The past year has been a very exciting one for the Center for Biomedical Ethics in many ways. Our study of comparative effectiveness research, or Research on Medical Practices – RoMP, as we call it – has been proceeding at breakneck speed. We’ve completed focus groups of IRB members and patients, and we’ve recently completed surveys of patients, the public, and IRB members. The results of this will soon be coming out and hopefully, will inform public policymaking in the area of oversight and regulation of comparative effectiveness research.

In addition, the Center for Integration of Research on Genetics and Ethics is winding down and nearing its end, and continues to publish on a wide range of topics, including a great deal of work in non-invasive pre-natal testing, and other issues in genetics and genomics. Chris Scott continues to actively publish on a wide range of topics in stem cell research and overall, our portfolio continues to be very broad. We are especially proud to report that The Revolutionary Optimists, a film by award-winning filmmakers Maren Grainger-Monsen and Nicole Newnham, has been nominated for a 2014 News and Documentary Emmy Award. The film aired on PBS’s Independent Lens.

Of particular note for this past year, has been the addition of Jacqueline Genovese, who has re-invigorated our Arts, Humanities and Medicine program, which has recently been re-named Medicine and the Muse. Jackie received a Master of Medical Humanities from University of Texas Medical Branch, and has been doing an amazing job helping to build the program. Jackie and Steve Goodman, along with others affiliated with the center, have launched the Stanford Medicine Music Network, to try and create a program that will be an analogue to the very successful medicine and writing programs that we already have in existence.

In addition to Jackie, the center has also welcomed Michelle Mello (see Faculty Profile) from Harvard who further deepens our strengths in areas around medicine, law, and public policy. We are also very happy to be welcoming Danton Char and Alvan Ikoku. Alvan will have a split faculty appointment, primarily in Comparative Literature, and secondarily in Medicine. Alvan’s research and teaching will continue to be in narrative ethics, literature and global health, and medical humanities. Danton Char, who will be a new faculty member in Anesthesiology, is a relative newcomer to the field of bioethics, but is in the process of both learning and publishing in this area, as well as helping us out with teaching. We all believe he has a very bright future ahead of him in bioethics.
State of the Center (continued)

CHANGES
Marsha Michie has gone off to be a faculty member at UCSF. Several of our post-baccalaureate fellows have also left to pursue PhD, MD, or JD programs, including Colleen Berryessa, Emily Liu, and Hywote Taye, who had been the Executive Editor of AJOB. We are pleased to welcome Bela Fishbeyn as the new AJOB Executive Editor, and Tacy Abbott as CIRGE Program Manager. (See People News for all the details.)

RESEARCH
The Center continues to be very successful at publishing in high impact factor journals, including publications in New England Journal of Medicine, PLOS Biology, Nature Biotechnology, Cell Stem Cell, as well as continuing to publish in major bioethics literature, including of course, the American Journal of Bioethics, which continues to have its editorial offices here at the Stanford Center for Biomedical Ethics.

EDUCATION
We continue to have outstanding evaluations for our Responsible Conduct of Research courses, and our undergraduate courses in Thinking Matters, and Human Biology. The team-taught course with Russ Altman on bioengineering ethics continues to have high enrollment and very high satisfaction ratings from the students. Our outstanding team of teaching fellows for our Thinking Matters course returns intact for this upcoming academic year, and we are pleased to have them involved in the life of the center. This year Sandra Lee taught STS1: The Public Life of Science and Technology. Maren Grainger-Monsen meanwhile has been making some specialized short films to assist in educating our medical students. Katrina Karkazis has been continuing our efforts to flip the classroom for our standard medical teaching for first and second year medical students. Course enrollments for one of the required scholarly concentration courses hit an all-time high this past year.

CLINICAL ETHICS
The month of August saw the consult service set a new record for the largest number of consults in a month, at least for the past decade or so, with 19 consults and 12 curbsides. We are still struggling with the loss of Clarence Braddock, and trying as best we can to muddle through without him!

24th Annual Jonathan J. King Lectureship

Discussing Palliative Care Earlier:
A Conversation Between Dr. Kalanithi and Dr. Quill

Timothy E. Quill, MD, FACP, FAAHPM
Georgia and Thomas Gosnell Distinguished Professor in Palliative Care
Professor of Medicine, Psychiatry and Medical Humanities
Palliative Care Division, Department of Medicine
University of Rochester School of Medicine

Tuesday, October 21, 2014, 5:30 pm
Li Ka Shing Center: Berg Hall B&C
Stanford School of Medicine

The Jonathan J. King Lecture is free and open to the public. No reservations necessary. Li Ka Shing Center is located at 291 Campus Drive, Stanford University. See map at http://med.stanford.edu/about/contacts/maps-directions.html.
You have done a lot of research at the intersection of law, medicine, and ethics in health care systems. What do you see as the biggest issues or challenges facing health care?

My work is pretty exclusively focused on a U.S. context, so I’ll speak to that. I think our issues are pretty clearly different from those of lower and middle income countries. For the U.S., we’ve recently done a fair job of grappling with the problem of access, in the sense that we’ve now moved from a situation where forty-four million Americans are uninsured to a situation where most Americans will have some form of insurance.

To my mind, the problem of access has now been eclipsed by the problem we didn’t address in federal health reform, which is cost. I think what we’ve learned from the last round of reform is that Americans are simply not ready to grapple with the cost dilemma in a serious way, meaning that, although our policymakers and our scholars understand that we have to do something to rein in costs, Americans themselves are not willing to give things up yet. As much as we hope and expect that some things will come from the strategies that are politically popular, like eliminating waste in health care, at some level there is going to have to be a reckoning and Americans are going to have to confront a future in which access to expensive services is somewhat more restricted. I think that is a political challenge that we have yet to surmount.

So you see that as the biggest issue.
I do. Our costs are climbing at a totally unsustainable rate and I think most of the measures that we’ve hit upon to bend that curve, bend it only a little bit.

Overwhelming, isn’t it?
It is, and it’s a deep problem. It really goes to the way that medical providers are paid, the incentives that they have from our payment system, from the liability system, from patients, and it really goes to the expectation that we have as patients, which is still that because we all pay so much for health care, we should get everything possible, and the best possible. That’s a vicious circle. We feel entitled because we pay a lot, but we pay a lot because we feel entitled.

You have also done extensive research on research ethics—what are some of the biggest issues that you have tackled?
My work in the area of research ethics has really been focused on understanding the influence that private industry has on biomedical research. Most of my work has looked specifically at the influence of the pharmaceutical industry, trying to understand how that affects the quality of scientific knowledge and medical advice that we get, and how it affects
physicians’ behaviors to have interactions with industry, and then, understanding and accepting that industry has a really important role in conducting research, trying to figure out better strategies for managing our relationships with industry. I don’t believe there can be a future in which industry is not a critical partner in research and medicine, but I do think we are growing in our sensitivity to the need to be aware of and manage that influence.

Has there been any research done on the effects of this advertising? Are people buying this?
Yes, we know that this advertising is successful in increasing requests for branded drugs and increasing prescriptions for branded drugs, leading to rising costs. One of the ways we know that is that companies keep investing in that area. These are very savvy companies, they analyze the returns on their investments, and we see investment in this area continuing to expand.

I wonder if it even creates the notion in some people that they may have a disease they didn’t know about, or that their doctor didn’t know about, or that perhaps they don’t have.
Yes, there have been assertions along those lines, too, that companies have sometimes invented a syndrome. Restless leg syndrome is the one that people talk about. For every one of those, there are probably two or three other situations where a condition is underdiagnosed and there is a plausible argument that these ads actually bring people into the office who otherwise wouldn’t be there, who need treatment.

What are some of the new issues that you hope to address in future projects?
One of the issues I’ve gotten really interested in lately is, how do we make the case for a strong government role in trying to stem the tide of non-communicable disease, like cancer, heart disease, stroke, things that are linked to behavioral risk factors like smoking, overeating, and not exercising? The media has covered the local experimentation that we’ve seen in this area, things like Mayor Bloomberg’s initiatives in New York to put calories on menu boards and to limit the size of sodas you can purchase. There are all kinds of these efforts to try to nudge Americans towards more healthy behaviors. Even the very modest measures have encountered tremendous backlash, so I’m interested in trying to understand the nature of that backlash. What values is it reflecting, who is driving it, is it really a populist sentiment, or is it actually being driven by industrial interests, like the beverage industry? They’ve put a lot of money into...
Faculty Profile (continued)

opposing these kinds of measures. What do we do about it, how do we go about persuading Americans that, because these health problems are so significant, there is a legitimate role for government to play in shifting behavior patterns through law?

We all agree we have a problem, but there is such a strong trope of personal responsibility that surrounds health behaviors, like eating, that it’s very difficult for public health to pierce that and assert itself in a way that Americans find acceptable. We accept a strong public health role in things like infectious disease. We all want very active government efforts to prevent the spread of those diseases, but something about this area seems different. The same is true, to some extent, for accidental injuries, as well. We are less likely to accept helmet laws, seatbelt laws, and things like that, even though the public health problems that they are addressing are much bigger than infectious disease. There is something about it that rubs Americans the wrong way.

It’s our individuality, I think.

Yes, that’s right. We think these are private behaviors in the private sphere. Some of the work that I’m doing now involves public opinion polling to try to understand Americans’ views of this area and how we could advise public health officials on how to communicate with the public about these kinds of laws in a way that will appeal to them.

You have been a proponent of integrating empirical research into your ethical and legal work. How do you see the relationship between empirical and normative or legal analysis?

Empirical work can never answer normative questions. Normative questions are questions about values. But I do think that there are judgments in the moral realm that rest on assumptions about the way the world is, or how things work. That’s where empirical research can really play a role. For example, if we think that adult children should be able to make end-of-life care decisions for parents who are incapacitated, that’s a “should” judgment, but it may rest on an empirical assumption that they understand what their parents would want, and are effective proxy decision makers. Empirical research actually suggests that that’s not right. Most of the time, adult children don’t understand and can’t predict what their parents would want.

I think the role for empirical research in the moral realm is exploring assumptions, and changing or challenging conventional wisdom in ways that might shift the way we turn our values into decisions. In the legal realm, the connection is even tighter, because a lot of legal decisions are based on factual judgments. For example, if you want to adopt a law that regulates advertising, the courts are going to require you to show that your regulation is going to significantly advance the public health goal for which you’ve adopted it. That’s an empirical question. Does regulating food advertising to children lead to reduced consumption of those foods by children? Without a good empirical research base, the courts can make decisions that are wrong, as a matter of law. The legal criteria that they’ve set up rely on empirical facts, and in a lot of areas we don’t have that kind of empirical research we need to make good decisions about law.

One of the other challenges is getting our research to judges and to legislatures. For a variety of reasons, they can have difficulties accessing, both physically and cognitively, the research that we’ve put out. One of the goals of my work is to try to put it in venues that are read by judges and lawmakers, and in a way that can be understood by them.

Do you think there is reluctance or just impediments to understanding?

I think it’s mostly impediments. I don’t think any judges are willfully disregarding evidence, but some of the impediments are very simple. For example, a lot of research is published in journals that are not readily accessible to judges. They are not things judges would think to read, like medical journals, that aren’t freely available online. If you search judicial opinions, you will often see much more citation to articles published in law journals by law professors, than to the original research that these law professors are writing about. There are
disciplinary or cultural barriers, and then there are a lot of
cognitive barriers for judges to understand science and
statistics.

Is there anything else you’d like to talk about?
I guess I’d just say that I’m really excited to be here. I come
from a school of public health, so it’s a change, not just in
university, but in my disciplinary home base. I think what
led me to be willing to abandon a school of public health
setting, where I really felt a lot of identity with its mission,
is that I think there are really exciting opportunities to do
interdisciplinary work here at Stanford, in ways that were
harder in my old setting. I really feel like I’ve got the
best of both worlds coming here to a world-class law
school where most of their recent hires have been people
who are not just lawyers but also have a PhD in another
discipline, so they approach the world as social scientists,
as I do. I also have access to world-class health policy
researchers, who I hope will keep me grounded in that
side of things. I think it’s going to be a wonderful fit for
my work and will open up a lot of new collaborations
and opportunities for growth.

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**Faculty Profile (continued)**

**New SCBE Faculty**

Michelle Mello is Professor of Law at Stanford Law School and Professor of Health Research and Policy at Stanford
University School of Medicine. She conducts empirical research into issues at the intersection of law, ethics, and health policy.
She is the author of more than 130 articles and book chapters on the medical malpractice system, medical errors and patient
safety, research ethics, the obesity epidemic, pharmaceuticals, clinical ethics, and other topics. Among other current projects,
Dr. Mello is studying disclosure and compensation of medical injuries as the recipient of a Robert Wood Johnson Foundation
(RWJF) Investigator Award in Health Policy Research.

From 2000 to 2014, Dr. Mello was a professor at the Harvard School of Public Health, where she directed the School’s Program
in Law and Public Health. In 2013-14 she completed a Lab Fellowship at Harvard University’s Edmond J. Safra Center for
Ethics. She currently serves as a Key Consultant to the National Program Office of the Robert Wood Johnson Foundation’s
Public Health Law Research Program.

Dr. Mello teaches in the areas of public health law and public health ethics. She holds a J.D. from the Yale Law School, a Ph.D.
in Health Policy and Administration from the University of North Carolina at Chapel Hill, an M.Phil. from Oxford University,
where she was a Marshall Scholar, and a B.A. from Stanford University. In 2013, she was elected to the Institute of Medicine.

Danton Char received his undergraduate degree in History from Harvard College and his Doctor of Medicine from the
University of California, San Francisco. He completed residency (anesthesia) and his first fellowship (pediatric anesthesiology) at
UCSF before pursuing additional specialization with a second fellowship (pediatric cardiac anesthesia) at Stanford University.
Since joining the faculty at Stanford, he obtained a Master's in Clinical Research at UCSF. His research has focused both on
perioperative outcomes in children with congenital cardiac disease and now, increasingly, on the ethical issues arising in the
care of these children, particularly issues arising with the use of extracorporeal cardiac support devices and issues arising with
the implementation of genetics and genomics to the clinical care of critically ill children.

Alvan Ikoku researches and teaches in literature and medicine, with specific focus on African and African diasporic
literatures, twentieth-century fiction, narrative ethics, and histories of tropical medicine and global health. He has written for
the World Health Organization, *Narrative Inquiry in Bioethics*, and *Virtual Mentor*, the ethics journal of the American Medical
Association. He has received president’s teaching awards at Columbia and Harvard Universities. And his research has been
supported by the Mellon Foundation, the American Council of Learned Societies, and the Rhodes Trust.

Ikoku's research is primarily concerned with literary, medical and bioethics discourses that take Africa and its diasporas as
points of representation. His writing has situated these discourses within post-nineteenth-century movements in world literature
and world health. And his current book project, *Forms of Global Health*, studies the place of the novel in the evolution of global
health as a medical specialty. Ikoku received his MD from Harvard and PhD in comparative literature from Columbia. Prior
to joining the faculty in 2014, he was an Andrew W. Mellon Fellow in the Humanities at the Stanford Humanities Center.
People News

Tacy Abbott is CIRGE’s new Program Manager. She joined Stanford in May 2012 as Administrative Associate for the Division of Medical Genetics and the MS program in Human Genetics and Genetic Counseling, and is very excited about also supporting CIRGE activities. Tacy has a BA in Sociology from UC Santa Cruz.

Colleen Berryessa, former CIRGE Program Manager, has moved to Philadelphia to begin a PhD program at UPenn to fulfill a lifetime goal of becoming a criminologist.

Emily Borgelt, was Project Manager of a NHGRI-funded R01 grant titled "Social Networking and Personal Genomics: Emerging Issues for Health Research,” and also worked on projects related to stem cell ethics and education. She will be applying for graduate school in the coming year, while spending the interim as a bakery entrepreneur.

Bela Fishbeyn, is welcomed as the Executive Editor of the American Journal of Bioethics, and Coordinator for SCBE’s Benchside Ethics Consultation Service. Bela studied bioethics at Columbia University in the inaugural class of the school’s MS Bioethics program. After completing her coursework, she was awarded a Fulbright Research Grant to Russia to work on her thesis. While in Russia, she investigated how the conceptual framework and moral attitudes behind Russian physicians’ understanding of addiction might influence the design of addiction related health policy. She also holds bachelor’s degrees in philosophy and photography, each with highest honors, from UNC-Chapel Hill. To complete these degrees, she conducted research for and wrote theses on both the influence of pornography on moral judgment and the structure of Jewish-Muslim relations in Russia.

Hayden Harvey, who has been a post-baccalaureate fellow at CIRGE since May 2012, will be taking a year off before applying to law school and spending the interim doing public interest work in Seattle, Washington.

Emily Liu, former post-baccalaureate fellow at CIRGE since August 2012, is beginning her MD at Stanford School of Medicine.

Marsha Michie, former post-doctoral fellow at CIRGE, has taken a new position as Assistant Professor in the Department of Social and Behavioral Sciences at the University of California, San Francisco. She will be supported on her NIH Pathway to Independence Award, which she obtained two years ago to pursue fellowship training at CIRGE, as part of a 5-year career development award from NHGRI. The final three years of funding from this award will support her research at UCSF as an independent investigator.

Hywote Taye, former Executive Editor of AJOB and Coordinator of SCBE’s Benchside Ethics Consultation Service since 2012, is beginning her J.D. at Harvard Law School.

Isabelle Wijangco, recently Project Manager for an NIH-funded grant studying attitudes about the ethics of research on medical practice, focuses on global health policy and women’s empowerment. After graduating from Stanford in 2012 with a B.A. in Human Biology, she was a Stanford Ford Fellow in Philanthropy at the United Nations Foundation in New York. There, she worked with the Every Women Every Child movement to launch a project demonstrating the multidimensional returns on investment in family planning. She also helped facilitate Global Health and Global South engagement in Post-2015, an unprecedented UN process to decide the next generation's international development priorities following the expiration of the Millennium Development Goals. Before then, she researched political determinants of health foreign aid at the Stanford Freeman Spogli Institute and worked on global health operations at the Office of the Surgeon General. She is currently beginning a pre-medical post-baccalaureate program at Mills College, as she hopes to combine a career in global women's health policy and medicine.
Recent Publications

Mildred Cho

Henry Greely

Katrina Karkazis
Jordan-Young, R. M., Sonksen, P. H., & Karkazis, K. (2014). Sex, health, and athletes. *BMJ, 348*, g2926. doi: 10.1136/bmj.g2926

Sandra Lee
Recent Publications (continued)

David Magnus

Nate Olson

Kelly Ormond

Christopher Scott

Audrey Shafer

Stanford Bioethics
Vol. 10 No. 1: Fall 2014
**Keynote Speaker: Perri Klass, MD**

Professor of Pediatrics and Journalism, New York University; Director, Carter Journalism Institute; Medical Director, Reach Out and Read; author of fiction and nonfiction, essayist for The New York Times, The Washington Post, Boston Globe and Discover Magazine. She is the recipient of five O. Henry Awards for short fiction and the Women’s National Book Association Award.

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**SCBE Upcoming Events**

**September 18, October 9, October 23, November 6, November 20, 2014**
7:00 – 9:30 pm
First Tuesday Evening Writing Workshop Series
Facilitated by Elyce Melmon
SCBE Conference Room (62)
1215 Welch Road, Modular A

**November 8, 2014, 8:45 am – 4:00 pm**
Saturday All Day Writing Workshop
Facilitated by Dr. Sharon Bray
Home of Dr. Audrey Shafer

**January 20, 2015, 12:00 – 1:00 pm**
CIRGE Journal Club
Speaker: Henry Greely, JD
SCBE Conference Room (62)
1215 Welch Road, Modular A

**April 16, 2015, 5:30 – 7:30 pm**
Medicine and the Muse: An Arts, Humanities and Medicine Symposium
Speaker: Perri Klass, MD
Li Ka Shing Center: Berg Hall
Stanford School of Medicine

**October 21, 2014, 5:30 – 6:30 pm**
24th Annual Jonathan J. King Lecture
Timothy E. Quill, MD, FACP, FAAHPM
Discussing Palliative Care Earlier: A Conversation Between Dr. Kalanithi and Dr. Quill
Li Ka Shing Center: Berg Hall B&C
Stanford School of Medicine

**October 28, 2014, 12:00 – 1:00 pm**
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