



## Newborn Screening: Ethical and Policy Challenges

by Leonard M. Fleck, Ph.D.

In the late 1960s the United States and other countries began to do “universal newborn screening,” primarily as a result of the work of Dr. Robert Guthrie, a microbiologist. The term “universal” denotes that *every* newborn infant was screened by taking a small sample of blood. Infants were screened for rare metabolic disorders that if treated immediately avoided devastating health consequences (an early death or profound neurological disabilities), e.g. phenylketonuria (PKU). PKU is an autosomal recessive inborn error of metabolism with an approximate incidence of one case in 15,000 births. Infants with this disorder are unable to process phenylalanine, which leads to severe mental retardation, seizures, and other neurological problems all of which can be avoided with the introduction of a very special diet shortly after birth. This is the beginning of the ethical and policy issues we address in this essay.

In the US several hundred infants are born each year vulnerable to PKU. We emphasize that the dietary intervention designed to address PKU is completely effective in preventing otherwise devastating consequences. It is difficult to imagine any caring rational parent refusing the “heel stick” that takes the few drops of blood needed to do this screening. Consequently, informed consent has not been part of doing this blood draw. Parents are often (not always) told why blood is being drawn, but they are not asked to give permission. From the perspective of public health authorities this seems reasonable since there are no risks to the child from the blood draw and this intervention clearly protects the best interests of each potentially ill child.

Over the next several decades a small number of other screening tests were added as medical research identified more of these metabolic disorders that were

rare and that needed prompt medical intervention to prevent otherwise devastating health consequences. Initially, cost was an issue since each test for each disorder was distinct, but in the 1980s a new technology was introduced, tandem mass spectrometry, which permitted doing dozens of these tests all at once. This technology was widely disseminated by the turn of the century. In just a few years after that the number of conditions for which we screened jumped from ten to fifty. Those inherited conditions now included endocrine, hematologic, and expanded metabolic disorders.

From an ethical perspective making newborn screening *mandatory* for PKU was clearly morally defensible because of both the certainty of the disastrous medical consequences and the availability of an effective therapeutic response. However, for some number of the newborn screening tests that have been added to the panel over the past several decades we have neither the certainty of the disastrous medical consequences nor the assuredness that an effective therapeutic response was available and affordable. We have discovered of late that (as with many medical disorders that are genetically linked) there are degrees of expression, both in terms of a span of time and degrees of seriousness. Hence, an infant might test positive for one of these disorders, but then the disorder might not actually manifest itself *for this infant* until the third, fifth or sixth decade of life (or never). If the relevant therapeutic intervention were very cheap and very safe (no matter what the actual disease expression might prove to be), then we could in good conscience provide the therapy no matter what. However, some of these *therapies* will themselves prove deadly for infants that are not imminently vulnerable to some specific disorder.

Another large problem is the false

positives connected to the screening process. Approximately 4,000 infants each year in the US are identified correctly as being afflicted with one or another of these very rare disorders. However, approximately 12,000 false-positive results are obtained as well. Correcting this error may take anywhere from several weeks to several months. This can cause considerable anxiety in the minds of parents. It’s tempting to treat this outcome somewhat casually; perhaps thinking that a little anxiety is a small price to pay to save 4,000 infants. But the anxiety is not a trivial matter. Parents in these circumstances are faced with the immediate decision of whether or not to start some treatment needed to save the life of the infant or to prevent irreversible neurologic damage when it might turn out that the treatment itself could be harmful if their infant is not a true positive.

Should our conclusion be that we should require explicit informed consent from parents for these tests? This would be extraordinarily time-consuming (and this not morally trivial when you consider how limited professional time is for caregiving). If we put that concern aside for the moment, are there other moral costs associated with seeking explicit informed consent for newborn screening? The short answer is that many parents who were just somewhat risk-averse might say, “There is only a very remote chance that our baby would have any of these disorders. Why risk the anxiety of a false positive result? Skip doing the newborn

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screening.” Let us suppose that no more than 1% of parents reacted this way. That represents 40,000 unscreened infants, which would mean (statistically) that about 40 infants with one or another of these disorders would slip through and suffer the negative health consequences. Should we accept that as part of the social cost of respecting the right of parents to make informed choices or informed refusals regarding newborn screening? Or should screening remain mandatory on the grounds that this is in the best interest of these infants?

The other large issues we need to address are ethical and policy concerns around the *use and storage* of these blood spots after screening. After the heel stick, five drops of blood are deposited on “Guthrie cards” for analysis. Only a tiny punch from one of these spots is needed to do this analysis. The extra spots are available in case additional analysis is required in the following weeks or months. Some states permit the destruction of these cards after a few months because their original purpose had been met. Other states preserve these cards for various periods of time ranging from less than a year (30 state programs) to more than twenty years.

Research done on these stored blood spots in the latter third of the twentieth century focused on quality control regarding newborn screening, the development of new and better assays, and some epidemiologic studies. This kind of research raises virtually no concerns regarding either violation of individual rights or threats to public interests. However, those blood spots contain the DNA of individuals, and in the era of genetic medicine, some risk exists regarding the privacy rights of individuals and their families. This risk might be reduced to nearly zero if the blood spots themselves were completely and permanently anonymized; however, this greatly reduces the value of the blood spots for a broad range of medical research.

Moreover, in some circumstances the future welfare of some individuals could be compromised. Imagine this scenario: In the course of doing cancer genetics research with these blood spots it might be discovered that individuals with a very

specific genotype were much more vulnerable to some specific cancer later in life than others with a different version of that genotype. Further, specific health measures could be taken to prevent the actual expression of that genotype so long as that cancer had not become clinically manifest. Those individuals could not be contacted if those blood spot had been completely and permanently anonymized.

We described a situation in which an early and effective intervention was available if one were the bearer of a specific cancer-prone genotype. We believe that the vast majority of individuals who might be vulnerable in that way would want to know this genetic fact about themselves so that they could take advantage of that intervention. But what if the only available preventive intervention had a 50-50 chance of making a difference, or worse, a 30-70 chance of making a positive difference? In this latter scenario embracing this information is not the only reasonable response.

We need a policy response sensitive to the rights and interests at stake. If we believe it is of utmost importance that we be sensitive to the privacy rights and autonomy rights of individuals, then we might say that individuals (or parents) should always be given the opportunity for informed consent or informed refusal for the use of their blood spot for any kind of medical scientific research. After all, this is (for good reason) the required practice for medical research generally. However, one reason why this practice is not seen as being especially onerous is that the patients involved in research are “right there” to discuss the research and its potential risks and benefits for them. In the case of research with the stored blood spots the “patients” who were the original source of those blood spots could be literally anywhere in the world, especially if ten or more years have elapsed since the spots were first collected. It could take an enormous amount of labor and economic cost to track down those individuals, so much so, that it might deter researchers from using this data. This would represent the loss of some quantity of potentially valuable medical research. So choices about alternative de-identification processes may raise questions about the extent

to which the state is or is not obligated to turn research intended for population-level health toward individual health benefit in addition to questions about the preference of research participants.

The basic moral and political argument that supports the view of many researchers is that the blood spots are anonymous and that their work presents no risks to individuals as such. This rationale has been persuasive to a large majority of state legislatures that have explicitly addressed the issue of research uses of these stored blood spots. But half of the states have not addressed these research options at all. About 19 states address in legislation the conditions under which medical research may be done with these stored blood spots (if they are de-identified). If the research does require linkage back to identifiable

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The Medical Humanities Report is published three times a year by the Center for Ethics and Humanities in the Life Sciences (CEHLS) at Michigan State University. The Center is an academic unit whose faculty teach in the medical, nursing, and veterinary colleges, as well as in Arts and Letters and Social Sciences.

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# The Ethics of Nudge in Health Care Decision Making

by Margaret Holmes-Rovner, Ph.D.

Informed patient choice is a cornerstone of bioethics and is increasingly assumed to be part of American health-care, finding a home in most proposals for healthcare reform. Reformers who hope for patient choice to “rationalize” health care assume several things. First, that people will act to maximize their chances of a good outcome. Second, that if patients understand the consequences of each intervention (or no intervention), they will act to pursue their own best choice. And third, that providers may pursue their economic best interest, but that informed consumers will act to counter-balance provider-driven over-utilization. Finally, this approach assumes that people are fundamentally rational, and that, therefore, implementing evidence-based medicine at the point of care can simultaneously reduce over-utilization, and increase patient satisfaction with care and communication. Behavioral economists, popularized by Thaler and Sunstein in their book *Nudge*<sup>1</sup>, show that these assumptions are flawed. They demonstrate that people’s decision making behavior is influenced by inertia and emotion, as well as rational choice. While doctors and patients in clinical encounters rarely explicitly address the price of medical services, I want to suggest that the principles Thaler and Sunstein outline should be applied to individual clinical decisions, and that biases introduced by inertia and emotion need to be corrected in the framing of clinical decisions. These suggestions go beyond the well-established psychological biases and heuristics established by decision psychologists.<sup>2</sup>

Strategies that are suggested by *Nudge* provide structure to information that makes it clear where the decision-maker’s behavior will lead. In addition, in social programs, where the individual’s best interest (the care that is most likely to increase life and quality of life) coincides with the society’s best interests in decreasing health care cost. The cheapest choice should become the default option, with latitude for the patient with the doctor’s advice and

consent to change the default if s/he wishes. As mentioned, there are at least two important forces that drive decision-makers away from the optimal rational decision, inertia and emotion. In health care, these forces produce several well-established inclinations among most patients. Rather than inertia in the usual sense of maintaining the status quo of doing nothing, most patients have well established treatment-seeking habits, regardless of the chance of a good outcome. Most Americans believe that American health care is the best in the world, and that technology produces cures for most diseases. Both the urge to “do something” and our ideology produces a procedure/treatment bias that is expensive and often produces untoward outcomes. I suggest that it is appropriate to aim to correct this bias, and influence patients to try cheaper alternatives, in non-emergent problems, before proceeding to more expensive ones. Making the cheaper (usually less interventionist) option the default, with the understanding that it can be changed if necessary, requires reframing many clinical choices, and adopting healthcare delivery procedures that present the default repeatedly along the continuum of care.

Is it ethical to bring the resource question to bear at the individual level? The objective in clinical bioethics is to guide clinicians to avoid two kinds of errors: 1) withholding potentially beneficial tests and therapies that the patient would want, and 2) imposing interventions that are not beneficial or not wanted.<sup>3</sup> The “resource problem” is often considered inappropriate in doctor/patient discussions of treatment options under this approach. However, the emphasis on “allowing” the competent, informed patient to refuse medical intervention reflects the present biomedical default option, “if in doubt, do everything possible.” In an era of more diagnostic and therapeutic technologies that add little benefit, this cultural bias no longer serves us well. One step toward a compromise that supports patient/clinician shared decision

making and clinical judgment, but moves away from modern excesses, is to make the frugal choice the default. Two classes of choices may present opportunities to introduce a frugal default: 1) those where tests and treatments do not produce improvement in morbidity and mortality (over-utilized interventions), and 2) the “toss-up problem.” Toss-ups are those problems where length of life is essentially the same, with any of the available options, but quality of life and side effects may vary. The latter is a problem that represents what has traditionally been argued to be the very essence of a situation requiring shared decision-making, with no constraints, in a completely balanced fashion. If clinical equipoise is established, then patients’ values for the outcomes and the side effects should be the driving force in clinical decision-making. I argue that this is only true if resource use is ignored. While arguing against open choice in toss-ups is more difficult than in over-utilized interventions, they may ethically be similar with a “nudge” solution. The differences between the two need not be dissimilar if the choices are framed with a frugal default option that can be over-ruled after a discussion of options.

An example of a toss-up problem is treatment of early stage prostate cancer. Here, watchful waiting, surgery, and radiation therapy produce the same length of life, with varying side effects, both physical and emotional.<sup>4,5</sup> Examples of over-utilized interventions include antibiotics for viral infections, and breast cancer screening with mammography for women under age 50. Percutaneous coronary intervention (PCI) vs. medical therapy for stable angina (stable coronary artery disease/stable CAD) is not a problem that is commonly thought to be a toss-up problem. It is well established, however, that length of life is not extended by PCI over medical therapy for stable CAD.<sup>6,7</sup> The benefit of PCI over medical therapy is that angina is improved over the first one-two years following the procedure. At three years, there

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## Perspectives on: Issues and Politics in Patient Privacy

In the last issue of MHR, John Hazewinkel, M.P.A., J.D. wrote about the benefits of using electronic medical records. The contributors to this InkLinks continue this discussion. InkLinks is a regular column in which readers reflect on issues related to the previous lead article. It is meant to tap the rich intellectual resources that this network provides. We welcome your contribution at [altimare@msu.edu](mailto:altimare@msu.edu).

### Many Challenges Remain: EMRs

John Hazewinkel's article is right to point out the many benefits of collecting, storing, and disseminating medical information by electronic means. He's also right to reject any false choice between protecting patient confidentiality, and implementing EMRs and other electronic health information systems. The real challenge is how to do both.

First, there are cultural dimensions of people's use and perception of electronic information media that are relevant to both invasions of privacy, and public reactions to those invasions. For example, some may feel it is socially less risky, and hence more tempting, to access electronic information. To invade someone's paper record requires in-person interaction with a medical records department, or a nursing station, with the attendant risk of being caught *in flagrante delicto*. An EMR can be invaded from the apparent seclusion of a computer monitor, perhaps located off site. The resulting perception of anonymity might of course be an illusion, but the chances of getting caught may still be small in a system with many thousands of electronic record accesses a day. The result can be a sense of greater impunity regarding unauthorized access.

It's also important to recognize that the moral consequences of breaches of confidentiality are as much a matter of perception as of fact. Breaches of confidentiality are morally problematic for two reasons. One is the violation of the individual right to privacy. But the other is the risk that such breaches will undermine patient trust in the confidentiality of their health information, with the result that they are less willing to share medically important facts about themselves. This leads to less accurate medical diagnosis and less effective, even dangerous treatment. The loss of trust, with its attendant consequences, is a function of the public's perception of vulnerability. The pervasiveness of the Web and the increasing availability of informa-

tion about others creates the impression that just about any information is available for those who know how to look, or are willing to pay. (Want to learn all about my criminal past? Pay \$59.95 at People Search Now.)

Widely publicized health information security breaches—even if they remain rare—feed a generalized anxiety about electronic privacy, an anxiety that now concerns electronic health information as well.

Another challenge is political—the fragmented US health care system. It is not surprising that EMRs and electronic prescribing are much more common in European countries than in the US. In 2001, only 17% of American primary care physicians used an EMR, compared with 59% in the U.K. (Harris Interactive). One reason, of course, is that in a single-payer system, a mandate to use EMRs can have teeth. But there's another reason more directly relevant to protection of privacy. In our system, there are many thousands of hospitals, clinics, practices, insurers, regulators, researchers, etc. operating across fifty different states, largely independent of one another. Significant variation exists in the confidentiality policies and practices governing their use of electronic medical information. These differences stem from both relevant state laws and Federal law like HIPAA, which leaves much to the discretion of individual health systems to determine what information can be shared and with whom. Increasingly, electronic information is crossing these institutional boundaries. As it does so, it will become imperative to harmonize policies so that patients can be assured that the terms on which they provided information about themselves and authorized its dissemination will be honored no matter where that information travels.

Part of the difficulty will be ethical. Balances will need to be struck between the deference owed patients' rights to control information about themselves,

and other values, goals and needs—including calls for health care research, improvement in the delivery of health care services, administration of reimbursement systems, marketing of health care services, and the patient's own medical best interests. By and large, these balances have been struck in private, behind institutional walls. Maintaining public trust in an electronic health information system may require increasing public participation in these choices.

These are just some of many challenges we will need to meet to enjoy the benefits of electronic health information systems while maintaining the respect for individual privacy that is integral to effective and sensitive health care practice.

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For references:  
<http://bioethics.msu.edu/mhr/contents.html>

### EMRs and the U.S. Health Care Industry

John Hazewinkel's fall 2008 Medical Humanities Report essay on patients' privacy warns against mistakenly viewing medical privacy and development of advanced, linked electronic medical records as "a utilitarian battle between greater goods and individual rights." The issues, in his view, have more to do with the culture of the health-care industry than with personal liberty. Government (he referred to the U.S. Government, but state governments are involved deeply too), he wrote, can't "fully address" information technology and privacy debates unless technological promise and the nature and complexities of information relationships among patients, providers, and payers are understood. He recognized that the emerging technology makes possible what I would term huge economies of scale in security violation. But he concluded that such violations likely would be few and that

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individuals, then the uniform requirement is that explicit informed consent must be obtained from individuals or their guardians.

We might imagine that a reasonable and relatively easy resolution to the ethical and policy issues associated with research uses of these dried blood spots would be to solicit informed consent from parents for de-identified uses of the stored blood spots. But there are two problems with this apparently easy resolution. First, in the case of Michigan and comparable states that have stored these blood spots for ten or more years, getting consent from the current crop of parents of newborns does nothing to legitimate the use of the blood spots that have been stored for all these years. Second, even for the current crop of parents of newborns we would have great difficulty justifiably speaking of “informed” consent being obtained. What precisely could those parents be *informed* about? No one would have a clue as to what future medical research projects might be proposed in connection with those blood spots. Nor could anyone say what the risks and benefits might be of those future possible research projects, either for the population at large or any sub-type of the population of patients. Nor could anyone say whether any of this future possible research might be offensive to the core values of any religious or cultural or ethnic group. So it seems disingenuous to refer to such a process as seeking *informed* consent.

In conclusion, I will leave the reader with this challenge. How should we resolve the ethical and policy challenges posed by these stored blood spots? Should we rely upon some group of medical scientific researchers to identify a reasonable policy? Or state legislators or bureaucrats? Or a broad process of rational democratic deliberation that would engage a suitably representative cross-section of citizens/future possible patients who would seek to strike a reasonable balance with regard to risks and benefits of such future research?

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is no difference in quality-of-life (symptoms) in similar patients randomized to medical therapy vs. PCI.

It seems reasonable, in this case, to present the benefits and harms of each

therapy, and to recommend a trial of medical therapy, before proceeding to coronary angiography and a PCI/stent. The diagnosis of stable CAD is mostly made on history and physical examination, allowing diagnostic testing, theoretically, to be kept at a minimum. This approach is likely to be counter intuitive to most patients and physicians, and is likely to produce fears that defensive medicine is needed in case the patient has a heart attack. However, it is also quite possible that here, as in physician admission of errors with patients, a frank and thorough discussion will be highly valued by patients, and that litigation will actually decrease.

Establishing an environment in which the least interventionist option is the default will require new approaches to informing patients, to physician guideline development, and to on-going quality improvement. Such approaches may serve both health care reform and strengthen the doctor-patient relationship. Does this approach smack of persuasion? Yes. But we have a moral duty to balance the ethos of unrestrained freedom of choice with a consistent ability to evaluate how much life and health can be gained by each incremental intervention. Health care is not a free good. Where there is nothing to be gained, treatment is futile, in a general sense. Our health care system should adopt an approach that lays out the case for the frugal alternative, being completely candid about the trade-offs involved, and with the option to over-ride the frugal default. Can providers game such a system? No doubt, since this approach supports the importance of clinical judgment. To make the system work will require transparency about the capabilities and limits of medical interventions.

Thaler and Sunstein have an acronym that suggests how they would restructure informing in healthcare (as well as finance and welfare). RECAP stands for recording, evaluating, comparing alternative prices. While monetary price is not yet a part of clinical encounters, price in terms of harms and benefits of interventions (including no intervention) constitute the immediate health price of each decision. Systematically evaluating likely outcomes, based on the evidence about the technology applied to people, is feasible in the many cases known to generate over-utilization, or to be a toss-up. In those

cases, little may be gained by intervention. In this increasingly important context, it is important to rethink the ethics of decision-making and informed choice. The standard approach of allowing competent, informed patients to refuse medical intervention is rooted in the old paradigm that assumes that doctors are the decision-makers unless over-ruled, and that doctors only recommend interventions that improve the health of the patient. An era of shared decision making and frequent over-utilization calls for a new approach.

For references and notes: <http://bioethics.msu.edu/mhr/contents.html>

## Study Abroad Opportunity

### Costa Rica

Michigan State University will offer an eight week study abroad program, “Ethics and History of Development and Health Care in Costa Rica” this summer, May 31 (Date Tentative). The 11-credit program includes one integrated course co-taught (in English) by Fred Gifford, Dept. of Philosophy at MSU, and Patricia Fumero, from the University of Costa Rica, and also 4 credits of Spanish language instruction. Students are housed with Spanish-speaking Costa Rican families within walking distance of our classrooms. Field trips include visits to a variety of health care settings, including clinics in rural and poor areas and various regional and national hospitals; students also travel to national parks and eco-tourism sites to explore environmental issues. For further information, contact Fred Gifford: [gifford@msu.edu](mailto:gifford@msu.edu) or see <http://studyabroad.msu.edu/programs/costaethics.html>.

### Student Testimonials on Costa Rica

This study abroad was one of the most mind-opening and fun experiences I’ve ever had. Dr. Gifford’s history and bioethics class began by giving students the tools and information to observe and critically analyze the Costa Rican health care system. Our assignments included reading a collection of carefully chosen and enlightening pieces by authors from all over the

# News & Announcements

## JUDY ANDRE

### Publications

- “Disease” in the *Encyclopedia of Environmental Ethics and Philosophy*, MacMillan, (November 2008).

### Presentations

- “Methodology in Bioethics,” for the 9th World Congress of Bioethics, Invited panel member, Rijeka, Croatia (September 2008).
- Colloquium on Virtue and the Self, at the Institute for Biomedical Law and Ethics, Ewha Women’s University, Seoul, South Korea (September 2008).

## LIBBY BOGDAN-LOVIS

### Publications

- DeVries, R., L. K. Low and E. A. Bogdan-Lovis. Choosing Surgical Birth: Desire and the Nature of Bioethical Advice. In *Naturalized Bioethics: Toward Responsible Knowing and Practice*, edited by H. Lindemann, M. Verkerk, and M. Walker, Cambridge University Press, Cambridge UK.

### Presentations

- “Pushed and Pulled: Intergenerational Perspectives on Child-birth Choice” at the Midwives Alliance of North America Annual Meeting, Traverse City, Michigan (October 2008).
- “Evidence-based Medicine Through the Looking Glass” Invited plenary session at the University of Toronto Critical Debates in Evidence-based Medicine: Where We’ve Been and Where We’re Going Workshop, cosponsored by the University of Toronto, Joint Centre for Bioethics, University of Toronto Institute for the History and Philosophy of Science and Technology, Canadian Institutes of Health Research, Situating Science: Cluster for the Humanist and Social Studies of Science, Toronto, CA (November 2008).

### Consultations

- As a member of the Cochrane Developing Country Network Advisory Board, participated in the session “Tapping Global Funding Agencies” at the 2008 Cochrane Colloquium, Evidence in the Era of Globalization, Freiburg, Germany (October 2008).
- In collaboration with the Michigan

Department of Community Health, conducted Neonatal Bloodspot Biotrust Community Engagement Dialogues: September 11 Marquette, MI; September 12, Munising, MI; December 17, Grand Rapids, MI.

## LEONARD FLECK

### Presentations

- “Reviewing the New Face of an Old Dilemma: Proposition 2 on Michigan’s Nov. 4 Ballot” at Michigan State University Club, Club Colloquy Lunch Program, East Lansing, MI (December 2008)
- “Just Caring: Health Reform and Health Care Rationing: Can these be Done Fairly?” for the Medical Humanities Symposium: Bridging Health Care and Human Experience, Drew University, Madison, New Jersey (November 2008)
- “Shades of Gray: Ethical Issues in the Care of Incompetent Elderly Patients.” for Lansing Community College Fall Gerontology Seminar Series, Lansing, MI (November 2008)
- “Researcher/Physicians: Moral Oxymoron or Moral Ideal?” and “Community Consultation and Medical Research: Slick Sell or Serious Engagement?” for Fall 2008 MSU IRB Conference, East Lansing, MI (November 2008)

## LINDA HUNT

### Presentations

- “Race, Genes and Personalized Medicine: Shortcut or Detour.” Paper presented on the Presidential Invited Session: Rethinking Race: Biology, Genes and Culture. Annual Meeting of the American Anthropological Association. San Francisco, CA (November 2008).
- “Issues in Health Care for Latinos of Greater Lansing.” Key note Address, Annual Meeting of the Latino Midwest Medical Students Association. Bath, MI (November 2008).

### Appointments

Full Professor, Michigan State University, Department of Anthropology, East Lansing, MI (2008).

## MARGARET HOLMES-ROVNER

### Publications

- Whitney S.N., Holmes-Rovner M., Brody H., Schneider C., McCullough L.B., Volk R.J., McGuire A.L. “Beyond Shared Decision Making: An Expanded Typology of Medical Decisions.” *Medical Decision Making*, 2008 Sept-Oct; 28 (5):699-705.
- Holtrop J.S., Stommel M., Corser W., Holmes-Rovner M. “Predictors of Smoking Cessation and Relapse after Hospitalization for Acute Coronary Syndrome.” Forthcoming. *Journal of Hospital Medicine*.
- Elwyn G., O’Connor A.M., Bennett C., Newcombe R.G., Durand M., Drake E., Joseph N., Khangura S., Politi M., Saarimaki A., Sivell S., Stiel M., Bernstein S.J., Col N., Coulter A., Eden K., Harter M., Holmes-Rovner M., Mounjid N., Perez L., Stacey D., Thomson R., Whelan, Wiejden T., Edwards A.

“Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards Instrument (IPDASI).” Forthcoming, *PLoS Medicine*.

### Presentations

- Elwyn G., O’Connor A., Bennet C., Newcombe R., Durand A., Drake E., Joseph N., Khangura S., Politi M., Saramaaki A., Sivell S., Stiel M., Bernstein S., Col N., Coulter A., Eden K., Härter M., Holmes-Rovner M., Mounjid N., Stacey D., Thomson R., Whelan T., van der Weijden T., Edwards A. “Assessing the Quality of Decision Support Technologies Using the International Patient Decision Aid Standards Instrument (IPDASI).” Presented at the Society for Medical Decision Making, Philadelphia, PA (October 2008).
- Dwamena F., Mavis B., Walsh K., Loyson A., Holmes-Rovner M. “Teaching Medical Interviewing to Patients.” Presented at the European Association for Communication in Health Care (EACH), Oslo, Norway (September 2008).
- Dwamena F., Gauden C., Olomu A., Lewin S., Smith R., Holmes-Rovner M. et al. “A Systematic Review of Interventions for Providers to Promote a

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Patient-Centered Approach.” Presented at the European Association for Communication in Health Care (EACH), Oslo, Norway (September 2008).

- Holmes-Rovner M., Charvet-Berard A., Whitney S. “Shared decision making: theory and practice: A symposium” presented at the European Association for Communication in Health Care (EACH), Oslo, Norway (September 2008).

- Elwyn G., O’Connor A., Bennet C., Newcombe R., Durand A., Drake E., Joseph N., Khangura S., Politi M., Saramaaki A., Sivell S., Stiel M., Bernstein S., Col N., Coulter A., Eden K., Härter M., Holmes-Rovner M., Mousjid N., Stacey D., Thomson R., Whelan T., van der Weijden T., Edwards A. “Development, Validation, and Inter-Rater Reliability of the International Patient Decision Aid Standards Instrument (IPDASi) as a quality appraisal tool.” Presented at the European Association for Communication in Health Care (EACH), Oslo, Norway (September 2008).

#### **Grants**

- Funded by Robert Wood Johnson Foundation: Health Care Financing & Organization 8/1/08 – 7/31/09. “Getting Tools Used: Lessons Learned from Successful Decision Support Tools Outside Healthcare.” J. Gruman is PI of this study and Margaret Holmes-Rovner is Expert Commentator.

#### **DAVID KOZISHEK**

##### **Presentations**

- “Responding to Existential Suffering at the End of Life” for Hospice Ethics Conference sponsored by Avalon Hospice (November 2008).

- “Poetry and Meaning in the Helping Professions.” co-presented with Karen Ogle, MD, for Foglio Conference on Spirituality and Medicine, Michigan State University Department of Family Medicine, East Lansing, MI (October 2008).

##### **Consultations**

- Planned and facilitated the 12th annual Foglio Conference on Spirituality and Medicine, The conference theme was “The Spiritual Life of Children Living with Serious Illness.” East Lansing, MI (October 2008).

#### **ANN MONGOVEN**

##### **Publications**

- “Maternal Virtue and Civic Virtue” will be published in Andrea O’Reilly, ed., *Mother Troubles: The Legacy of Sarah Ruddick*, Demeter’s Press, Forthcoming Winter 2009

##### **Presentations**

- “Putting the Trust in Biotrust” at the MSU annual IRB educational conference. The presentation explored ethical issues at stake in a proposed state population-wide tissue repository for health research (October 2008).

##### **Consultations**

- Continues to serve on the Biotrust Public Engagement Working Group a state-academic-private partnership (2008).

#### **GERALD S. SCHATZ**

##### **Publications**

- “Ethical Lawyering in the Protection of Human Subjects of Behavioral and Biomedical Research” *Michigan State University Journal of Medicine and Law*, forthcoming.

##### **Presentations**

- “Medical Privacy, Confidentiality, and Disclosures” for Michigan State University Department of Medicine Grand Rounds, East Lansing (January 2009).

- Spoke on International Law and Informed Consent for Behavioral and Biomedical Research in Malawi, Faculty of Law, Chancellor College, and Medical Rights Watch, College of Medicine, University of Malawi (October 2008).

- Spoke on Rights, Institutions, and Ethics in U.S. Health Care, Medical Rights Watch, College of Medicine, University of Malawi (October 2008).

##### **Appointments**

- Elected to Board of Directors, Citizens for Responsible Care and Research (2008).

#### **TOM TOMLINSON**

##### **Presentations**

- “Under the Influence: Physicians and the Pharmaceutical Industry” Infectious Disease Core Conference, Department of Medicine, MSU, Lansing (September 2008).

- Should there be a free lunch? Physicians and Pharmaceutical Companies. Infectious Disease Core Conference, Sparrow Hospital, Lansing, MI (September 2008).

##### **Appointments**

- Member, Health Colleges Conflict of Interest Planning Task Force, MSU
- Member, Genetic Sciences Ethics Advisory Committee, MSU
- Elected Treasurer, American Bioethics Program Directors

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fascinating discussions that were medically and developmentally relevant.

On top of science and medicine, we attended Spanish classes in small groups where every student, some with no Spanish experience and some fluent, learned a tremendous amount of the language.

I gained an enormous amount from this trip, including new friendships, the guidance of a professor and teacher’s assistant, a second Costa Rican family, further Spanish-speaking skills, and a strong medical, historical, ecological, and personal knowledge of a fascinating country. I would, and do, recommend this program to other students.

Saumya Pathak  
MSU Student

My trip to Costa Rica was an amazing and eye opening experience. Living with a Costa Rican family provides a priceless opportunity to experience family living while building on your ability to speak the language. The staff at the Spanish institute was incredibly accommodating—from making sure our class level was appropriate to guiding us across the country.

The ethics program continually brought up new issues at the local level and was a very powerful experience. We were fortunate to see health care facilities through “in the field” exposure; this made concepts discussed in class concrete. I would recommend this program to anyone interested in Spanish and medical ethics.

Andrew Thompson  
MSU Student

## MEDICAL HUMANITIES REPORT



Center for Ethics and Humanities in the Life Sciences  
Michigan State University  
C-208 East Fee Hall  
East Lansing, MI 48824-1316

### Upcoming Brown Bag Talks

**Feb. 18** noon C-102 East Fee  
Misha Strauss, Ph.D., "Overworked and Underpaid: Primary Care, Professional Integrity, and the Promise of the Medical Home"

**April 15** noon C-102 East Fee  
Michael Imperiale, Ph.D., "Dual Use Research in the Life Sciences"

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worrying about it would not be worth the cost I in health-care system efficiency.

I agree that the issues are complex and that the cultures and complexities in U.S. health care must be understood better in order to inform these policy and acquisition discussions adequately. After that, we mostly diverge. For me, the promise of better electronic medical records systems for improvement of health care and for cost-savings is clear, but realization of that promise is far from certain. The answer is not to make light of security worries or to oppose sensible records systems against security concerns; that's a false dichotomy. A real tension, with which Hazewinkel did not deal, emerges from the health-care cultures, complexities, and interests. As President-elect, Barack Obama noted two goals for electronic medical records systems: Cost-control and improved health care. How might that play out? Will vendors peddle and payers, institutions, and agencies buy and put into operation systems tailored to push cost-control at the expense of medically indicated care for the individual patient? Competent, appropriate medical care might be expensive,

but wrong care is unethical, a waste altogether, and a liability.

The big problem in these regards is how to use these systems to facilitate competent and appropriate care. This requires knowledge of medical cultures especially. The precedents aren't shiny. The National Institutes of Health (NIH) tried twice to develop a much-needed electronic medical records system, but NIH physicians and physician-scientists were too overworked to participate in its design. The system they got was difficult to use, and there were confusions over authorization, access, and priority. Even some relatively new electronic medical records systems come with built-in medically inappropriate automaticities, for example pop-up recommendations and choices entirely inappropriate for the individual patient; are too inflexible for adequate information entry; are too hard to read; and, as the news illustrates, may be insufficiently secure. Some current systems seem to demand a standardization of care in ways that pre-empt a physician's individualized judgment.

Advanced electronic medical records systems are useful and needed. If this

technology is to fulfill its promise, then payers, buyers, and developers need first to understand how doctors and ancillary medical personnel work, what they do, what they need, and when, in widely differing circumstances; they need to understand the culture of doing medical care. Too often, the technology is evaluated primarily from an administrative standpoint, at worst as no more than a coding and billing machine. Much more attention must be paid to medical purposes and human factors-in this instance why and how people use these systems. The justifications for their design and use should be medically and ethically sustainable. These concerns are too important for doctors to leave to systems developers. If doctors are to participate in these developments, then their employers, health-care institutions, payers, and public agencies have to care enough about effective medicine to free them up to do so. Otherwise, much of the talk about this route to improved medical care seems hollow.

*Gerald S. Schatz, J.D.  
Center for Ethics and Humanities  
in the Life Sciences*