To Be or Not: A Brief History of the Health Humanities Consortium

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Abstract

The Health Humanities Consortium (HHC) was established in 2015 to “promote health humanities scholarship, education, and practice through transdisciplinary methods and theories that focus on the intersection of the arts and humanities, health, illness, and health-care.” As the founding co-chairs of the HHC, we provide a history of the founding of this organization in this article, describing the journey of its creation, the choices and challenges it faced as a new organization, and our hopes for a rich future.

Keywords Health humanities · Consortium · Organization · Leadership · History · Conference

“To be or not to be is not a question of compromise. Either you be or you don’t be.”

--Golda Meir

In ancient Athens, the agora was a forum for public life, where citizens would gather to conduct commerce, perform religious rituals, and engage in public debates on the most pressing issues of the day. On a warm May afternoon in 2015, approximately sixty people sat, facing one another, across the space of a round forum on the grounds of the University of Colorado Anschutz Medical Campus outside of Denver. After three days of presentations, performances, and conversations, this diverse group of scholars, educators, artists, and clinicians debated whether to form an independent affiliation of people working across the multiple landscapes and domains in the medical/health humanities and arts.

With neither name nor affiliation except that of her home institution, Tess Jones had organized the first U.S. health humanities and arts conference, which was also the fourth such meeting for the International Health Humanities Network (UK). Guided by the vision and energy

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of self-declared “first professor of health humanities and founder of the discipline,” Paul Crawford and his colleagues at the University of Nottingham had created a global network of health humanists, established a database resource. And made a commitment to holding biennial international meetings (Media Relations 2020). Their focus was on the impact of arts practices and humanities epistemologies for the health and well-being of the public and for the practice and practitioners of health care (IHHN n.d.). If those gathered in Colorado would also find value in meeting together regularly, then perhaps we needed an organization to ensure that it happened.

Some of the most pressing and pertinent questions immediately raised concerned identity: “We aren’t a field or a discipline, so what would this entity be?” asked someone in the forum. Someone else raised the perennial issue of accessibility: “Existing professional organizations are already too expensive for most humanists and artists to attend.” And finally, the question of competing with long-standing and securely funded organizations such as the Modern Language Association and the American Society for Bioethics and Humanities was quickly raised and then, just as quickly, dismissed: “Most health humanists and artists never attend MLA or ASBH anyway,” responded one attendee.

By the end of an energizing and wide-ranging ninety-minute discussion, the group agreed that a health humanities organization *was* needed and should be founded. They then identified and articulated four overarching goals:

- to support an annual meeting of people interested in the topic
- to engage in more rigorous critical inquiry across all aspects of the field
- to strive to be more inter-, multi-, and trans-disciplinary
- to embrace and encourage the growth in baccalaureate level health humanities programs.

Answers to more practical questions such as what this new organization would be called, what it could do, and what fields or disciplines it should represent were left unanswered.

However, the new entity—whatever its name, mission, and membership—needed a leader, and because she had organized this meeting and was a founding figure in medical/health humanities (and also happened to be standing in the middle of the room), the crowd literally called for Jones to take on that role. “I agree to serve,” she said, “but only if...” in a silent pause her eyes looked around the forum, “...Craig Klugman co-chairs with me.” With no prior inkling of this and thinking his work had been more in bioethics than humanities up to that time, Klugman was speechless. “We match well,” Tess continued. “You’re bioethics, and I’m humanities. You identify as male, and I identify as female. You are in the east, and I’m in the west. You’re gay, and I’m straight.” A silence settled over the room as it dawned on every participant that Jones had just outed him, yet Klugman nervously replied, “We can talk about it.” The crowd enthusiastically roared its approval. Immediately after, Jones apologized for both outing and blindsiding him, but she knew in that moment that as partners, “We could get things done.” One important difference between them that she didn’t note was where they each did their work: Jones at a health sciences center, Klugman at a liberal arts university. That element of their shared leadership was crucially important in keeping the goal of inclusivity front and center.

Prehistory

This article holds several assumptions: one, that the health humanities exist; two, that the humanities and arts in health, pre-health, and health professions education are of value; and three, that other comprehensive chronicles of the medical/health humanities have already been written. Here, we focus specifically on the founding of the Health Humanities Consortium.

The medical humanities have a long and impressive history especially vis-à-vis medical education. The term itself derives from medical historian George Sarton (1948) who used the phrase, “medical humanities,” in an obituary crafted for *Isis*, the journal of the History of Science Society. While many have and will continue to debate the origin and evolution of the field, there are some facts to ground the conversation. For instance, in 1967, Penn State College of Medicine established the first department of humanities in a medical school. Joanne Trautmann Banks, a literature scholar and educator, became its first humanities faculty member in 1972, signaling the growing interest in literature and medicine. Along with history of medicine, the turn towards narrative in various forms and from various perspectives has become a standard feature of humanities programs in medical schools across the U.S. (Klugman 2018).

In 1969, the Society for Health and Human Values (SHHV) was established. Though broad in its approach, SHHV was dominated by philosophers and religious studies scholars. In 1998, SHHV joined with the Society of Bioethics Consultation (SBC), and the American Association of Bioethics (AAB) to form the American Society for Bioethics and Humanities (ASBH), which is still the dominant bioethics and humanities organization in health and medicine. The nature of this consolidation signaled several trends that became evident in the character of ASBH. First, two of the three parent organizations were bioethics focused, and with the recent move toward professionalizing clinical ethics, bioethics dominated the bulk of the organization’s work (Health Humanities Task Force 2019). Second, what had been a mutual dialogue among different disciplines in SHHV became more rigidly hierarchical in ASBH with bioethics ranking first and other humanities inquiry and practice a distant second. Fewer medical humanists remained active members in ASBH because they found the programming at the annual meeting less relevant and because the cost of attending simply became too high.

Moreover, because of the growth and professionalization of bioethics, medical humanities programs were being subsumed under it in medical schools. “Centers for Humanities and Ethics” were reforming as “Centers for Bioethics and Humanities,” curricular time previously dedicated to humanities content and methodologies was repurposed for bioethics, and both fields lost time to new “integrated” curricula that did away with stand-alone classes (Klugman 2018).

In response to these trends, the Pennsylvania Medical Humanities Consortium (PMHC) was established in 2002 with the goal of bringing people together, regionally, in conversation. The PMHC held annual state-wide meetings to discuss medical humanities issues in curriculum development, educational practice, and research. A decade later, Paul Crawford would establish the IHH in order to expand not only the institutional reach of humanities programs in medical schools and clinical practices throughout the United Kingdom but also to expand the field’s content areas, practices, and actors in order to “embrace interdisciplinarity and engage with those marginalized from the medical humanities” (Jones et al. 2014, 7). Thus, what had become a recognizable descriptor of the field, *medical*, was now being challenged and replaced with the more inclusive, *health*.

In light of this turn towards inclusivity as well as the diminishing presence of the humanities across leadership and programming in ASBH, a group of scholars and educators met in 2010 to envision next steps for the field. Seated at the table was Professor Lennard Davis, preeminent critical disability studies scholar from the University of Illinois Chicago. A pioneer himself in the development of an academic field (he is founding editor of *The Disability Studies Reader*, now in its sixth edition), Davis was explicit in his advice to the group: “You need a reader, and you need an organization.”

“You need a reader”

Taking Davis’s words to heart, Jones, Delese Wear, and Lester Friedman, all seated at the same table in 2010, went on to publish the *Health Humanities Reader* with Rutgers University Press in 2014. The *Reader* is a vast and diverse collection of inter- and multi-disciplinary critical analyses and pedagogical practices in the humanities, social sciences, and arts, all of which explore institutional structures, cultural representations, and lived experiences around medicine, health, illness, and disability. Inspired by Crawford’s work, the editors argued for a shift from “medical” to “health” humanities in the U.S. with the content of the *Reader* itself as the most persuasive reason to “adopt the more encompassing, contemporary, and accurate label of our current academic enterprise” (Jones et al. 2014, 6). Such a change in lexicon meant a decentering of medicine and, to use Crawford’s word, an embracing of all health professionals, of patients and their families, and of communities.

Thus, by the time of the 2015 meeting in Denver, the groundwork had already been laid for the second part of expanding *and* solidifying the field—creating an organization. The PMHC had disbanded and gifted their resources to Jones to establish another, larger organization. However, not all attendees at Colorado were enthusiastic about such changes and advancements. The fifty-plus year history of *medical* humanities in the U.S. was offered as reason enough not to change the name of the field or to spin off as a unique society. Many of those present held faculty appointments in *medical* schools, teaching *medical* students and working primarily with *medical* colleagues. Moreover, Tom Cole, Nathan Carlin, and Ron Carson (2014) had published the first major textbook, *Medical Humanities: An Introduction*, to define, once again, the field and to describe its philosophical and pedagogical underpinnings for teachers and students.

Two years later, in 2017, Jones would join colleagues Michael Blackie, Rebecca Garden, and Delese Wear in publishing an article, “The Almost Right Word,” in *Academic Medicine* to further the argument for moving from *medical* to *health* humanities (Jones et al. 2017, 932 – 925). Editor David Sklar (2017) bolstered support for the change in a subsequent editorial for *Academic Medicine* in which he wrote: “By looking beyond the traditional areas of health care delivery to a broader purpose of promoting population health, preventing illness, and efficiently using societal resources, we discover that many of the same areas identified by Jones et al. that concern the health humanities—such as poverty, race, and violence—are also concerns of medical education” (Sklar 2017, 1647). Momentum seemed to be growing in support of this project’s goal of expansiveness and inclusiveness, captured in that one-word change.

Something new

Everyone involved had some inkling about what a formidable task it would be to form a new organization. The first step was to assemble a Steering Committee (SC) to advise the co-chairs and to create a climate of democracy, which reflected what the new health humanities would be.¹

At the 2016 HHC meeting in Cleveland, the SC met to discuss two questions—who are we, and what do we call ourselves? There was little interest in a formal, professionally managed society like ASBH, which would necessitate higher dues, and thus, the term, “Society,” was dismissed. “Association” also seemed too formal, and “Affiliation” didn’t emphasize the key activity of coming together. The group finally settled on the idea of a “Consortium” of scholars, educators, and artists united in an informal collaboration.

A related discussion followed over the scope of the organization—knowing that there was growing interest in the American Association of Medical Colleges (AAMC) in arts and humanities in medicine,² we agreed to a dual focus on baccalaureate and non-medical graduate arenas. This commitment has been tested. For example, one potential annual meeting organizer wanted to host the conference as a training session for physicians on the value of arts in medicine, and we had to pass on what would have been a well-funded, well-promoted, and well-attended meeting at a major institution. However, from organizational challenges to personal ones (such as the occasional tension when MDs speak over their non-MD colleagues), the HHC has continued to maintain its position that the humanities, arts, and social sciences have inherent value—a subtle distinction from the instrumental value of the medical humanities in the work of teaching and modeling specific clinical skills that will foster more respectful and compassionate relationships of physicians with their patients and families.

The next tasks were designing and launching a website and writing bylaws. Klugman pulled both together, presenting both visuals and text for a web presence, a mission statement, and the outline of policies that comprise the first draft of HHC bylaws. Over the next eighteen months, the SC debated, crafted, edited, and finally approved the documents.

However, it was not until the 2017 HHC meeting in Houston that we held the first general business meeting of the Consortium. Membership until then had been loosely defined as anyone who attended an HHC meeting, but we were now proposing a more traditional scheme of voluntarily joining and paying dues which would give one rights in the organization—to attend the business meeting, to vote on proposals, to run for election on the Steering Committee, and to receive a discount at the annual meeting. Dues were kept low to encourage participation, but being a dues-paying member was not required to attend or present at the annual meeting, ensuring that finances would not be a barrier to being part of the community. Leadership also announced that they were filing papers of organization for state recognition.

Along with that year’s *Academic Medicine* publication and Sklar’s editorial endorsement as well as the formal state recognition as an organization, the health humanities was emerging as both a real field and the HHC as a legitimate organization. For example, new and existing educational programs began adopting the change in nomenclature, from *medical* to *health* humanities, and professional organizations such as the Modern Medical Library Association formally adopted Health Humanities as the name of one of its caucuses, replacing Medical Humanities. Through Modern Language Association’s long-standing “Literature, Medicine, and Medical Humanities Community” Klugman and Erin Lamb (2017) put out a call for papers on the health humanities “as a unique field of study,

promoted through international organizations and journals, formalized through a wide variety of curricular structures with similarly varied learning objectives. This diversity raises the question of what counts, or doesn't count, as health humanities?" The HHC was meeting its goal of becoming both a network and a resource.

Michael Blackie, as Treasurer, arranged for the HHC, through the University of Illinois Chicago (UIC), to become a legal entity as a 501(c)(3) and for UIC to manage the finances. The SC also adopted a formal mission for the organization: "The Health Humanities Consortium is a U.S.-based collaboration of scholars, educators, and artists that seeks to promote health humanities scholarship, education, and practices through interdisciplinary methods and theories that focus on the intersection of the arts and humanities, health, illness, and healthcare" (HHC 2021).

By the time of the 2018 meeting at Stanford School of Medicine, the HHC was a legal entity with bylaws and working groups.³ And given that the organization was now three years old, Jones and Klugman announced their plans to step down as founding co-chairs the following year, proposing Lise Saffran (University of Missouri, Columbia) and Quentin Eichbaum (Vanderbilt) as successors. The bylaws had also set three-year terms for the SC, so a call for willing candidates was made. New leadership was formally installed the following year at Chicago alongside a formal membership program and working groups.⁴

By the spring of 2020, the HHC expected to share substantive accomplishments at its annual meeting in Nashville, Tennessee, on the campus of Vanderbilt University. However, because of the national lockdown in response to the COVID-19 pandemic, the meeting was canceled. The 2021 spring meeting was virtual, hosted by the Penn State College of Medicine in Hershey, Pennsylvania. It showcased a maturing organization, represented by seventy-five dues-paying individual members and six institutional members.

It is also a changing and growing organization: Saffran and Eichbaum stepped down as co-chairs in 2021 to be succeeded by Erin Lamb (Case Western) and Sarah Berry (SUNY Oswego). The Curriculum and Assessment Committee (CAS) announced the formal adoption of a National Center for Education Statistics Classification of Instructional Programs (CIP) code which academic programs could begin using immediately. CAS continues to field inquiries on how to establish health humanities baccalaureate programs. They have published a new program toolkit in this issue of the *Journal of Medical Humanities* that includes information on existing programs, steps to build a program, learning objectives, and sample curricula. They have also collaborated with Rice University in establishing an interactive syllabus repository. Finally, the new Humanities Alliance Network founded by Tracey Leavelle (Creighton) and Gina Camodeca (D'Youville), which brings together academic programs and persons interested in the health humanities, have now joined the HHC as a subgroup, and Bernice Hausmann (Penn State) has proposed that a Humanities Administrators Network become an independent committee within the Consortium.

What comes next

With the inauguration of Berry and Lamb, Jones and Klugman have departed the SC from their roles as "immediate past co-chairs." One of the signs of successful leadership and organizational development is that it continues to exist even without you. That we are now on our third set of co-chairs suggests that we have been successful in creating a sustainable organization. As the HHC has expanded, so too have baccalaureate and graduate programs in the health humanities. For many of us, that marker of success has

brought the greatest joy and sense of accomplishment. From Craig's vantage point at a liberal arts university to Tess' distinct perspective at a major health sciences center, we have had the opportunity and the reward of witnessing learners move through health humanities majors, minors, concentrations, certificates, graduate degree programs, and fellowships to become compassionate and skilled health professionals and/or "critical, discerning participants" in the future of health care as patients, caregivers, and policy-makers (Blackie and Lamb 2014, 490).

Endnotes

¹ Michael Blackie (University of Illinois, Chicago) immediately signed on as Treasurer and was also joined by Stephanie Brown (Rochester U), Katherine Burke (Cleveland Clinic), Nathan Carlin (University of Texas Health Science Center at Houston), Quentin Eichbaum (Vanderbilt U), Les Friedman (Hobart and William Smith Colleges), Rebecca Garden (Syracuse U), Erin Lamb (Hiram College), Bradley Lewis (NYU), Lise Saffran (U Missouri), Audrey Shafer (Stanford U), Danielle Spencer (U Columbia), and Gail Werblood (U Illinois-Chicago).

² The American Association of Medical Colleges (AAMC) convened leaders in the medical/health humanities in summer 2017 with the goal of mapping the current landscape of the arts and humanities in medical education and determining the benefits of integrating the arts and humanities in medical school curricula. That initial conversation launched a multi-year project, The Fundamental Role of Arts and Humanities in Medical Education (FRAHME), which resulted in a published scoping review of US and Canada programs and, in 2021, a published monograph; an on-line resource for medical schools that wished to create and/or expand arts and humanities programs; and a grants program (<https://www.aamc.org/what-we-do/mission-areas/medical-education/frahme>).

³ Working groups included Education and Assessment (Craig Klugman and Erin Lamb); Conference Planning and Support committee (Tess Jones); and a CIP Project (Sarah Berry), a code used by the U.S. Department of Education to collect metrics on the graduates of academic programs. By having a medical/health humanities code, we would be able to see where graduates of medical/health humanities programs went for further training or for jobs.

⁴ These included International Collaboratives (Lise Saffran and Quentin Eichbaum); Disability Access and Content (Rebecca Garden and Sarah Blanton); and Arts (Katherine Burke). Burke also joined the officers in a newly created Secretary role.

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