instead, their journal, BMJ Medical Humanities, is collaborating with interesting projects and previously unpublished authors before an article is even written to help them shape and hone their work. Seeking out publishers with more open minds and progressive approaches could help researchers find more encouraging avenues for publishing their interdisciplinary work.

Challenge: Medical humanities embraces a very wide variety of topics

Another aspect which has exacerbated the challenge of explaining medical humanities to 'outsiders' is the sheer breadth of topics being studied. Whilst an established field like medicine has all kinds of specialisms like respiratory medicine or psychiatry, medical humanities currently brings everything together under one umbrella. As mentioned earlier, there is resistance to defining the field too rigidly and this openness (and oft-mentioned generosity of spirit) and has created a supportive home for scholars who feel that they don't fit in elsewhere. However, this openness might also dilute impact, with researchers' time and effort being spread too thinly to make significant inroads to challenging the status quo in any particular area.

Fig 2: Large, high profile and/or award-winning medical humanities projects

The Aging Prostate: A Constant Torment

https://liu.se/en/research/constant-torment (Swedish Research Council)

This project explored how the prostate has become an object which is used to explain changes in the male body, sexuality, and masculinity, both historically and today. Based at Linkoping University, Sweden, and led by Prof Ericka Johnson, the project drew together insights from medical sociology, medical history, STS (Science, Technology and Society), and feminist science studies. A key project output was the book 'A Cultural Biography of the Prostate'.

Autism Through Cinema

https://www.autism-through-cinema.org.uk/ (Wellcome, 2018-2023)

This project explores the role that film has played in embedding social norms of human communication, how autism has been displayed on film, and what an alternative, more inclusive film language might look like. The research team, based at Queen Mary University of London and led by Prof Steven Eastwood, are working in collaboration with Project Art Works, City University, and the University of Birmingham. The project will culminate with a feature-length film co-created with a group of neurodivergent artists called The Neuroculture Collective.

Black Health and the Humanities

https://www.blackhealthandhumanities.org/ (Wellcome, 2020-22)

This project led by Dr Josie Gill and Dr Amber Lascelles (both University of Bristol) sought to understand how Black people's physical and mental health is shaped by racism and racist environments. They developed a researcher training programme and resources bank on the theories and methods of Black humanities and medical humanities drawing on art, film, history, philosophy, music, and literature.

Hearing the Voice

https://hearingthevoice.org/ (Wellcome, 2012-2022)

This project studied the experience of hearing voices that others don't. They sought to find out what voices are like and why they happen, to help those who are distressed by their voices, and to explore how hearing voices is an important and meaningful part of human experience. Under the leadership of Prof Charles Fernyhough (PI and Director) and Prof Angela Woods (both Durham University) the project brought together researchers from humanities, social sciences, and psychology with clinicians, voice-hearers, and other experts by experience. Significant project outputs included the world's most comprehensive website about hearing voices (understandingvoices.com) and a new clinical tool for the management of unusual sensory experiences (MUSE). Hearing the Voice won Best Research at the 2020 Medical Humanities Awards.

Imagining Technologies for Disability Futures

https://itdfproject.org/ (Wellcome, 2020-25)

This project combines arts and humanities, design, robotics, and users of assistive technologies to increase understanding of how disability and embodiment are currently represented and used, and the ways in which technology can enhance lives in the future. They also question what ideas of body and personhood are at stake in these processes. It is led by Prof Stuart Murray (University of Leeds) with collaborators at the Universities of Exeter, Sheffield, Dundee.

Life of Breath

https://lifeofbreath.webspace.durham.ac.uk/ (Wellcome, 2015-2020)

This project explored breathing and breathlessness and their relationship to both illness and wellbeing. It was led jointly by Prof Jane Macnaughton (Durham University) and Prof Havi Carel (University of Bristol). Life of Breath incorporated insights from medicine, philosophy, anthropology, history, arts, literature, people affected by lung disease, and people who use their breath in interesting ways. Project outputs included policy recommendations, the first interpretive exhibition on breath, and a dance for lung health programme. Life of Breath won the Inspiration Award and was shortlisted for Best Research in the 2018 Medical Humanities Awards.

Reimagining Reproduction in Africa

(Wellcome, 2021-2026)

This project explores what it means for African women, men, and couples to have (or not have) children. They frame this topic in terms of love, care, new beginnings, and better futures, rather than the more typical narrative of pathology, mortality, and irresponsibility. Led by Prof Nolwazi Mkhwanazi (University of Pretoria, South Africa) the project includes collaborators from Ghana, Mozambique, and Uganda, working across demography, social sciences, medical humanities and science and technology studies.

Sensing Spaces of Healthcare

https://hospitalsenses.co.uk/ (UKRI Future Leaders Fellowship, 2020-24)

This project focuses on the ways we experience hospitals through our senses and the unanticipated negative consequences of hospital design which only considers the visual aesthetics of a space. It incorporates a range of perspectives from archival research to participatory arts to understand the impacts of both sensory over and under-stimulation. The ultimate aim is to develop improved guidance for hospital design. Project lead Dr Victoria Bates (University of Bristol) received the Leadership Award in the 2020 Medical Humanities Awards.

Shame and Medicine

https://shameandmedicine.org/ (Wellcome, 2020-2025)

This project is researching shame in various aspects of health and medicine, including clinical practice, patient experience and medical student education. It is led by Prof Luna Dolezal (University of Exeter) in collaboration with Dr Matthew Gibson (University of Birmingham) and Barry Lyons (Children's Health, Ireland). Their approach combines studying philosophical and cultural representations of shame in medicine, with empirical studies exploring how race, ethnicity, class, gender, and disability impact on the experience of shame. Planned outputs include guidance on shame-sensitive practice, podcasts, and graphic medicine resources.

Waiting Times

https://waitingtimes.exeter.ac.uk/ (Wellcome, 2017-2022)

This project explores all the different ways that waiting is inherent in contemporary healthcare – from waiting rooms and waiting lists to 'watchful waiting' and waiting to die. It brings together insights from literary studies, linguistics, psychosocial studies, psychotherapy, art practice, and history. Led jointly by Prof Laura Salisbury (University of Exeter) and Prof Lisa Baraitser (Birkbeck University of London) the team includes collaborators from Tavistock and Portman NHS Foundation Trust, Queen Mary University of London, and the University of Plymouth.

Opportunity: Consider focusing efforts on a smaller number of themes to increase impact

Some contributors wondered if there might be value in taking a more deliberate and focused approach around a smaller number of themes, which need not be fixed in perpetuity. This approach would help build stable partnerships, create influential relationships with change-makers, and enable the field to respond more effectively to hot topics and themed funding calls. Topical issues suggested where medical humanities might have much to contribute were mental health, social determinants of health, and culturally safe healthcare.

Challenge: Medical humanities has an uneasy relationship with medicine

In many (but not all) countries medical humanities emerged within medical schools and has gradually expanded and relocated to sit more comfortably in other disciplinary homes. This means there has been a long, and at times difficult, relationship between medicine and medical humanities. Framed at times as a parent/rebellious child dynamic, the relationship to medicine is seen as subservient in some countries and antagonistic in others.[23] There is also undoubtedly a power imbalance with medicine holding both a financial and cultural advantage. The conversations which contributed to this report revealed there may be conscious and unconscious bias on both sides.

Opportunity: Medical humanities researchers can build bridges

The truth appears to be more nuanced. Interviewees working in the NHS were sure that many health professionals would be interested. They highlighted the frustration that some medical practitioners feel with the limited options available to them, but also the overwhelm of the relentless day-to-day demands of their jobs. They felt that to make progress the onus is on medical humanities researchers to make the first move, suggesting that they seek out opportunities to interact, for example attending medical conferences or spending time in healthcare settings, as a way of finding open-minded collaborators.

Opportunity: Seek to collaborate more with public health

The historical connection with medical schools and medical education means that the focus of medical humanities collaborations has often been with front line clinical staff. Two interviewees working in health-related roles felt that medical humanities scholars could potentially achieve more impact by seeking to partner more with public health rather than primary healthcare. In the UK the NHS provides care for people who are ill or injured, but health promotion is delivered by public health services (formerly Public Health England, now Office for Health Improvement and Disparities, and equivalents in Scotland, Wales, and Northern Ireland). Public health is also an interdisciplinary field which already recognises the complex mix of biological psychological and social factors which contribute to health and wellbeing. They are focused on tackling many of the same complex challenges as medical humanities including social determinants of health, obesity, gambling, addiction, and pornography. Furthermore, much of the responsibility for public health is devolved to local authorities which could make relationship building much easier.

ENGAGEMENT

"Nothing about us without us."[25]

Challenges

- Lack of understanding, skills, and confidence in engagement as this is a new concept for some and an evolving area for all
- Accessing funding and other resources, including engagement-specialist staff, to support engaged research
- Finding collaborators and navigating relationships with them
- Managing the boundaries between researcher and participant for those studying an area of personal significance

Opportunities for Change

- Employing specialist professional staff with the expertise to advise and train, support relationship building and coordinate the practicalities of engaged research
- Building relationships with communities of interest as advisers and partners as early as possible in research processes (ideally well before funding application submission)
- Providing training, coaching, mentoring, and other financial and non-financial support for both researchers and partners
- Acknowledge that everyone is learning and that it is better to proceed imperfectly than not to try at all, building in time for experimentation and reflection
- Developing mentoring and support for researchers whose subject matter places them in a personally challenging or vulnerable position

As outlined in the previous section, engagement is one of the core pillars of the medical humanities approach. Exactly what is meant by 'engagement' is a moot point. Here the term engagement is used to encompass various approaches to involving non-academic partners in research including co-production, participatory research, engaged research, and public involvement. They are all two-way processes which involve interaction and listening with the goal of creating mutual benefit. This explicitly excludes involving people purely as research subjects (i.e., doing research 'on' people) and dissemination-style public engagement (e.g., public lectures) although both have their place. This is engagement which helps shape the research in some way, for example influencing the methodology, research questions or outputs. The non-academic partners involved might be doctors or other healthcare professionals, service users or other people with lived experience of the issue in question and their carers, charities, community organisations, activists, and other advocates.

This engagement makes research better by ensuring that it is informed by real world health concerns which can potentially make it more impactful, but most importantly it is ethically the right thing to do. Medical humanities often deals with very sensitive information, with people's personal experiences. In the past there has been criticism that researchers just 'take' people's stories without giving anything back.[26] The phrase *'Nothing about us without us'* came to prominence through disability activism in the 1990s,[25] but nicely sums up the driving force behind contemporary research engagement – that research should incorporate the views of those currently or potentially affected by it. Engagement, co-production, and participatory action research give partners some ownership over the research process which preserves relationships and rebalances power. Funders also increasingly expect engagement to be embedded within projects. Whether researchers want to do it or not, or even know that it is expected, there is no avoiding it.

Challenge: Lack of understanding, skills, and confidence in engagement

The UK 'impact agenda' appears to have worked in favour of medical humanities. The field is seen as having the potential to deliver real world impact for the humanities, something which has historically been hard to evidence (although, as discussed in the Research Culture section, this may simply mean the evidence criteria are flawed). However, this is a rapidly evolving area and even within recent years there have been considerable shifts in what is considered quality engagement.[27,28] Many funding agencies now require engagement to be embedded in all research. For UKRI engagement is a cornerstone of their new strategy[5] and Wellcome looks for engaged research approaches rather than add-on public engagement. This means academics are under pressure to engage even if it is outside of their skill set or doesn't fit with their research. It is interesting then that, beyond access to funding, few researchers surveyed considered a lack of engaged research skills or collaborators to be a barrier. Although this might mean researchers are confident in their skills in this area, from personal experience it is more likely that they are not truly aware of what engagement really means, its growing significance, and the implications for their career.

Opportunity: Professional and financial support for researchers and partners

That said, many of the researchers interviewed can see the huge potential of working in a more engaged way and want to do it well. Common concerns were the challenges of finding suitable research collaborators, and having the necessary time, resources, and skills. Time, space, training, mentoring, and funding is required for both researchers and partners. Where available, facilitation or other professional engagement support can be invaluable for relationship building and research design. Some contributors suggested brokering would be helpful to match up researchers and partners. Developing these relationships should also begin as soon as possible, and not when an application deadline is imminent. This will enable genuine relationships and collaborative ways of working to develop so that partners feel valued.

It is also essential that better models are developed for properly recognising partners contributions and compensating them for their time. At present partnership agreements are often lacking and there may be no scope to add partners to funding bids or even to pay them via university finances. When large wealthy universities are working with, for example, individuals on benefits or cash-strapped charities this lack of process creates resentment, an additional barrier and reinforces toxic power dynamics which can jeopardise the quality of the research partnership.[29]

Opportunity: Expect it be awkward at first

It should also be emphasized that collaborations are often messy and imperfect. Balancing everyone's needs and interests will inevitably lead to compromise, but potentially more impactful results. Adopting a curious and experimental approach with time for reflection and change can help relieve the pressure to do it perfectly.

Challenge: Blurring boundaries between researcher and participant

Many medical humanities researchers are driven by a sense of activism or of wanting to make a difference in the world. Often this drive stems from personal experience of the issue in question. This raises another challenge which, although not entirely unique to medical humanities, can be tricky to navigate.

The growth of engaged research, disability activism, and attempts to rebalance power relationships in medical spaces means that the line between researcher and participant is increasingly blurred.[30] As previously discussed, this is an important shift, but one that raises a number of questions. Should the researcher disclose their personal experience to the people they are working with? Such a disclosure can help break down barriers and build trust but can put researchers in a vulnerable position. On the other hand, is it acceptable for someone with no personal experience of an issue to research it or will they forever be viewed as an outsider? Some would also question whether a researcher can be objective if they are motivated by personal experience or activism? However, objectivity, whilst expected for the sciences and medicine, is much less prized in social science and humanities.

Furthermore, lived experience and engaged research approaches can create an extra emotional burden as researchers may uncover traumatic experiences or become closely entangled with their participants. As these research approaches become more common, these ethical questions and personal difficulties will continue to emerge and will need to be considered.

Opportunity: Open dialogue, mentoring and support

It is essential that these blurred boundaries are explored. Medical humanities researchers who are motivated by personal significance truly want to understand the lived experience of their collaborators and often, to help amplify their voices or make their lives better. It seems inappropriate to restrict them, but they will need help to walk this path. Mentoring and support should be available for researchers whose subject matter places them in a personally challenging or vulnerable position. There will be much to learn from other sectors who deal with challenging subject matter such as the uniformed services, activist organisations, and counselling.

> *"We often work closely with a lot of very difficult and personal subjects. That proximity can place a real strain on mental health. Approaching this conversation as PhD student without collaborators to share struggles with has, at times, been too much. This may be helped by readily available therapy or a forum where researchers can open up and discuss these issues"*[12]

Fig 3: Medical Humanities Research Centres and Networks Around the World[33]

EQUALITY & DIVERSITY

"We are relentlessly white."[31]

Challenges

- European culture and the English language dominate medical humanities
- People working in medical humanities are disproportionately white and female
- Perceived lack of representation and poor job prospects are likely dissuading students from more diverse or less advantaged backgrounds from considering humanities

Opportunities for Change

- Deliberately working to draw in more diverse perspectives and source materials
- Using positive action in recruitment, financial support, and mentoring to encourage promising scholars
- Collaborate more with medicine, biomedicine, and allied professions (where the workforce tends to be more diverse)
- Do more outreach with school age children before they begin to specialise for A-levels and equivalents

Challenge: European culture and the English language dominate

Within the methodological principles that underpin medical humanities research there is a clear principle that considering multiple perspectives makes research better. Incorporating a range of disciplinary perspectives is now standard, and including non-academic voices is increasingly common. However, it appears that considering a range of cultural perspectives from different strata of society and from around the world is much less common. Medical humanities is concentrated in English-speaking countries (UK, USA, Canada, Australia), ex-British colonies like India and Hong Kong, and nations where English is a universal second language such as Scandinavia (Fig 3). Throughout the world the classic (and elite) European and Anglo-American cultural canon dominates creating, perhaps unintentionally, 'norms' in the field. The framing of orthodox medical encounters, e.g., doctor/patient relationships, and Western ideals of living well also dictate the field.[32]

Challenge: Medical humanities researchers are predominantly female

As demonstrated by the cohort who have contributed to this report, medical humanities researchers across the world are predominantly white and female. For this report the interviewees were 77% female and survey respondents were 81% female. An abundance of female academics is certainly something to celebrate. Although care is needed here too, to make sure that this is embraced as a strength rather than seen as a weakness. As a female-led field it may be easier to ignore or sideline. Indeed, collaboration and relationship building can be seen by some as the 'housekeeping' or 'women's work' of research.[30,34] However, women have historically been sidelined in art and culture, and more poorly treated in healthcare[35] so it is perhaps unsurprising that they are drawn to the change-oriented medical humanities approach. As discussed in the section on Research Culture, there is a huge opportunity for medical humanities to demonstrate the power of a different kind of research culture.

Interestingly in the survey, there were some quite clear differences in the challenges faced by men and women. The top two concerns for men were around publishing and recognition. They also placed establishing and navigating collaborations and workplace relationships in their top 10 – issues which were placed in the teens and twenties by women. In a female-dominated culture there is a possibility that these concerns might be sidelined in the same way that women's concerns can be neglected in a masculine workplace.

Challenge: Medical humanities researchers are predominantly white

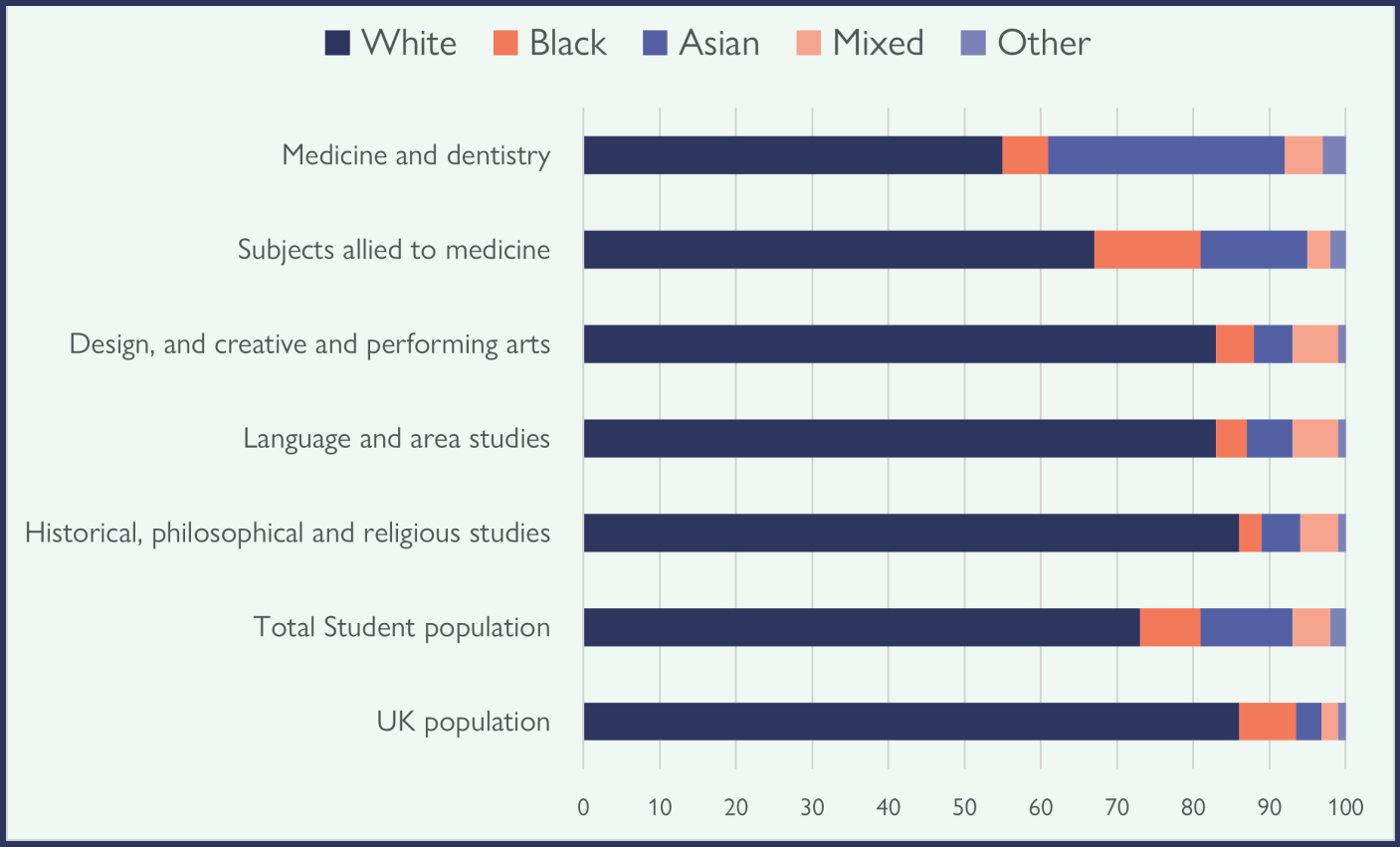
The whiteness of medical humanities is perhaps less cause for celebration. Respondents to our survey described themselves as 79% White, 9% Asian, and just 2% Black. This lack of diversity might be traced back to a lack of diversity in the 'pipeline'. As shown in Fig 4, UK undergraduate students in the arts and humanities are disproportionately white. A lack of ethnic diversity amongst undergraduates will lead to a lack of diversity in postgraduate students and then academics. However, compared to the overall UK population, people of colour are actually over-represented in undergraduate studies as a whole, and are particularly high within in medicine and science. [36,37]

So, what is it about medicine and science that make them so much more enticing or welcoming to people of colour than arts and humanities? It is well known that careers where people can't see themselves or their culture represented are less appealing and English and history as taught in UK schools are predominantly white and Eurocentric.[38,39] Black students are also more likely to drop out of university or graduate with a lower grade making postgraduate study inaccessible.[38] And even if they do make it through the higher education system, they might then be less likely to obtain the funding which would enable them to build a career in academia - the Wellcome Trust has recently admitted that their funding systems are structurally racist with the success rates of BAME applicants considerably below white applicants.[40]

Challenge: People from lower socioeconomic groups are under-represented

Furthermore, academics are predominantly from well-educated and more affluent backgrounds. A US study found that academics are up to 25 times more likely to have a parent with a PhD (exacerbated even more in prestigious institutions) and are considerably more likely to have grown up in an affluent area.[41] There is no reason to expect the UK to be very different given that people from lower socioeconomic groups are under-represented in higher education across all subjects especially the humanities.[36] Studying arts and humanities is generally seen as risky with fewer career opportunities. With the added burden of student loans and tuition fees these subjects will be even less attractive to students from less-affluent backgrounds.

Fig 4: UK undergraduate student population (2020/21) comparing selected subjects of study and ethnicity[36]



Challenge: People with personal health issues can feel excluded

It is ironic that for a field concerned with health, researchers with mental health concerns, disabilities or chronic health conditions report feeling excluded from academia because they can't integrate into the traditional university structures. One respondent said, *'As a chronically ill, neurodivergent person, am at a disadvantage when it comes to the kind of networking required.'* They also reported that the shift from online back to in-person non-socially distanced events, felt to them like a backwards step making them feel excluded again (after briefly feeling included).

Opportunity: Positive action, flexibility, and financial support

Uncovering the issues which are hindering the diversification of the medical humanities workforce is the first step to changing things. Some interviewees had practical suggestions for how to begin to make changes. A first step might be actively seeking to draw in perspectives from other cultures, potentially excluding (or de-emphasising) the usual canon. There may also need to be some radical action around funding distribution, recruitment, and mentoring to support promising students and researchers from non-traditional backgrounds. A contributor who had worked in South Africa reported success with head-hunting or closed recruitment processes as a way of increasing diversity. Another avenue that might be considered is funded scholarships, at undergraduate or postgraduate level for students from certain under-represented groups. A shift away from traditional indicators of esteem (as discussed under Research Culture) will also likely benefit less conventional scholars. In the short term it may be useful to look towards collaborating more with science and medicine to draw in, not just a wider range of disciplinary perspectives, but also a more diverse range of people. In other words – go to where the people are, rather than expecting them to come to medical humanities. There might also be an opportunity to develop hybrid roles with people working part time in both HE and other sectors such as science or healthcare.

Opportunity: Schools outreach

To help draw in a more diverse undergraduate population there is perhaps something to learn from other subjects. Over the last 20 years there has been a concerted campaign to promote courses and careers in STEM (science, technology, engineering, and maths) with outreach, engagement, events, and competitions. This has led to record numbers of students studying STEM subjects at university.[42] These efforts have shown that the seeds of future career choices are planted very early, often at primary school, and that family influence is key.[43] Most universities now have coordinated opportunities to get involved in schools' outreach and medical humanities could offer some interesting and engaging activities particularly around challenging health-related debates.

Opportunity: Leaders committed to change

Strong but compassionate leadership, humility and open-ness will also be required. Change is difficult for most people, especially when they might feel like their entire career is being brought into question. It is also crucial to recognise that this is work that everyone needs to be engaged with – not just the managers or the few staff from non-conventional backgrounds. People from more diverse or less affluent backgrounds have already had to work harder than their white or wealthier counterparts to reach academia in the first place. Although it is crucial to involve them, it is unfair to expect them to shoulder the additional burden of solving entrenched inequality.[44]

Opportunity: Mobilising medical humanities to research solutions

Another suggested solution was that medical humanities is well placed to make a significant contribution to the urgent need to tackle health inequalities (which disproportionately affect people of colour, those with disabilities and the less affluent) and provide culturally safe healthcare. If the field can commit resources and work in collaboration with the more diverse medical workforce there is the potential to make a significant difference, not just to equalizing academia, but to equalizing healthcare.

APPENDIX 1: CONTRIBUTORS

This report is primarily based on one-to-one interviews, formal and informal discussions at meetings, and an online survey as detailed below. It also includes some of the author's professional experience as Project Manager for Life of Breath (2015-2020) and Manager of the Institute for Medical Humanities (2017-2021).

Meetings

- IMH Away Day, Durham, 25 February 2022 [18 attendees – estimated demographics: 72% Female, 28% Male; 22% ECR, 22% Mid-career; 28% Senior; 28% Non-academic]
- IMH/Linkoping meeting, Durham, 1 April 2022 [34 attendees – estimated demographics: 62% UK, 38% Sweden; 74% Female, 26% Male; 15% Student, 15% ECR, 32% Mid-career, 21% Senior, 18% Non-academic]

Interviews

- Dr Marie Allitt, University of Edinburgh, UK
- Prof Helen Chatterjee, University College London, UK
- Dr Guy Dodgson, Cumbria, Northumberland, Tyne & Wear NHS Foundation Trust
- Dr Claire Hooker, University of Sydney, Australia
- Prof Ericka Johnson, Linköping University, Sweden
- Dr Manali Karmakar, Vellore Institute of Technology, India
- Dr Alison Morehead, Queen's University, Canada
- Prof Stuart Murray, University of Leeds, UK
- Prof Ian Sabroe, Sheffield Teaching Hospitals NHS Trust and University of Sheffield, UK
- Dr Brandy Schillace, BMJ Medical Humanities Journal and Author
- Dr Carla Tsampiras, University of Cape Town, South Africa
- Prof Paula Whitty, NHS North East Quality Observatory Service and NIHR Applied Research Consortium North East & North Cumbria
- Siân Williams, International Primary Care Respiratory Group and Health Consultant

Survey

The survey was conducted through Microsoft Forms. Participation was voluntary and anonymous. The survey was open for 10 days (24 June-3 July 2022) and was advertised via IMH mailing lists, Twitter and the MedHealthHums Jiscmail group. The survey was completed by 102 people. Although it seems to include a good range off people and perspectives the results cannot claim to be a representative sample and there will be a bias towards people already engaged within IMH networks.

It included 30 statements (challenges identified through the meetings and interviews) with a Likert scale (No barrier, Slight barrier, Moderate Barrier, and Serious barrier plus a Not applicable option). For analysis these were converted to a numerical score (No barrier = 1, Slight barrier = 2, Moderate Barrier = 3, Serious barrier = 4, Not applicable = 0). This means that the scores could be averaged and compared for different demographic groups. A higher number indicates a more significant barrier. The scores were ranked, and the challenges ordered from 1 (most significant barrier) to 30 (least significant barrier).

List of Statements

- Understanding or articulating what it means to do medical humanities research
- Knowing how best to do interdisciplinary research
- Accessing training on interdisciplinary methods and approaches

- Accessing funding for interdisciplinary medical humanities research
- Accessing other resources (including time, space, staff etc) to support interdisciplinary research
- Finding academic collaborators for interdisciplinary research
- Navigating relationships with academic collaborators
- Finding avenues to publish interdisciplinary work
- Getting recognition for non-conventional outputs
- Pressure to demonstrate real world impact
- Pressure to do engagement or engaged research
- Knowing how best to do engagement/engaged research
- Finding non-academic partners/collaborators
- Accessing funding/resources to support engaged research
- Navigating relationships with non-academic research partners
- Navigating the boundaries between researcher and participant (when studying a topic of personal significance/experience)
- Knowing how to frame research findings for a medical or non-academic audience
- Accessing opportunities to disseminate your research to a medical or non-academic audience
- Knowing how to engage with change-makers (e.g. policy, professional bodies)
- Knowing how to decolonise or diversify your work
- Finding more diverse colleagues/communities to collaborate with
- Finding secure employment
- Identifying alternative career paths and transferable skills
- Finding/retaining research assistants/post docs with interdisciplinary research skills
- Finding/retaining professional staff skilled in supporting interdisciplinary/engaged research
- Being hindered by administrative processes or bureaucracy
- Difficult relationships or power dynamics with colleagues or collaborators
- Feeling isolated within your department or institution
- Finding opportunities to network with like-minded scholars
- Being able to access to relevant training/ development opportunities

It also included open text boxes for participants to identify any other challenges and suggest potential solutions. Demographics questions recorded career stage, gender, ethnicity, and geographical location as well as information about subject specialisms and relationship to medical humanities.

Survey participant demographics

- Career Stage: 2.0% Student (Undergraduate or Masters); 23.5% Student (PhD); 34.3% Early career; 24.5% Mid-career; 14.7% Senior; 1.0% Retired
- Work sector: 86.3% Academic; 8.8% Health; 2.9% Charity/NGO; 2.0% other
- Gender: 81.4% Woman, 13.7% Man; 2.0% Non-binary; 2.9% Prefer not to say
- Ethnicity: 8.8% Asian; 2.0% Black; 3.9% Mixed; 79.4% White; 3.9% Any other ethnicity; 2.0% Prefer not to say
- Location: 55.9% UK; 21.6% Europe; 12.7% North America; 5.9% Asia; 3.9% Any other country

APPENDIX 2: SUMMARISED SURVEY RESULTS

Fig 5: Averaged and ranked survey results broken down by different characteristics

(1 = most significant barrier, 30 = least significant barrier; deeper colour = more significant barrier; groups with fewer than 4 replies were aggregated; *Non-binary is not included to protect anonymity due to the small number of replies.)

	Barrier		Accessing funding for interdisciplinary medical humanities research	Accessing other resources (including time, space, staff etc) to support interdisciplinary research	Accessing funding/resources to support engaged research	Getting recognition for non-conventional outputs	Being hindered by adminstrative processes or bureaucracy	Knowing how to engage with change-makers (e.g. policy, professional bodies)	Pressure to demonstrate real world impact	Feeling isolated within your department or institution	Accessing training on interdisciplinary methods and approaches	Finding avenues to publish interdisciplinary work	Finding secure employment	Finding more diverse colleagues/communities to collaborate with	Knowing how best to do engagement/engaged research	Finding opportunities to network with like-minded scholars	Finding academic collaborators for interdisciplinary research	Accessing opportunities to disseminate your research to a medical or non-academic audience	Identifying alternative career paths and transferable skills	Being able to access to relevant training/ development opportunities	Navigating relationships with academic collaborators	Knowing how best to do interdisciplinary research	Navigating relationships with non-academic research partners	Finding non-academic partners/collaborators	Knowing how to decolonise or diversify your work	Pressure to do engagement or engaged research	Difficult relationships or power dynamics with colleagues or collaborators	Understanding or articulating what it means to do medical humanities research	Knowing how to frame research findings for a medical or non-academic audience	Finding/retaining research assistants/post docs with interdisciplinary research skills	Navigating the boundaries between researcher and participant (when studying a topic of personal significance/experience)	Finding/retaining professional staff skilled in supporting interdisciplinary/engaged research
All		100%	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
By Career Stage	Student (PhD)	24%	2	3	1	5	11	17	18	7	8	9	6	16	14	4	10	12	19	13	15	20	21	22	23	24	27	26	25	29	28	30
	ECRs	34%	2	1	6	3	10	5	8	17	7	18	4	13	15	22	12	19	9	16	11	14	20	21	25	23	26	24	27	28	29	30
	Mid career	25%	1	3	2	5	4	12	6	8	10	7	29	20	11	24	14	18	28	16	26	15	21	17	22	19	23	25	27	9	30	13
	Senior	15%	4	3	2	6	1	7	13	9	22	11	16	8	17	12	20	10	5	24	18	23	21	29	14	27	15	25	19	28	30	26
By Gender*	Woman	81%	1	2	3	4	5	6	7	8	9	13	10	11	14	17	15	12	18	16	19	20	21	23	22	25	26	24	27	28	29	30
	Man	14%	3	7	4	1	18	22	19	6	12	2	13	26	11	5	9	23	14	20	15	16	8	10	24	21	17	27	25	29	28	30
By Ethnicity	White	79%	2	1	3	4	5	6	7	8	9	13	10	11	12	18	15	16	20	14	21	17	19	22	23	25	26	24	27	28	30	29
	Any other ethnicity	21%	1	6	2	3	8	12	16	15	13	4	9	19	17	5	14	11	7	20	10	21	22	23	25	18	24	28	27	30	26	29
By Location	United Kingdom	56%	1	2	3	4	5	6	10	12	8	11	7	13	9	18	14	15	23	16	20	19	21	17	24	22	27	25	26	29	28	30
	Europe	22%	2	1	3	4	5	6	8	9	7	13	10	14	12	24	28	19	11	22	18	15	23	20	25	27	16	26	29	17	30	21
	Asia	13%	3	9	8	4	10	24	17	14	5	6	1	15	27	7	23	12	2	21	16	11	29	30	13	26	18	22	25	19	28	20
	North America	6%	2	3	5	1	10	16	7	6	23	9	22	11	21	8	4	14	17	15	12	24	13	26	19	25	20	28	18	27	30	29
	Rest of the world	4%	1	3	4	8	10	23	5	2	18	15	29	21	13	6	9	11	24	12	22	19	16	20	25	14	17	7	28	26	30	27

APPENDIX 3: AUTHOR AND ACKNOWLEDGEMENTS

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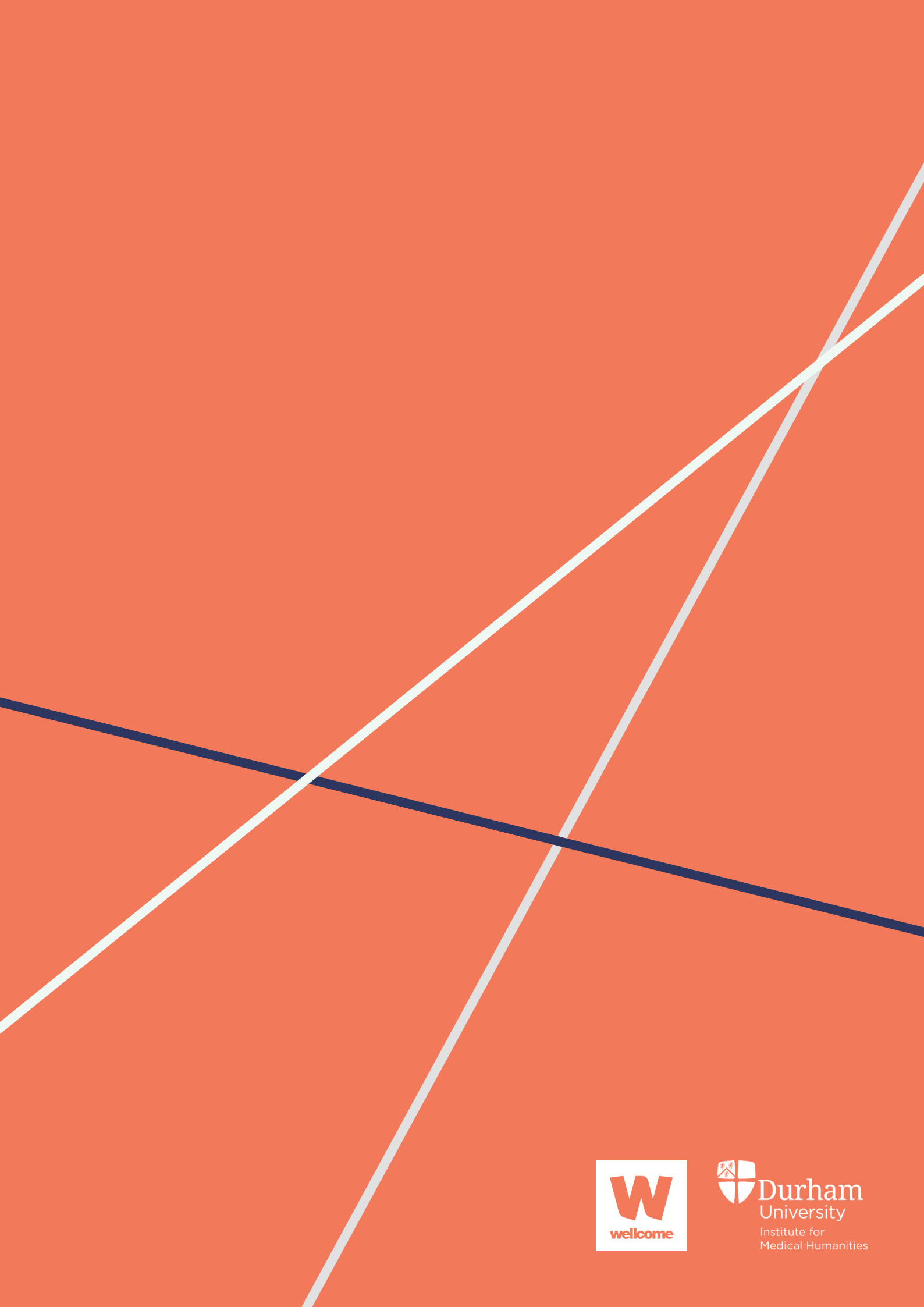
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