

NCTF 7th On-line Session Transcript
Joined on March 18, 2008 at 9:00 PM

Moderator (bob): Hi folks, We're about four minutes from starting, still logging people in.

Moderator (Patrick Hamlett): I'm going to close off everyone

Moderator (bob): Let's get started by quickly looking at the teams up tonight & when.

Moderator (Patrick Hamlett): I'm going to close off everyone' chat & activate Team 6

Moderator (bob): Slide up - first hour Team 6 for the first half-hour & Team 1 the second half hour.

Jennifer T NH: whoa

Moderator (bob): Teams for the second hour are now visible. Note when you are active.

Moderator (bob): Team 6 will be up first are now chat active.

Moderator (bob): I hope all of you have read the written responses on the web page.

Moderator (bob): Team 6 - You are now free to address questions to Dr. Berry who is here with us.

Johan B Ga to Patrick Hamlett, bob, Tina Nдох: hello all

Jonathan R GA to Patrick Hamlett, bob, Tina Nдох: I enjoyed reading them although I wish Dr. Tillery had written as much as Dr. Berry

john k nh: Thanks!

Moderator (Patrick Hamlett) to Johan B Ga: Johan: You are NOT CHAT ACTIVE, please do not make comments until the second hour

Johan B Ga to Patrick Hamlett, bob, Tina Nдох: ok

john k nh: Dr. Berry, could you expand on the "Common Rule" as it relates to studies on human subjects?

Madhavi D WI to Patrick Hamlett, bob, Tina Nдох: Hi Dr. Berry, How important do you really think are enhancements outside the realm of medical treatments?

Moderator (Tina Nдох): Madhavi D WI to Patrick Hamlett, bob, Tina Nдох: Hi Dr. Berry, How important do you really think are enhancements outside the realm of medical treatments?

Moderator (Tina Nдох): This message is from Madhavi

john k nh: And what dangers does these new (or not so new) NBIC technologies pose for ethicists in regulating testing, clinical trials, and marketing to humans?

Dr. Berry: The common rule applies to federally funded and much other research. It aims to protect the dignity and safety of human subjects by requiring institutional review boards (IRBs) at institutions conducting research to ensure that human subjects are given information so they give informed consent and that the risks and benefits of the research are in balance.

john k nh: Thanks!

john k nh: Especially genetically based somatic therapies, and more problematically, germline research.

Dr. Berry: I think the significance of enhancements is growing. We increasingly struggle to differentiate therapy from enhancement with drugs such as Prozac. We once would not have considered administering drugs to children to make them more attentive. There is good evidence that, all else being equal, if people are given an opportunity to enhance themselves (or their children) they will take it -- assuming risks are limited. Most of us use caffeine

john k nh: Also, Dr. Berry, have you read the portfolio provided to us "NCTF Background Materials"?

kokila r ga: Dr. Berry, thank you for the incisive definitions - especially of experts. However, given the complexly pluralistic society we live in, I wonder if "people" will include all our voices - especially the economically weaker sections of society? What measures, do you think, the international community take to ensure democratic participation of all involved members of the global community?

Dr. Berry: These pose challenges to ethicists for a number of reasons. We have long relied on the medical notion of relief of suffering and disability and curing disease. When we are no longer so sure of what the baseline is -- normal human functioning (what is that?) or something better than normal -- how do we decide? What are our criteria? No longer simply the risk and benefit analysis of medicine. We are in the realm of what is the good life, what does it mean to be human, and what are the implications for human society for the long term.

john k nh: About Prozac and children, but aren't studies showing, that all things being equal, the side effects outweigh the benefits-- increasing suicidal tendencies for example--for children?

kokila r ga: The long term side effects are not apparent but are masked by the initial excitement of finding the cure.

Peter C NH: Human enhancements via nano-tech -- most likely accessible first to the already privileged -- will give those people further advantage. Do we, as a society, have an ethical obligation to focus our

not-unlimited resources on technologies that affect (protect or enhance) broader groups of people or even the environment itself?

Jennifer T NH: Dr. Berry- You seem to feel that public involvement is crucial to shaping public policy. Though on such a technically complex topic such as nanotechnology, how can the public be properly informed as to be able to form educated opinions to help shape the discussion on regulation?

john k nh: But Dr. Berry, doesn't medicine agree for the most part that there are "normal limits" such a lab values, for example. How can tax dollars be spent for therapies that more often exaggerate responses rather than enhance them?

joseph p wi: No the actual data show an increase in suicides after withdrawal.

Dr. Berry: Genetically based somatic cell therapies have already proved to be problematic to regulate and to assess. There have been problems with the eagerness to get therapies to market and the great unknowns about risks to human subjects. The result has been at least one death of a human subject -- Jesse Gelsinger -- who did not have a life-threatening condition. As we move into germline engineering, the larger issues of what should be unrevisable about the human being, what limits should be placed (if any) on parental choice (IVF is largely unregulated) loom ...

john k nh: So, you must keep taking your medicine or you are more likely to kill yourself? Sounds like blackmail by big Pharma to me!

Moderator (bob): We must exercise patience tonight. Dr. Berry is typing as fast as she can, but questions are coming in faster.

john k nh: She's doing great

Moderator (bob): If Dr. Berry overlooks a question you submitted, try it again later.

john k nh: Who?

joseph p wi: No, it is the importance of realizing "experts" are not truly isolated, unbiased, fully cognizant.

alan h ca to Patrick Hamlett, bob, Tina Ndoh: i joined late...which team is active?

kokila r ga: Actually it is difficult to keep up with this question-answer session - a transcript would really help identify the questions with the answers

Dr. Berry: Yes, it is one thing to have access to private education and all the other benefits of wealth-- we have at least a sense that others can compete if they work hard -- but another thing to have one's genome revised before the race begins. Assuming the revisions are beneficial, the social justice or distributional issues will be large. Should we fund

genetic engineering of children to some degree for some purposes as we fund public education -- so all can get some of the advantages? If not, the wealthy get ahead. But if we do fund, we are suggesting that this is a good thing -- like public education

Moderator (Tina Ndoh) to alan h ca: Alan, your team is up, you may ask Dr. Berry questions

john k nh: I vote no on that use of tax money

john k nh: for the wealthy

magdav wi: Dr Berry. What do you see as the area(s) of concern that we should focus on. There seems to be so much going on that it is hard to narrow our focus when it comes to new technology and nano tech.

Moderator (Tina Ndoh): Kokila, the transcript will be posted to the website for review

Dr. Berry: Complexity makes public involvement very difficult -- it's true. But nuclear energy is complex too -- yet, with time and reflection and some baseline understanding, we can begin to weigh and balance the economic, environmental, and other benefits. My sense is that many -- far from all -- but many members of the public are willing to learn enough to debate the issues knowledgeably.

joseph p wi: But I would Dr Berry to expand/explore why we are so quick to fear enhancement esp for those with less. Why shouldn't an IQ less than say 50? 80? 100?

joseph p wi: Joseph P Wi that is, enhance them

Dr. Berry: "Normal" is a difficult term. It suggest the top part of the bell curve that seems to characterize most aspects of human life. It sometimes takes on a "should" character too. All of us should strive to be in the "normal" range for our lab values, our height? our weight? our intellect? But what if enhancement can change the bell curve, shift it this way or that? Then the norm shifts and we all must race to keep up. But I think your question suggests something else as well -- is more always better? Definitely not, though sometimes this gets lost in the discussion. We need to think through when more is better and why, and when it is not.

kokila r ga: Do we also enhance the ones with already higher IQ?

kokila r ga: Where do we stop? Will we aim for an optimum IQ that everyone can uniformly reach?

john k nh: Doesn't genetic "enhancement" still smack of the public policy disaster of eugenics and the likelihood that it could lead to efforts to develop another Hitler-like Master Race?

john k nh: With the Craig Ventors of the world taking the lead?

alan h ca to James B AZ: Dr berry..to add onto kikila's question...do we as individuals decide whether we get enhanced or does someone decide for us?

alan h ca: Me to James B AZ: Dr berry..to add onto kkilas question...do we as individuals decide whether we get enhanced or does someone decide for us?

alan h ca: oh man..the last question was for dr berry

Dr. Berry: In my view, the race after more as better in many areas of human life is misguided. If we stop and think about what is good in human life -- friendship, accomplishment, enjoyment of pleasures -- a higher IQ, being taller, having x-ray eyes ... are not good ways to focus our energy on having a good life. And yet ... it is so tempting to think that if the experts can offer it and if the next door neighbors might use it, then we gotta have it. That's where the public, the folks who live their lives in the realm of friendship, parenting, and so on, can ask questions, challenge these ideas, and redirect our energies toward curing, caring, etc., that support the goods of life. All of this in my view, of course.

john k nh: Doesn't your use of a statistical model, but then injecting normative values raise questions of the model's structure?

john k nh: Patient well being came first, not the lab values bell curve, in other words.

Peter C NH: Dr. Berry, I agree. Stated another way, most of us are far from realizing the potential we are born with. Why enhance at all? Isn't this the ethic of the 'quick techno-fix'?

Moderator (bob): We're within five minutes of switching to Team 1 as chat active. Team 6 - Refrain from throwing in new questions in order to give Dr. Berry a chance to answer one's already asked.

joseph p wi: Joseph P--But Dr Berry, is less more and shouldn't those with less, have the same opportunities as those us with more: money, education, health, freedoms, intelligence?

Dr. Berry: Regarding eugenics, there is a bit of debate about what was bad about eugenics. This ties together a few of your questions. Was it bad because the science was mistaken (it was). Was it bad because it was coercively applied by the government to individuals rather than undertaken as a matter of individual choice or choice for one's children. If only bad because the science was bad and it was coercively applied, then we would not have a problem with a new eugenics that is based on sound science and offered up to individuals as a matter of choice. But I think there were more problems with eugenics, involving a mistaken view of what is important and good in human life, that we are now facing in a more challenging form than before. We all agree that Nazism was horrible. It's inconceivable in our democracy, I think, that we will have a coercive eugenics like that. But what choices should we make as

individuals and as a political community when other choices are presented to us by new technology?

Moderator (bob): WE are switching to Team 6 as chat active. Be patient while we institute the changeover.

Dr. Berry to Patrick Hamlett, bob, Tina Ndoh: g

alan h ca to Patrick Hamlett, bob, Tina Ndoh: you mean team 1?

Moderator (bob): Team 6 - Please refrain from comments or questions, Team 1 will now be chat active.

Moderator (Patrick Hamlett) to Dr. Berry: ???

Moderator (bob): Sorry I did mean we're switching to Team 1. Got lost for a minute.

Moderator (bob): TEAM 1 - yer up!

DonB NH: Some may argue that our modern society, with the increasing consumption and reliance on pharmacological cures at all ages, is on a trajectory that diminishes individual responsibility and places greater control of our lives into the hands of drug companies. Nanotech has the potential to greatly accelerate movement in that direction. Is that what we want?

Jonathan R GA to Patrick Hamlett, bob, Tina Ndoh: I have some experience with IRB's. Almost ten years ago now I was a member of the CAB (Community Advisory Board) at ARCA, the AIDS Research Consortium of Atlanta. It was my experience that even though WE were supposed to be the ones who decided which studies went forward, and which did not, that the pharmaceutical companies were very adept at manipulating the CAB, and that THEY always made the ultimate calls anyway. Unless the RECOMMENDATIONS of IRB's are made somewhat binding, how do you propose we correct that?

John E WI: Dr. Berry: Are you aware if there has ever been a case where a citizens group has had an effect on bringing the FDA into action (e.g., to stop or recall a drug)?

Jane L NH: Dr. Berry, would it be fair to say that we need to be able to define the areas of enhancement before we can discuss uses or regulation? Can you be specific in to which area of enhancement you refer?

Moderator (Tina Ndoh): From Jonathan R: I have some experience with IRB's. Almost ten years ago now I was a member of the CAB (Community Advisory Board) at ARCA, the AIDS Research Consortium of Atlanta. It was my experience that even though WE were supposed to be the ones who decided which studies went forward, and which did not, that the pharmaceutical companies were very adept at manipulating the CAB, and that THEY always made the ultimate calls anyway. Unless the RECOMMENDATIONS of IRB's are made somewhat binding, how do you propose we correct that?

Moderator (Patrick Hamlett) to Jonathan R GA: Jonathan: do you want that sent to the whole room? Select "This Room"

Dana A WI to Patrick Hamlett, bob, Tina Ndoh: Dr Berry, Thanks for joining us. First, wasn't eugenics all the rage in the US in the 1910s and 1920s? Forced sterilization of patients--women mostly, I think--in mental hospitals and such was not uncommon, so your hope that in our democracy a coercive eugenics is inconceivable seems already to have been overridden, although not to the extent practiced by the Nazis, I'll agree. Next, I thought your written response was downright eloquent on the topic of public involvement. It seems to me that since 1980 the mega-trend in the federal government has favored de-regulation over regulation and that sometimes the speed of getting drugs to market has been favored over more thorough testing. Do you see these forces at play in NBIC development? Thanks.

Jonathan R GA: I don't need to send it again do I? since Ms. Ndoh did.

Moderator (Tina Ndoh): From Dana A: Dr Berry, Thanks for joining us. First, wasn't eugenics all the rage in the US in the 1910s and 1920s? Forced sterilization of patients--women mostly, I think--in mental hospitals and such was not uncommon, so your hope that in our democracy a coercive eugenics is inconceivable seems already to have been overridden, although not to the extent practiced by the Nazis, I'll agree. Next, I thought your written response was downright eloquent on the topic of public involvement. It seems to me that since 1980 the mega-trend in the federal government has favored de-regulation over regulation and that sometimes the speed of getting drugs to market has been favored over more thorough testing. Do you see these forces at play in NBIC development? Thanks.

Moderator (Patrick Hamlett) to Dana A WI: Dana: Make sure your messages go to "This Room"

Dana A WI to Patrick Hamlett, bob, Tina Ndoh: ohh, thanks!

Moderator (bob) to Jonathan R GA: No need to send again. Tina already posted your question.

Dr. Berry: Sorry, I just lost a post in transition. OK, regarding pharma/nano and its control over us. Yes, I think there is certainly a risk that we need to be mindful of -- but I hasten to add that we have enjoyed enormous benefits from pharm (including Prozac and others for some) and I think we can from nano as well. The great difficulty is like that of the grocery store. With so many choices, we can bring home lots of stuff and we can eat lots of stuff. The hard part is both choosing just what we should bring home and what/how much we should eat.

Allison A GA: who is held accountable for the horrific offenses against individual in pursuit of ends that are not beneficial to humanity?

Jonathan R GA: In the same vein, how much longer will we continue to let Executive Privilege continue to dictate scientific progress?

Moderator (Patrick Hamlett) to Steve Helms Tillery: Steve: Hope you're flexin' your typing fingers...

Moderator (bob) to Allison A GA: Allison. I think that question is going to need some clarification.

Dr. Berry: Regarding the FDA, yes, there was tremendous involvement during the first wave of the AIDS epidemic in getting FDA to reconsider its approaches. I think the agency strives mightily to balance all the factors involved. Disapproval, tight regulations deny those in need access to possible benefit. Over approval puts us at risk of drugs that might be hazardous -- and we have discovered this with some drugs already out on the market then recalled after larger experience revealed greater risks. A difficult task for FDA and they continue to adjust their approach. But public involvement is important.

Jonathan R GA: Or, to put it another way, do you have any ideas on how to make process of deciding what science gets funded more fair?

Dana A WI: Jonathan/Dr Berry, that was the subtext to my question(s)--is there a way to protect something as radical as NBIC from being subject to the vagaries of the current political winds?

Dr. Berry: Yes, I think we should define areas of enhancement carefully and reflectively -- considering all the implications, for the biological and social being (not just "simple" risk benefit assessment) and for society. I think we would be wise to do this rather than attempt to create governing principles -- enhancement is bad, therapy is good -- when we can't even tell the difference and the implications for each of us and society will depend crucially on the details.

Allison A GA: I guess what I would like to know is...who will that responsibility for any or all mishaps while trying to find the "cure" so to speak

Jonathan R GA: As I understood it, in the case of Celebrex, and that other drug that was similar, the FDA suppressed information that was unfavorable to the drug's manufacturer, and people died. What can we actually do about that situation?

Dr. Berry: I think, for example, (I think this post was lost), we might need to enhance ourselves if a deadly disease threatened the human race. An easy case. Harder case -- some might think it's great to have a better memory. But what do we know about memory, whether it is better to forget some things and remember others -- and should we tamper. Beyond this, enhancing our kids to glow in the dark versus enhancing ourselves to do it. I wouldn't favor the former. Be my guest for the latter (assuming it wouldn't be very harmful to the person who undertook the enhancement).

Allison A GA: would it be the scientist? or the govtment?

John E WI: It seems that ethical and environmental concerns always come AFTER new technologies are employed or hit the market, instead of using

our so-called wisdom to predict potential negative consequences. What do you suggest we need to do to change this approach?

Dr. Berry: Regarding the power of citizen members on IRBs and elsewhere, I think this will be a continuing worry. Expertise combined with motive (for profits, success, glory, etc.) are very powerful. But there are examples of individual efforts that make a difference. And, key to ongoing and systemic success will be efforts to design the PROCESS of policymaking, at the institutional IRB level and at the level of the political community, to integrate ongoing public involvement. I see this as a crucially important project in the era of enhancement, and all of you are participating in one effort related to this.

Jonathan R GA: I have also heard that parents can currently pay to have GPS installed on their children's cell phones, and the logical extension of that will be chips and GPS implanted in the human body. On the one hand, if parents care about their children, this seems like a good thing, but on the other hand, something about the ability of allowing some individuals the ability to track others, especially if that ability is not shared, seems inherently unfair and potentially EVIL. There I said it, E-V-I-L.

Dr. Berry: When I say that individuals can make a difference and the public can reject wrongful efforts, like eugenics, I should say that this won't necessarily be accomplished before many suffer. That's perhaps the thing that is most worrisome as we contemplate preparing for the era of enhancement. It's easier to see what is mistaken or worse after the fact and all the implications come clear. It's much harder to foresee these things and forestall them.

Jane L NH: Doesn't each enhancement require its own set of regulations....meaning isn't it impossible to make policy before the fact?

Dr. Berry: Addressing some more of your questions, accountability sometimes consists of law suits (several followed after the death of a human subject, Jesse Gelsinger, in a gene therapy experiment). It sometimes consists of institutional penalties -- including fines and having research programs shut down (this happened at U Penn where the experiment on Jess Gelsinger was conducted). But nothing can undo the harm. The law is a crude instrument, just the best we have to win some justice after the fact. Better, much better, to prevent.

Stuart S AZ: How do you prevent without stifling innovation?

Dana A WI: I'd just like to say, too, that I'm hopeful that increasing diversity in the higher levels of scientists and engineers will infuse the ranks of decision makers in those groups with more people who do think about ethics, and consequences, and the effects on seven generations down the road of the decisions 'we' make today.

Tim H GA: Br. Berry, could you please give us a little more detail on what happened to Jess Gelsinger?

John E WI: I think humanity has gotten stuck that it is always too hard to anticipate problems in the future. There are so many ways of modeling potential outcomes available--and we have our history for gosh sakes!

janine w CA: john e you are right on target!

John E WI: Thanks!

Jonathan R GA: Yeah. Who was this Jess Gelsinger, and what did they do to him?

janine w CA: wasn't he a "volunteer"?

Dr. Berry: Regarding particular enhancements and the possibility of preventive policies. Right, it is hard to anticipate and regulate in advance for several reasons. FDA regulates drugs, biologics, and devices. Which category would nanorobots fall into? We do have to create some categories to develop regulatory expertise, and we are always going to be chasing after categories that fail as they are pressed by new discoveries that challenge them. There will always be a need for categories and our categories will always be in need of revision. Beyond this, would GPS or glow in the dark be particular revisions we should permit or proscribe, for individuals or for children? And how do we implement these particular choices -- at the level of doctors or "enhancement" professionals according to acceptable standards of practice? This might be the best we can do, building on what we do now in medicine and related fields.

Moderator (Patrick Hamlett) to Teresita B CA: Teresita: Welcome -- you're team is active in 8 minutes

Abraham E CO to Patrick Hamlett, bob, Tina Ndoh: if you want to let everyone know here's a quick rundown on Jess Gelsinger:
http://en.wikipedia.org/wiki/Jesse_Gelsinger

foster f GA to Patrick Hamlett, bob, Tina Ndoh: ?now known acceptable levels of practice contradicts "NANO"

Moderator (Tina Ndoh): All, here is a message from Abraham E: if you want to let everyone know here's a quick rundown on Jess Gelsinger:
http://en.wikipedia.org/wiki/Jesse_Gelsinger

Moderator (Tina Ndoh): Thanks Abraham

janine w CA: I know my implanted technology has a sticker on it that says it is regulated by the FCC & FDA so there is dual agency regulations

Dr. Berry: Yes, we surely do not want to stifle innovation -- key to better lives for millions -- and we don't want to be afraid of it or stand still. I think innovators appreciate the opportunity to pursue their research wherever it takes them (invention requires freedom) and regulation should never be absolute and based on fear of the unknown, but, instead, responsive to the particulars of applications as they present themselves. A difficult balance, that suggests that the regulatory system will have to extending to funding choices, such as

those of NSF and NIH, to our patent system (which, in a sense, funds research) as well as to IRBs, FDA, and medical or enhancement professionals.

John E WI: Dr. Berry: How are you able to type so fast and perfectly (you aren't nano-enhanced, are you)?

Moderator (bob): TEAM 1 - Five minutes until handoff to Team 2. Please refrain from introducing new questions to give Dr. Berry a chance to answer the one's already asked.

Jonathan R GA: Reading about Mr. Gelsinger did not make me any more hopeful that this is all gonna be okay!

Allison A GA: i do appreciate you time Dr. Berry and your insight. thank you

Dr. Berry: Regarding another way to achieve a thoughtful and well balanced regulatory approach, yes, the education of scientists and engineers. This is something I am particularly interested in and, thankfully, the funding agencies (NSF and so on) are interested in as well. I believe that educating future inventors/researchers in ethics and policy will be an important part of arriving at good policies. It is not possible for present-day researchers to think of themselves as just pursuing whatever they want for the joy and challenge of it (although that is part of it). They are charged with a public purpose by virtue of receiving public funding and because of the implications for human beings and society of their work.

Moderator (bob): Great questions Teams 6 & 1. We will be switching to Dr. Tillery for the second hour & giving Dr. Berry a much deserved rest.

Jonathan R GA: Thanks Dr. Berry ... your insights made this make more sense to me ... I can only hope what we are doing here DOES help someone or something down the road. Thank you for giving us your time.

Allison A GA: lol

Dana A WI: Thank you, Dr Berry!

John E WI: Thank you Dr. Berry

Dr. Berry: Footnote to previous post -- diversity of perspectives due to life experience, membership in various groups, etc., is also important. It is amazing what we can learn from each other that we never thought about if we simply have exposure to people with a different perspective. So the diversification of higher education in science and technology as well as the infusion of ethics and policy instruction, I think, can make a difference.

Jane L NH: Thank you, Dr. Berry....very enlightning...

Moderator (bob): We are disabling chat for Team 1. & switching to Team 2 as chat active.

Dr. Berry: On Jesse Gelsinger, long, sad, and important story. Google the name, follow the trail of NY Times articles, and then explore more broadly and you'll get a sense

Rexxor A GA: Ms Berry, policy makers always have to play catch up with thing like this, things that move so rapidly. Shouldn't we realistically be on the side to err with caution instead of trying to restrict what we don't know?

Moderator (bob): The background on Dr. Tillery is now posted along with the question he answered .

Jonathan R GA to Patrick Hamlett, bob, Tina Ndoh: Who is going to get to question Dr. Tillery, Team 2 and who else?

Moderator (bob): TEAM 2 - You are good to go.

Frank C NH: Dr. Tillery: Is nano tech upgradeable, and/or reversible? If we develop a Super Soldier 1.0 will he be upgradeable to 2.0. But what happens when his hitch is up and he returns to Society 0.0? Can he, would he be de-nanoed?

Moderator (Patrick Hamlett) to Jonathan R GA: Team 3

Teri B CO: what about viruses?

Teresita B CA: can you elaborate on military applications of neural implants?

Diana I GA: Dr. Tillery- I am curious about the research you are doing and how you think it is going to apply to humans?

Darlene J AZ: What happens if the brain probe is put in too deep and alters the person's personality to be dangerous...who takes care of that?

Teresita B CA: What are the gaming applications you refer to?

Moderator (Patrick Hamlett) to Dr. Berry: Hey, good work! It's Miller time!

Trisha B. AZ: Dr. T: Is your work with primates the first step in better understanding Telepathy applications with humans?

An L CO: Are international relationships strengthened through collaboration on these enhancements?

Teri B CO: Have you read Ishmael?

Johan B Ga to Patrick Hamlett, bob, Tina Ndoh: would these brain probes be used as a type of lobotomy

Trisha B. AZ: Dr. T: What part of nanotechnology are you most excited about and what uses will there be in your lifetime?

Moderator (bob): As I said earlier, we'll have to exercise patience. Dr. Tillery can answer only one question at a time.

Diana I GA: How close is your research to being applied at any level to humans?

Steve Helms Tillery: One of the issues which Dr. Berry very ably discussed was the difficulty in foreseeing what directions technology is likely to go. At this stage, there is no Super Soldier 1.0, nor to my knowledge any particular technologies on the immediate horizon to create a permanent super soldier. However, there are ways to envision what might be on the horizon to a limited extent. At this stage, for example, it is clear that we can have a device which inputs data directly into the brain using electrodes. Based on the work in our lab and others, it is also clear that these technologies can work faster than the nervous system to pipe data in and out. So, for a military application, one could envision a system that enables a fighter pilot to gain a few 10s of milliseconds that could be crucial in a dogfight at 60 mph.

Steve Helms Tillery: Wow, you guys throw questions out quickly! ... So, I'm more interested in medical applications, and yes, several human trials are already ongoing. The first trials of this technology (brain-machine interface, or BMI from here out) have been in patients who were profoundly paralyzed, and only able to communicate using eye signals. These were people who had normal brains otherwise, and thus had normal needs, hopes, wishes, aspirations, etc, but no way to move. The first experiments involved interfacing these individuals to computers so that they could type sentences using brain signals.

Steve Helms Tillery: More recently, a group called Cyber kinetics has been testing implants in individuals with more movement capability, to see how generally they would be able to control devices. These patients have been able to control a "smart room"... meaning a room where temperature, lighting, television, etc., was controlled from a computer. By altering their brain signals, they were able to directly control the computer, much as I can type using brain control of my fingers.

Diana I GA: That sounds fantastic!

Teri B CO: That is amazing.

Johan B Ga to Patrick Hamlett, bob, Tina Ndoh: Great so we would be able to interface w/ our computers

Teresita B CA: With the capacity to think-command, what are the risks?

Marissa S WI: This might be a complicated answer, but what aspect of cochlear implants (or any of these other implants) involves nanotechnology?

Trisha B. AZ: So could my brain signal my computer to read my emails

Frank C NH: Is there a point at which humans cannot be enhanced? Much as I can't take a 286 to a 386 to a 486 to Pentium etc., is there a point where science says, "We can't do anything else with you."

Steve Helms Tillery: This type of interface is going to be getting better and better over the next decade. We know enough about how the brain works, from decades of prior work, to understand what kinds of signals the brain is capable of generating. The main roadblock at this stage is designing the actual physical interface between the brain and the computer... the electrodes which go directly into the neuronal tissue. The brain (and any other part of the body) considers that to be a foreign invasion, like a splinter, and tries to get rid of the implant, or at least wall it off with scar tissue. Thus, new technologies involving a combination of genetic engineering and finer electronic technologies will likely come into play

Johan B Ga to Patrick Hamlett, bob, Tina Ndoh: Or will we always be upgrading our implants to keep up with current tech.

Steve Helms Tillery: Cochlear implants are a great case of mixed results in neuroprosthetics. To date, there is nothing that is nano-technology in cochlear implants, the manufacture of the implanted device itself is actually rather prosaic, involving building a soft implantable device with wires inside it that are used to control an array of electrodes.

Moderator (Patrick Hamlett) to Johan B Ga: Johan: Your Team is active during the second half hour, starting at 10:30pm -- please hold your comments until then

Johan B Ga to Patrick Hamlett, bob, Tina Ndoh: ok

Steve Helms Tillery: The main risks thus far are actually of the more clearly medical variety than of the science fiction variety... infections induced during surgeries, incidental damage to tissue around the implant site, things along those lines. Generally, if there is a complete failure of a device or an infection, the devices are explanted (removed) and the problematic area allowed to heal

Trisha B. AZ: Could you also speak on what might be the 'dark side' of converging technologies. Or maybe there is none...

Marissa S WI: Even though cochlear implants don't involve nanotechnology, I think they're a good example of what sort of issues can arise with implants. Within the deaf community there are strong supporters of cochlear implants and strong opposers. People aren't forced to get the implants, of course at the same time many people can't afford them, which can be to their disadvantage seeing as the ability to hear (not the cochlear implants lead to great hearing ability) is highly valued and useful in our larger society.

Steve Helms Tillery: Another common treatment is Deep Brain Stimulators, used in the treatment of a variety of disorders such as Parkinson's disease. These are very invasive, since they have to be implanted deep into the brain, and so are used only as a final stage of treatment when

medications begin to be ineffective. In most cases, these are implanted on only one side of the brain initially, and this seems to be an effective treatment. There have been isolated reports of DBS systems leading to cognitive changes. In these cases though, one can change the stimulation parameters of the implants, and reduce such side effects.

Darlene J AZ: This sounds a little to 'frankenstein-ish' to me with wires implanted deep into the brain tissue...maybe the reason there is difficulty with these treatment is because they are not suppose to be made at that level? Ya think?

Teri B CO: who pays the bill for these implants--insurance, research grants?

janine w CA to Patrick Hamlett, bob, Tina Ndoh: I have a spinal cord neurostimulator and am waiting for the day it becomes a chip in my brain

Trisha B. AZ: Are these stimulators waking up a sad brain. or killing some of the brain cells off

Steve Helms Tillery: Marissa, you are right on the mark. And in fact this is becoming very contentious again because it appears that in the case of congenital deafness, cochlear implants are most effective if implanted at a very young age , less than 3 years most likely. Therefore, the technology and science could conceivably come into direct conflict with the idea that people should be free to choose these technologies for themselves. It doesn't do to say that people can have the technologies removed or turned off later: in the case of deafness for example, a person who was successfully implanted as a young child would not ever be a member of the Deaf Community

Teresita B CA: You project that there will be \$8.8 billion of biomedical applications by 2012 --- in what areas and products?

Moderator (Tina Ndoh) to janine w CA: Janine, would you like/ be willing to share this with the entire room?

Frank C NH: Are you concerned that procedures you are developing now will become mandatory in the future? Insurance companies requiring remediation rather than spending a fortune treating lifelong disabilities?

janine w CA to Patrick Hamlett, bob, Tina Ndoh: YES

Trisha B. AZ: Who is gong to pay the 8 billion and change

janine w CA to Patrick Hamlett, bob, Tina Ndoh: not only that but i just found out that i have an increased risk of cancer at my implant sites - which i am more than willing to live with considering the benefits of my implant

Moderator (Tina Ndoh): This message is from Janine W (CA-team 6) : I have a spinal cord neurostimulator and am waiting for the day it becomes a chip in my brain

janine w CA to Patrick Hamlett, bob, Tina Ndoh: my surgeon also does the deep brain stims and i have met some of the patients and seen how much it helps them

Steve Helms Tillery: I'm not sure what you mean Darlene ... certainly the DBS systems have been extremely effective treatment for a lot of people. We freely offer people medications to help with their Parkinsonian symptoms, why would we not offer a technological aid if it was helpful? Trisha, believe it or not, it's not actually clear exactly why these implants work. They might turn on neural activity, or they might interrupt it.

Darlene J AZ: I'd like to see \$\$\$ put into prevention rather than intervention/treatment...it seems that would be more cost effective...

foster f GA to Patrick Hamlett, bob, Tina Ndoh: Jannine:/ dorsal column stimulator?

Moderator (Tina Ndoh): Here is follow up info from Janine: not only that but i just found out that i have an increased risk of cancer at my implant sites - which i am more than willing to live with considering the benefits of my implant my surgeon also does the deep brain stims and I have met some of the patients and seen how much it helps them

Steve Helms Tillery: I think we are all in favor of prevention, but we have not found preventative measures for a whole lot of disorders

janine w CA to Patrick Hamlett, bob, Tina Ndoh: not only that but i save my insurance company lots of money by having the implant - and i'm on my second system - i wasn't kidding the other night when i said that i had to recharge...

Diana I GA: can you speculate on the merits of enhancement vs remediation as it applies to giving people an advantage in physical feats or mental challenges?

Moderator (Tina Ndoh) to janine w CA: Janine, thanks for sharing your experience with the group

Steve Helms Tillery: Janine, thank you for that input. I think it's important to realize that, even with all the limitations in our capabilities, we would like to help as many people help as possible.

An L CO: Prevention ideally yet focusing on current needs is also just as important

Moderator (bob): Team 2 - You have 5 minutes until handoff to Team 3. Please refrain from introducing new questions while Dr. Tillery catches up on the ones already asked.

Trisha B. AZ: Education is the preventable measure.

An L CO: Intelligence is different than applicable wisdom

Trisha B. AZ: Dr. T are you jazzed about the future?

An L CO: Gracias Assistant Professor Tillery

Steve Helms Tillery: Regarding some of the darker questions ... I think that Dr. Berry's points about having a careful evaluation of these technologies as they become available is crucial. There are researchers working on neural chips that they hope can be used to help with memory disorders for example. Well in my work I can tell you that many people often ask why we limit ourselves to basic communication or control of a robotic arm, but instead think about controlling some kind of super strong arm, or a fast wheelchair, or some other super skill. I think it's inevitable that these issues will come up if it becomes possible to offer memory or cognitive enhancements, and we need to keep on top of that.

Steve Helms Tillery: Trisha, yes, Very Jazzed!!!!

Steve Helms Tillery: Short finger break here...

Marissa S WI: Thank you for your time and helpful input, Professor Tillery.

Steve Helms Tillery: My pleasure... regarding cost questions, there is a report online, and I will try to find a link to it before the session is finished

Teresita B CA: Good luck in your continued research.

Moderator (bob): We are ready to switch to Team 3. Get ready. Team 2 will be deactivated.

emily m NH to Patrick Hamlett, bob, Tina Ndoh: Hello-

James B AZ to Patrick Hamlett, bob, Tina Ndoh: How much, if any, is private industry being courted to help fund nano-research to ease taxpayer burden?

Moderator (bob): Team 3 - You are now active.

Nichole C Co: Thank you for joining us today. Welcome.

Steve Helms Tillery: Thank you Nichole, it is a pleasure

Angel D. NH: Yes, thank you for your time.

Lynda Z AZ: Sorry Dr. Tillery, for addressing you as Steve (that is for when we have a beer after work). It didn't click for me that you were our expert. In deference to your education and work, I will address you as Dr. in this venue.

Angela C CA: Thanks for being here, Dr. Tillery.

Moderator (Tina Ndoh): Message from James B: How much, if any, is private industry being courted to help fund nano-research to ease taxpayer burden

Steve Helms Tillery: No worries Lynda ... the report on the projected industry in neurotech can be found here:
<http://www.neurotechreports.com/>

Johan B Ga: Johan...wouldn't most of the cost be subsidized by the Gov't

Angela C CA: Dr. Tillery: I would like to return to the questions about cost: Do you think (in general) an increased reliance on complex technology contributes to the rising cost of healthcare?

Angel D. NH: But then we run into the same issues, what issues get what money.

Nichole C Co: I am really excited about what can be done with nanotechnology. Is there any particular issue that concerns you personally?

Lynda Z AZ: If the devices you are working on are perfected to the extent that they are safe and they work, how expensive would they be, not including the surgery?

Angel D. NH: What is the potential for something like the "music training" in Clockwork Orange?

Angela C CA: The statistics show our country is spending more and more on medical care, but we're not getting any healthier. Do DBS, implants, etc, aggravate this problem?

Steve Helms Tillery: To this stage, most of the main research I'm familiar with has been funded by taxpayer funds. Much of this comes from the National Institutes of Health and DARPA. However, as technology comes online and begins to look like it might be marketable, private companies and foundations begin to play a role. For example, the Mann Foundation has had a major role in funding research into cochlear implants. Likewise, some of the clinical trials I described earlier were funded by investment funds to Cyberkinetics.

emily m NH: Hello- I hear a lot about patents within pharmaceuticals & agribusiness. Not necessarily for the best of the public but for the profits of specific private companies (and extending patents through regulation manipulations). Do you see nanotech following this pattern?

les k wi to Patrick Hamlett, bob, Tina Ndoh: i hope it's not a problem but i might have to leave in about ten mins..

les k wi to Patrick Hamlett, bob, Tina Ndoh: something urgent came up

Moderator (Patrick Hamlett) to les k wi: Les: Ok

Steve Helms Tillery: The devices themselves typically cost somewhere in the few to tens of thousands of dollars, but it is actually difficult to

factor out the cost of the surgery, as that usually dominates the cost of the application. For example, a cochlear implant costs 60 - 100K, including the surgery. The price of the device is wrapped into the procedure, but without the procedure the device has no value.

Johan B Ga: It seems all of the private sector would accelerate the technology, mainly and obviously for profit

Lynda Z AZ: Dr. Tillery, I have heard people who feel that allowing genes to be patented was a mistake. How do you feel about that and would patenting be involved in your work?

Steve Helms Tillery: The mixing of private sector with public sector is an interesting and difficult problem. It would seem obvious to me as a researcher that the private sector would be most interested in high quality products, but then incidents like those we hear of with drug marketing remind me that the private sector really only has one agenda, which is to make money. I don't think that this is necessarily evil per se, but I do think that it is something we should bear in mind when there is the possibility of harm to individuals if products are not honestly and openly evaluated and tested. This should be one benefit of the taxpayer based system, that all of us should be insistent that work performed under taxpayer support be done in an open environment, without hiding things for any particular reason. If I begin to patent my work however (and yes, I have filed for a patent, but did not follow through), then I have a need to protect the technology that I am developing from my competition.

Teresita B CA to Patrick Hamlett, bob, Tina Ndoh: Does private insurance/govt medical care cover cochlear implants at this time?

Steve Helms Tillery: It's a rather complicated knot, and I don't have good insights into how it should be untied, except with lots of honest dialogue, and open discussion of what is going on with these technologies and how the market is responding to them.

Angel D. NH: But how can we guarantee other countries will follow the same rules of disclosure and caution?

Steve Helms Tillery: Nichole, I am very fortunate to be blessed with good health as is my family, so this work for me is a fulfilling blend of science and social impact.

Moderator (bob): While we await a response from Dr. Tillery let me point out that we have two more experts scheduled for Thursday (20th). Teams 4, 5, 6 & 1 (in that order) will be active for questioning for one half hour each.

les k wi to Patrick Hamlett, bob, Tina Ndoh: yay!

Johan B Ga: Johan Ga. if the technology is beneficial to humankind, it seems it would be expedited and that your patent would happen quickly

les k wi to Patrick Hamlett, bob, Tina Ndoh: i need to go... see you all thursday

Moderator (Tina Ndoh) to les k wi: Thanks Les, see you Thursday

foserf GA to Patrick Hamlett, bob, Tina Ndoh: lost connection now back

Don S WI to Patrick Hamlett, bob, Tina Ndoh: Bob - can you tell us who our expert will be so we can have appropriate questions in mind?

James B AZ: Since our own personal healthcare is dependent on our own insurance policies, wouldn't it be useful to include insurance companies in r&d? This could help alleviate possible problems because they would be the ones paying the claims if a product fails or has harmful side effects.

Nichole C Co: I think there is lots of positive potential. We were given the opportunity to survey individuals regarding this type of technology. Unfortunately, I found many people pessimistic and very untrusting. In order for it to work we need to work together as a society. I really hope this can happen.

Steve Helms Tillery: Angel, that is a great question, and I think we should be cautious about how we handle what goes on in other countries. Many people worry that other countries might engage in unfair trade practices, or unregulated research that could harm subjects, patients, etc. This is a good worry, and one response it seems to me is to insure that we continue to produce well educated students who are interested in science and technology who can help maintain our position as a leader in the development of both ideas and technology. I have seen that there is a concern here about ethics and ethics training, and I'm in favor of pushing that, but I'm more concerned about science literacy and the role that a lack of literacy plays in shaping the public policies towards science education.

emily m NH: If the private sector can accelerate the technology for profit (reap the rewards) can we mandate a way that these same companies are held accountable to any short-term/long-term negative effects (not just with lawsuits, but that the company is responsible for the product in its entirety - good & bad)? I have heard that certain groups are trying to do that with the effects of dealing with the "remains" of obsolete computers.

Johan B Ga: If possible how would the implants be upgraded

Lynda Z AZ: We have to be careful about thinking profit is always bad. Many moral people work for profit and profit drives many helpful experiments.

Angel D. NH: And who would pay for the upgrades?

Angel D. NH: And what if your implant was no longer being upgraded?

Angel D. NH: Hopefully your chip is not a dvd-because blu ray is now winning.

Steve Helms Tillery: Emily and James, I think those are interesting ideas. I do think that companies should be held liable for their actions and decisions, but in the cases where it has happened, it has sometimes seemed to be dominated more by public outcry and political maneuvering than by honest evaluation of the impact of the technology. An odd case in point would be breast implants, where despite a lack of scientific evidence regarding the health aspects of silicone leakage, companies paid enormously. This is also I think a good case with respect to enhancement, since the potential for enhancement is obvious, and yet one can envision cases where the implants might be therapeutic as well.

Moderator (bob): While we are waiting again - Please note that I posted a slide displaying Thursday's expert guests on the whiteboard. Their written responses will be available at the website tomorrow (one is already up). Please review these responses to prepare for the session.

Moderator (bob): Again - Teams 4, 5, 6 and 1 will be active in that order for on half-hour each.

Angela C CA: Dr. Tillery: can you clarify when you said "companies paid enormously"? Were these insurance companies? Or the makers of the implants?

Steve Helms Tillery: Great questions on how implants will be managed. Many implants are unchangeable once implanted except for firmware which regulates how the electronic components of the implants behave. This is true for pacemakers, deep brain stimulators, and cochlear implants. Careful design has led to implants that could be "upgraded" without requiring explanation, or new implants. Instead the existing implants could be upgraded by programming through the skin, without even involving a surgical procedure. As technologies like wireless and Bluetooth improve, it will become easier to make substantial programming changes to the implants.

Moderator (bob): Team 3, you have 5 minutes remaining. Please refrain from introducing new questions so Dr. Tillery can answer those already asked.

James B AZ: Thank you and Dr. Berry for your time and valuable insight.

Steve Helms Tillery: I'd like also to point out the obvious that technology can go off in surprising directions. For example, neuronal implants have long relied on using electrical devices both to get signals out of the nervous system, and to put signals into the nervous system. In terms of the brain, electrical stimulation is a rather blunt instrument, impacting large areas of tissue in ways that are very unnatural. This is one of the reasons that we are not certain why deep brain stimulators work. In the last year, a molecular biology has enabled us to take a gene from a light-sensing algae and make neurons into light sensors (you can read about it here:

<http://edboyden.org/05.09.boyden.html>). Now there is a rush to use this technology to provide a whole new way to make brain-machine interfaces, including for motor prosthetics like the ones I work on, cochlear implants, visual prosthetics, and even tactile prosthetics so that a prosthetic hand could provide sensation. This is one crucial reason

Steve Helms Tillery: we want to be cautious about how we regulate the technology... if we are over general, we can completely miss brand new trends in technology.

Moderator (Patrick Hamlett): Many thanks to our guest experts, Dr. Berry & Dr. Tillery -- good work all!!!

Angel D. NH: Night everyone.

emily m NH: thank you.

Charles P CA to Patrick Hamlett, bob, Tina Ndoh: Well, I feel enhanced and upgraded just having learned so much; thanks Doctors and Fellow Forum Folks! Goodnight!

Steve Helms Tillery: Thank you all for your insightful and thoughtful questions... I hope I have answered them well enough to inspire some curiosity

Nichole C Co: Thank you Dr. Berry and Dr. Tillery.

Abbey J WI: thank you

Virginia P WI to Patrick Hamlett, bob, Tina Ndoh: good night

Teresita B CA to Patrick Hamlett, bob, Tina Ndoh: Great expertise tonight!

Angela C CA: Thank you for your time!

foserf GA to Patrick Hamlett, bob, Tina Ndoh: Many thanks to the esperts

Dana A WI to Patrick Hamlett, bob, Tina Ndoh: To the Moderators--Would you consider an idea that might improve our chats with the experts? That is, would you consider holding individual questions in a queue for the expert--if it could be done with the technology we're using-- and releasing one as the one before it is answered? As we've been doing it, it's hard to tell sometimes which question the expert is answering--and oftentimes questions get skipped. The experts are clearly doing yeopersons' work as quickly as they can, but maybe if y'all could release the questions in some more orderly fashion, it might help. Thanks for considering.

Moderator (bob): We are about out of time. Dr. Berry is still with us on-line. Give Drs. Berry & Tillery a warm round of applause for their efforts tonight.

Teresita B CA to Patrick Hamlett, bob, Tina Ndoh: clap, clap, clap!

Johan B Ga: Johan B Ga thank you and goodnight

joseph p wi to Patrick Hamlett, bob, Tina Ndoh: thank you

Darlene J AZ to Patrick Hamlett, bob, Tina Ndoh: bye

Jonathan R GA to Patrick Hamlett, bob, Tina Ndoh: Thank you both for your time and insights.

alan h ca to Patrick Hamlett, bob, Tina Ndoh: good night

foserf GA to Patrick Hamlett, bob, Tina Ndoh: to all participants, I am proud to be associated with you on this project

Jonathan R GA to Patrick Hamlett, bob, Tina Ndoh: Goodnight everyone until Thursday ... I am beat!

Steve Helms Tillery to Patrick Hamlett, bob, Tina Ndoh: Is it dinner/beer time for me now?

Angela C CA: Our moderators-- may I make a suggestion for the future? It is much easier for me to read long responses when the expert "splits it up" or posts as he/she types.

Lynda Z AZ to Patrick Hamlett, bob, Tina Ndoh: why am I not on the participant list?

Angela C CA: That way we don't get a big chunk of text all at once.

Angela C CA: I don't know if others feel that way? Just an idea.

alan h ca: good job moderators

foster f GA: concur; a long response flashes and creates a backup

emily m NH: makes sense

Moderator (Tina Ndoh): Messages from participants:joseph p wi to Patrick Hamlett, bob, Tina Ndoh: thank you

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John E WI: very impressive responses by our guest experts!

magdav wi: I actually prefer the longer text...

Trisha B. AZ: Good night sleep tight

Moderator (Patrick Hamlett): Steve: You're done -- Thanks!!!

Steve Helms Tillery to Patrick Hamlett, bob, Tina Ndoh: My pleasure... goodnight

alan h ca: hey Angela...good questions tonight'

Madhavi D WI: wonderful discussions

Madhavi D WI: goodnite all

T Romanick Az: Yes that was a very informative session. Goodnight to all!

Lynda Z AZ to Patrick Hamlett, bob, Tina Ndoh: why am i not on the participant list?

Moderator (bob): Dr Berry - Many thanks.

John E WI: until Thursday.....

Dr. Berry: Thanks, it was great to participate.

alan h ca: good night everybody

Moderator (bob): See you Thursday. Hopefully you saw the message about who will be chat active.

Foster f GA: got it and looking forward

Lynda Z AZ: why am i not on the participant list

Trisha B. AZ: Lynda you are

Stuart S AZ: You are near the top of the list, Lynda

Lynda Z AZ: not on my computer

Trisha B. AZ: look up at the top

Foster f GA: bob and colleagues: GREAT JOB

Lynda Z AZ: ok. i'm back! now good evening

Foster f GA: Good night from GA!