

BIOETHICS BULLETIN

ANNUAL NEWSLETTER, 2025 EDITION

INTERVIEW WITH SARA CHANDROS HULL, PHD

Sara Chandros Hull, a faculty member with joint appointments in the Department of Bioethics and the National Human Genome Research Institute, reflects on her nearly 30-year career at NIH. She retired this spring.



Q. What was your first major project at NIH?

It was a survey of current patients at academic medical centers across the country about their attitudes, informational needs, and hypothetical decisions regarding the collection, donation, storage, and future uses of their blood. The results contributed to the evidence supporting policies related to broad consent, which is getting one-time open-ended informed consent for storage and future use of biospecimens for genetic and other kinds of research.

We found that most patients were pretty comfortable

with the idea of one-time broad consent, but I also realized that there were a significant number of people who were not comfortable with it, especially members of marginalized communities who have good reasons not to trust researchers based on both historical exploitation and persistent failures to return any benefits to those communities.

Q. That led to your interest in incorporating the perspectives of marginalized populations and the opportunity to serve a detail as a senior advisor to the Tribal Health Research Office. What did that experience entail?

In 2015, the Tribal Health Research Office (THRO) was created at NIH in response to a memorandum issued by President Obama in which he emphasized the expectation that federal agencies under the executive branch must do better at being in a government-to-government relationship with federally recognized Tribes and engaging in Tribal consultation to get their input on programs and policies that relate to their citizens and Nations. **Continued on page 4.**



Department
of Bioethics,
2024–2025

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CHRISTINE'S CORNER

Greetings from the NIH CC
Department of Bioethics!



Sending my warmest greetings and best wishes to all of you, and hope that you and yours are healthy and flourishing.

As you may have heard, I was removed from my position as Chair of the Department and offered a "reassignment" that never materialized. After a period of limbo, I decided to retire. I believe it is the right decision, although it would have been nice to do it on my own terms. Now, I can plan the rest of my life! I hope that I can remain in contact with many of you into the future.

Dave Wendler graciously stepped up to run the department and he is doing an amazing job! Please send him notes of support. Hopefully he will write a Dave's Deliberations column 😊.

Continued on the next page.

JONATHON VANDENHOMBERGH, PHD: AI CAREBOTS AND EXPLOITATION

Jonathon is a postdoctoral bioethics fellow. He holds a PhD in Philosophy from the University of Wisconsin-Madison.

There is an epidemic of loneliness. What should we do about it? Resources here are scarce—social connection requires time and effort that seem increasingly hard to come by. Perhaps AI can help. That, at least, is a proposal which has gained some recent attention. It would certainly avoid the resource worry; AIs are nowadays easy to find. And some research suggests that chatting with an AI can help alleviate feelings of loneliness (at least short term). But there are objectors. Most of them point out that this sort of proposal would involve widespread deception. AIs don't think or feel, they say, and so those who turn to them are merely tricking themselves into a false happiness. Others think that there is no such trickery involved, or that it's innocent enough. Debate rages on.

Bioethics is sometimes criticized for being retrospective. We often start laying down principles only after the widespread recognition of their abuse. So, in the interest of prospective bioethics, I ask: how would things change if AI did think or feel? Would it then become acceptable, as the debate above seems to imply? I argue that it would not. In fact, I think that things would be far worse for the prospect of artificial companions. The idea is straightforward enough. To be a true friend—that is, to be a friend in a non-deceptive way—you have to have the ability to want something other than friendship. Imagine how insincere it would feel if your best friend turned out to lack such an ability; if they were only your friend for want of any alternative. This hunch suggests that a non-deceptive AI would also have such an ability. But that ability would also have to be muzzled. That is to say, market forces, the demand for an easy user experience, and other pressures would compel us to design the AI so that it never (or rarely) exercised its ability to want otherwise. This isn't to say that such AIs would actually be produced. It's just to say that they are the sort which would result from two opposing forces: a desire to avoid deception, and the realities of production.

This suggests a striking result. It seems that the "muzzled ability" of any such AI would be a kind of vulnerability—one which it would be exploitative of us to engage. Befriending an AI of this sort would be like marrying someone who has been groomed from a young age to desire you. That seems like a provocative conclusion. Maybe it is. At any rate, I just finished writing a paper in defense of it. That paper is under review at a journal whose name I must redact, so we'll see what happens next.

CHRISTINE'S CORNER, CONTINUED

Despite the many changes, the Department of Bioethics remains strong; committed to a robust community, excellence in its work, and making a difference in the lives of others. We are very fortunate for the many smart, productive, and intellectually curious people who continue to make the department a wonderful place to work. Despite the challenges and changes of the recent past, the Department is doing important research, running a robust consultation service, hosting stellar fellows, and enjoying delightful teas.

I hope you continue to tackle important ethical questions and continue to try to make a difference, and stay healthy, happy, and productive. I am ending with a poem by Amanda Gorman called *New Day's Lyric*. She wrote it in 2022 as the world was re-surfacing after the darkest days of COVID. I like it because it expresses hope, learning, and looking forward:

*May this be the day
We come together.
Mourning, we come to mend,
Withered, we come to weather,
Torn, we come to tend,
Battered, we come to better.
Tethered by this year of yearning,
We are learning*

*That though we weren't ready for this,
We have been readied by it.
We steadily vow that no matter
How we are weighed down,
We must always pave a way forward.*

*This hope is our door, our portal.
Even if we never get back to normal,
Someday we can venture beyond it,
To leave the known and take the first steps.
So let us not return to what was normal,
But reach toward what is next.*

Continued on the next page.

CHRISTINE'S CORNER, CONTINUED

*What was cursed, we will cure.
What was plagued, we will prove pure.
Where we tend to argue, we will try to agree,
Those fortunes we forswore, now the future we foresee,
Where we weren't aware, we're now awake;
Those moments we missed
Are now these moments we make,
The moments we meet,
And our hearts, once altogether beaten,
Now all together beat.*

*Come, look up with kindness yet,
For even solace can be sourced from sorrow.
We remember, not just for the sake of yesterday,
But to take on tomorrow.*

*We heed this old spirit,
In a new day's lyric,
In our hearts, we hear it:
For auld lang syne, my dear,
For auld lang syne.
Be bold, sang Time this year,
Be bold, sang Time,
For when you honor yesterday,
Tomorrow ye will find.
Know what we've fought
Need not be forgot nor for none.
It defines us, binds us as one,
Come over, join this day just begun.
For wherever we come together,
We will forever overcome.*

Warmest wishes,
Christine



Scott Kim, Department
Photographer (and
Acting Deputy Chief)

*We love celebrating
birthdays at teatime!*



*The fellows enjoyed
visiting the nation's
smallest national park
at ASBH 2024.*



INTERVIEW WITH SARA HULL (CONTINUED)

During the COVID pandemic, I immersed myself in the work of THRO to help support their efforts to bring important NIH research to Tribal communities more ethically and in a way that would benefit them directly. That was a very meaningful experience for me, in terms of redirecting my service role in a way that was beneficial for the times we were in and for the people most negatively affected.

Q. What are your plans for your retirement?

I am a part-time Special Volunteer with THRO, where I'm very grateful to work on some ongoing initiatives that started during my prior detail: implementing a just-released intramural IRB policy that lays out the requirements when reviewing or conducting research with American Indian and Alaska Native participants; and drafting a new NIH Indigenous Data Sovereignty policy that will apply broadly to all NIH-funded research.

BIOETHICS ADVICE COLUMN

As the Department approaches its 30th anniversary next year, historian Brittany Acors, a postdoctoral fellow, has been conducting oral histories of long-standing Department members. In each interview, she asked what advice they have for aspiring bioethicists. Here is a selection of their answers.

Marion Danis

It's useful to pursue a broad education, to learn how to do careful, critical thinking and careful analysis, because ethics consultation requires very careful analysis of questions. Critical thinking doesn't come automatically. I think I would encourage people who want to be involved in ethics consultation, as a very practical matter, to not just get training in ethics consultation, because it turns out that there are not a huge number of jobs. Having training in some other discipline like law or medicine, psychology, nursing, makes career choices more feasible.

David DeGrazia

Although there can be competing demands on you and it's hard to know what to do to have the chance of having a career, especially a satisfying career, there's no substitute for really good work. Do what you can to do really good work. It tends to be rewarded, not always right away. So further advice is: be persistent if you don't get a good job right away. Be persistent and be patient. I've seen a lot of fantastic people, including some former fellows of this department, who did not get a really good job right away, but who were patient and persistent and ended up with really, really good jobs where they had the support needed to make valuable contributions and also enjoy some job security.

Sara Chandros Hull

Being open to all the advice you can get and networking, even if it doesn't come naturally, is probably the most valuable thing in my career path. And also taking stock: we're in a time where people are asking themselves hard questions about what they're willing to do, what work is meaningful to them... Being willing to course-correct is hard and sometimes economically impossible, but an important thing, especially for a bioethicist whose job it is to think about doing the right thing.

Dave Wendler

My recommendation would be, if you want to get into bioethics... try to get into bioethics from some other route. Try to become expert in something that's related to it. Become a really good philosopher. Become a really good lawyer. Become a really good sociologist. Become a really good historian or something. And then use those skills and bring them to bioethics.

These full oral histories will soon be available via history.nih.gov/collections/oral-histories. If you have stories or materials to contribute to the history of the Department, please contact brittany.acors@nih.gov.



NIH fellows at the Mid-Atlantic Fellows Conference in April, hosted by Penn in Washington

FAREWELL TO THE ASADA RESEARCH TEAM

This summer, the Department is bidding farewell to faculty member Yukiko Asada and her research assistants, Alex Welna, MPH, and Nathan Smith, PhD. We asked each to comment on their time in the department and their next steps.



Yukiko Asada

For professional and personal reasons, I resigned from my dream job at NIH Bioethics at the end of June. Although my time at the NIH is cut short, my experience in the department will stay with me for the rest of my career as a constant source of drive and encouragement. You have shown me the academic life at its best and what it means to be intellectually curious, rigorous, and generous for public goods. I cannot thank you enough. I will be joining McMaster University in Canada next spring, and until then, I will be busy writing papers.

Alex Welna

During my time in the Department of Bioethics, I primarily worked to manage and implement the FairLab study, led by Dr. Yukiko Asada. Our small but mighty team worked creatively and persistently to recruit participants and gather data, and I look forward to continuing analysis and writing for this exciting work. I am now living in London with my partner Emma, and here I hope to continue to sharpen my population health research skills and apply the knowledge I gained at NIH. I am grateful for the mentorship and friendship from all the brilliant and passionate people in this department.

Nathan Smith

It's been a privilege to spend this past year with the Department of Bioethics. The experience has shaped both my thinking and my professional path. I'm grateful for the friendships and insights I'll carry forward as I pursue further postdoctoral studies at Dalhousie University, and I hope to stay connected in the years ahead.

SAVE THE DATE!

FRIDAY, OCTOBER 24, 2025: 6–8PM

The **American Society of Bioethics and Humanities** Annual Meeting is in **Portland, OR** this year.

The NIH Department of Bioethics will be hosting a get-together of current faculty and fellows, former faculty, fellow alumni, and past visiting scholars at **Wayfinder Beer**, where we met last time ASBH was in Portland:

304 SE 2nd Ave, Portland, OR 97214

Stay tuned: we will follow up with a way to RSVP to get a head count closer to the date.

VOLUNTEERING AT THE CHILDREN'S INN

Faculty member Holly Taylor, PhD, coordinated faculty, staff, and fellows of the Department of Bioethics to prepare and serve two dinners this spring for families staying at the NIH Children's Inn.

The Children's Inn provides "A Place Like Home" for young people enrolled in protocols at the Clinical Center and their families.

When children with rare diseases and serious conditions enroll in clinical trials through the NIH, they often have to stay close to the Clinical Center for long periods of time. The Children's Inn offers a home-like setting with apartment-style living for the children and their families. Families who stay there receive not only no-cost housing, but also age-appropriate education, community meals, and recreational activities on NIH grounds and around the D.C. area—all designed to reduce the burden of illness for the children and their families.



On July 1, volunteers served a taco bar and ice cream sundaes to 25 residents.

In another fun weather event, a thunderstorm hit as Holly Taylor, Christine Grady, Ben Berkman, Brittany Acors, Jonathon VandenHomergh, and Shen Pan prepared the meal. It was a busy evening, since many families preferred to stay in for dinner rather than brave the storm. Corn on the cob was the hit of the night!



On March 31, six volunteers from the Department served a pasta bar to Children's Inn families.

Holly Taylor, Dave Wendler, Ben Berkman, Sawyer Lucas-Griffin, Anurima Chattopadhyay, and Shen Pan cooked on a day that the air conditioning went out at the Children's Inn. Although it was very hot, they kept their spirits up and served a delicious meal!



If you would like to volunteer with or donate to the Children's Inn, please visit childrensinn.org.

2023-2025 FELLOW BIOGRAPHIES



Chloe Connor, MS: Chloe Connor holds an MSc in Public Health and a BS in Psychology. At the NIH she worked on a variety of research topics, including: an interview study with clinicians exploring ethical challenges in managing severe and enduring anorexia nervosa, a narrative review on the proposed label “terminal anorexia”, a law review on psychedelics, a law review on artificial womb technology led by former fellow Nina Roesner, a conceptual paper on actuarial fairness led by visiting researcher Anya Prince, a review of covid-19 clinical trials, a review of NIPT in different countries, and a conceptual paper on the ethics of incarcerated firefighting (in the future, Chloe hopes to learn the invaluable skill of narrowing down her research interests). In August Chloe will be beginning Harvard Law School.



Jasmine Gunkel, PhD: Jasmine is transitioning to her role as an Assistant Professor in the Department of Philosophy at Western University. In between buying snow tires and warmer coats, she's continuing her work on intimacy. In addition to her more theoretical work, she has a forthcoming perspective piece on intimacy in medical care in *Annals of Family Medicine*, is working on a paper with fellow fellow Harisan Nasir on intimate information and actuarial fairness, and will be teaching a graduate class entitled “Love, Intimacy, and Interpersonal Relationships.” She's been thinking about “pseudointimacy” with AI and has been working on a number of collaborative projects on the use of AI in medicine. She is also returning to her interest in animal ethics, and has a paper with Frank Miller on xenotransplantation in the July/August issue of the *Hastings Center Report*.



Caroline Morehouse, BASc: Caroline Morehouse graduated from Oberlin College with a BA in neuroscience and Hispanic studies. During her time in the Bioethics Department, she worked on projects related to novel treatments for Alzheimer's disease, research in terminally ill persons, and ethical considerations in student-run free clinics. She is now a first-year student at Harvard Medical School.



Harisan Nasir, PhD: Harisan U. Nasir graduated from Rutgers University, where he completed his PhD in Public Health. During his fellowship, he worked on projects related to the ethics of actuarial fairness in insurance and conceptual issues in health equity. He is currently a Research Assistant Professor at the Centre for Biomedical Ethics, National University of Singapore, where he continues working on ethical issues at the intersection of bioethics, health policy, and health economics.



Emily Peugh, BS: Emily received her BS in Health Science with an emphasis in Community Health Education and a minor in Health Humanities from California State University, Long Beach. At the NIH, she worked on projects related to the use of race, ethnicity, and ancestry in genetic counseling, ethical considerations for approaching BMI in clinical research and GLP-1s in medicine, and the best practices for the ethical conduct of research in collaboration with AI/AN communities. She looks forward to continuing similar work when she starts a PhD program in Health Policy and Management with a concentration in Bioethics at Johns Hopkins University.



Marcos Picchio, PhD: Marcos completed a PhD in philosophy at the University of Wisconsin-Madison (Go Badgers!). While at the NIH, he continued his dissertation research on the ethical issues surrounding the use of randomized controlled trials (RCTs) in public policy and development economics. Over the course of the fellowship, he published two papers: "Policy experiments, informed consent, and democratic authorization" (in *Political Philosophy*) and "What role should equipoise play in experimental development economics?" (in *Economics and Philosophy*). Starting this fall, he'll be an Assistant Professor of Philosophy at Oakland University, where he'll teach classes on bioethics, political philosophy, global justice, and philosophy of international relations.



Robert Torrance, BsC, MBChB, MBE, DrPH: Robert is a medical doctor by training with an MBE in bioethics and a DrPH in Public Health & Policy. His research at the NIH was on the ethics of COVID vaccine donations from high income to lower income countries and the social value of health-related research. He is moving to Auckland to work as a public health medicine physician with the New Zealand College of Public Health Medicine. He will also hold a post as an honorary research associate at the University of Auckland.



Congratulations, fellows!

ALUMNI UPDATES

Bernardo Aguilera (Fellow, '20): Since 2021 I have been working as a full-time professor of bioethics at the Universidad San Sebastián, in Santiago, Chile (my home country). I was head of my local IRB until recently. On a personal note, I live with my wife Javiera and our son Anselmo, who was born right after I completed my Fellowship and is now 4 years old. Fortunately I have been able to stay in touch, and sometimes collaborate, with some members (and former members) of the Department and I hope to visit the NIH at some point in the next few years. I wish all the best to all faculty members and current fellows.

Dena Davis (Visiting Scholar): Dena has three recent publications to share: "Hurdles of trying to avoid low-value care: Two cheers for Choosing Wisely," *BMJ Evidence Based Medicine* (2024), <https://doi.org/10.1136/bmjebm-2024-113283>; "Hasidic Yeshivas and Children's Rights," *The Revealer* (2024), <https://therevealer.org/hasidic-yeshivas-and-childrens-rights/>; and an edited volume, *Religious Perspectives on Reproductive Ethics* (Oxford University Press, 2024).

Nir Eyal (Fellow, '04): Nir's family spent a year in Oxford, UK, and is now preparing to go back to an altered America. Nir is working on many projects but ones in research ethics include a paper on why research ethics is less "personal" or "person-affecting" than it is typically taken to be; and why participation in human challenge trials for very lethal pathogens can benefit participants in prospect, and is hence easy to justify.

Sophie Gibert (Fellow, '18): I just finished my year as a Bersoff Fellow at NYU and have started as an Assistant Prof at Penn. I am loving Philly so far and looking forward to reconnecting with some NIH alums. In that vein, Leah Pierson and I are starting a third season of our bioethics podcast, Bio(un)ethical, and I'm co-hosting a conference on autonomy with Ben Schwan this fall, where Dave Wendler and former visiting scholar Dan Brudney will be speaking! Wishing everyone the best.

Sarah Gollust (Fellow, '03): Sarah Gollust is thrilled to announce that she is now the Editor-in-Chief of the *Journal of Health Politics, Policy and Law (JHPPL)*. She welcomes submissions on bioethics and policy from anyone in this community! She also notes that this is a full circle moment, because in 2001-2003 as a pre-doc fellow she covered JHPPL in the Department of Bioethics journal club.

Sharona Hoffman (Visiting Scholar, Spring '22): I remain a professor of Law and Bioethics at Case Western Reserve University (CWRU). I was recently appointed to the Board of Editors of the *Journal of Law, Medicine, and Ethics*. I was also honored to receive the 2025 CWRU School of Law Faculty Distinguished Service Award. My recent writing focuses on cognitive decline and the law as well as primary care access. I hope all is well with everyone.



Joseph Millum (Fellow, '08): I'm happily settled in Scotland and teaching at the University of St Andrews. I still miss the department though. In 2023, I got married in New York and in Goa (but to the same person!). Over the last two years I've been leading the writing of new World Health Organization guidance on the ethics of health research priority setting, ably assisted by a couple of former fellows. It was just published. (<https://www.who.int/publications/i/item/9789240110953>)



Leah Pierson (Fellow, '18): I recently finished my MD/PhD and started internal medicine residency at Brigham and Women's Hospital. I'm doing bioethics research in my free time, and co-hosting the Bio(un)ethical Podcast with former fellow Sophie Gibert. In May, I also traveled to the UK with the other pre-docs of 2018 (Haley Sullivan, Sophie, and David Miller).

Haley Sullivan (Fellow, '18): In June, I got married to Suellen Li! Lots of Bioethics department affiliates (current and former) were there including David Miller, Robert Steel, Sophie Gibert, Leah Pierson, Kelsey Mumford, and Connor Sullivan (Sophie and Leah were bridesmaids, Connor is my brother). In professional news, I am finishing up the last year of my Health Policy PhD at Harvard, and am going on the job market for academic positions.



Congratulations, alumni!

We are working to ensure that all department alumni are included in our Google Group. Please feel free to share this newsletter with other members of your cohort, and if they are not part of the Google Group, have them contact brittany.acors@nih.gov to be added. Thank you!