Past, Present and Future of Genomes, Environments and Traits: 140 Characters at a Time

by Dan Vorhaus

The first annual Genomes, Environments, Traits (GET) Conference took place yesterday. The GET Conference was an incredible success, with panels, breakout sessions and presentations from all manner of genomic pioneers and futurists, as well as a tremendous audience, both in person and online. In the next few days I'll share a few thoughts about what we learned at the 2010 GET Conference, as well as what we might expect by the time the 2011 event rolls around. There will also be video from portions of the GET Conference available soon.

In the meantime, if you missed the conference, there was plenty of live Twitter coverage. Everything I tweeted from @genomicslawyer can be found below, and there's much more at the #GET2010 twitter notebook. Thank you to all those who helped cover the conference online, including GET Conference pioneers (Rosalynn Gill, Misha Angrist), moderators (Carl Zimmer, David Dobbs, Dana Waring Bateman), journalists (Edward Winstead, Emily Singer, Kevin Davies, Aaron Rowe), sponsors (Priscilla Oppenheimer), exome sequence winners (Jonathan Eisen) and many, many more.

Now for Genomes, Environments and Traits in 140 character snips:

- And with that #GET2010 draws to a close (except for the cocktails). Thanks to everyone that joined us in person and remotely.
- #GET2010 voting on the winning exome sequencing right now...and the winner is @phylogenomics!
- Conde: showing demo of the @Knome consumer browser. Very slick interface, though it costs w/ hefty price tag #GET2010
- Conde: have come a long way from when they launched (at a price of $350K / sequence). Trying to build Rosetta Stone for genomics #GET2010
- Final piece of #GET2010: Jorge Conde of @Knome is giving away a free exome sequence. Winning idea to be selected by audience via live vote
- Detailed coverage of Ion Torrent winners at #GET2010 from @bioitworld: http://bit.ly/c1SuzZ
- First Ion Torrent winner: John Iafrate, Long Le from Mass Gen. Second winner: Mitchell Sogin from MBL at Woods Hole. #GET2010
- Rothberg: giving away machines for cancer, safe water research. Goal is to democratize sequencing in the same way as computing #GET2010
- Ion Torrent actually giving away a pair of machines at #GET2010. One for cancer sequencing in clinic, one for safe water detection
- Jonathan Rothberg, Ion Torrent: describing the machine he's about to give away. "Watson meets Moore" #GET2010
- Wrapping up a great #GET2010 conference. Awards presentations from Ion Torrent and @Knome. Will have live voting for exome seq coming up
- Enriquez: areas (e.g., Singapore) may not succeed if they are unwilling to tolerate difficult ppl. You need the right climate #GET2010
- Enriquez: moving from reading to copying to understanding to writing life code. And that will be a big deal when we get there #GET2010
- Enriquez: little labs that an build bridges will generate large economies. That's how we move economy, healthcare forward #GET2010
- Enriquez: one difficulty is scientists who continue to focus on research, not the bridges to commerce #GET2010
- Enriquez: describes Harvard as a "desert of an ecosystem," especially in comparison to MIT, Stanford, etc. Why is this? #GET2010
- Enriquez: why are certain places (MIT) so good at building this bridge, while others (Harvard, except HMS) are so lousy? #GET2010
- Enriquez: we need to grow the economy, which means we need to build a bridge to commercialize these technologies #GET2010
- Enriquez: genomics data is becoming so massive that it is beginning to drive large-scale industries (e.g., IBM, Intel development) #GET2010
- Enriquez: big companies - GE, Dupont, etc. - are leveraging this data. This is not all little startups #GET2010
- Enriquez: the growth here is spreading way beyond pharma, the way IT eventually mushroomed outward #GET2010
- Enriquez: if I was going to be investing in 10-15 years, I'd want to be focusing on the brain today. Will be big generator of cos #GET2010
- Enriquez: we now have single labs (eg Church) generating economies equivalent to small countries. This transition is disruptive #GET2010
- Enriquez: going to require exascale computing to manage data on this scale + ability to generate data surpassing ability to store #GET2010
- Enriquez: first zettabyte of data was generated by human species in 2009. Thinks single hospital will deal with that in 5-6 years #GET2010
- Enriquez: moved from human genome project (bounded in size, 3 billion bases) to an unbounded project: G+E+T. Much more complex #GET2010
- Enriquez: points out that the composition of meetings like #GET2010 is changing. Seeing ppl, companies we weren't seeing 2-3 years ago.
- Final Prototypes of the Future speaker is Juan Enriquez of Excel Ventures: "Bridges to Commerce and Other Dirty Words" #GET2010
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• West: now turns to sequencing. What data will that provide that genotyping didn’t? Describes process, consent to data #GET2010
• West: used raw data download feature from @23andMe. Huge dataset across family, analysis conducted in Excel #GET2010
• West: decided to use family genotype data to examine compound heterozygosity for DVT. #GET2010 (What qs were you asking at 17?)
• West: deep vein thrombosis as ex: diagnosis enables direct treatment, reduces risk. But not straightforward to measure. #GET2010
• Agreed. RT @phylogenomics: Anne West, high school student at #GET2010, is remarkably polished presenting before nobel winners, CEOs, etc
• West: starts by reviewing her family’s medical background. history of Alzheimer’s, heart disease, cancer, diabetes, etc. #GET2010
• Now up, Anne West (Harker High School) discussing her family’s whole genome sequencing (Illumina) / genotyping (23andMe) #GET2010
• Lincoln: need quality samples to get meaningful results. Low quality tumor samples = low quality results. Garbage in, Garbage Out #GET2010
• First q from @phylogenomics (from Twitter to #GET2010 floor). Unpublished genomes shouldn’t count. Lincoln agrees w/ need for public genomes
• Lincoln: challenges: determining what data means (interpretation), determining what data to keep (storage) #GET2010
• Lincoln: learned a lot about DNA sequencing, cranking out data. The bottleneck is finding high-quality samples & interpretation #GET2010
• Lincoln: will be “shocked” if don’t end 2010 with thousands of sequenced genomes. Thinks fully loaded cost (data+analysis) is $10K #GET2010
• Lincoln: accumulating lots of data that is not even being seen let alone interpreted Need quality, low-level algorithms to min data #GET2010
• Lincoln: humans don’t just have one genome: cancer is a disease of genomic changes. Sequencing of tumor-normal pairs important #GET2010
• Lincoln: now describing differences between exome / WGS sequencing, using Miller family as example #GET2010
• Lincoln: need to look to families, prospective parents, newborns, pre-natal, healthy individuals, clinical cohorts, etc. #GET2010
• Lincoln: this is good, but the numbers need to get much larger. Genomes need to come from variety of groups. #GET2010
• Lincoln: ended 2009 with 100-200 genomes deeply sequenced (not all published); CG did 60 or so alone #GET2010
• Lincoln: this type of story is now becoming much more common. Will continue to do so as WGS expands #GET2010
• Lincoln: sequencing changed the clinical resolution. Avoided liver transplant, changed diet instead. Infant recovered #GET2010
• Lincoln: describing case study of WGS for hypercholesterolemic infant; found putative cause after few days of data analysis #GET2010
• Lincoln: starts with discussion of what GWAS has/has not shown (rare vs. common variant point) #GET2010
• Now up, Steve Lincoln from @CompleteGenomic talking about an infrastructure for the future of human genome sequencing #GET2010
• Q: do you believe in probiotics? Knight: not a believer (at least for brand he studied), but evidence not yet published #GET2010
• Knight: it’s a bit like weeding a garden with a bulldozer and hoping what grows back is what you want. #GET2010
• Q: do you recommend using anti-bacterial soap for hand-washing? #GET2010
• Describing #BioWeatherMap. @tgoetz has a great analogy: we are the Earth, the microbes are the weather passing over us #GET2010
• Knight: goal is to expand from dollar bills (churches vs. strip clubs) to other surfaces (crosswalk buttons, schools, etc.) #GET2010
• Knight: #BioWeatherMap can be a keystone example of open-access, citizen driven science. Still needs support #GET2010
• Knight: finishes with a call to action for #BioWeatherMap. Broad-scale sampling across environments, integration w/ PGP data #GET2010
• Knight: conclusions? diff ppl, diff sites harbor diverse microbiota. Prospects for personalized medicine are excellent #GET2010
• Knight: looking at microbiota on dollar bills, comparing those collected from churches vs “adult establishments” #GET2010
• Knight: describing microbiota sampling 20 min after birth. Sharp contrast in communities based on birth type (c-section v natural) #GET2010
• Knight: showing changes in his own phenotype as well based on gut microbes. Lost 60 lbs after trip to Peru, antibiotic regimen #GET2010
• Knight: now describing how microbiomc communities produces different phenotypes in the host (mice obesity) #GET2010
• Knight: sampling microbiomes at 27 different body sites. “That’s a lot of different places to stick a q-tip” #GET2010
• Knight: research shows that very few microbial “species” are shared. Same results in human gut & human hands. #GET2010
• Knight: describing his open source data integration analysis pipeline (QIIME). Sequencing, barcoding, tree creation #GET2010
• Knight: is there a Wallace-esque biogeography line that separates microbial keyboard on our keyboard? Knight’s data says yes #GET2010
• Knight: returns to Darwin. Recall that most life, and most biological evolution, is microbial #GET2010
• Knight: microbial abundance raises the question: how human are we? #GET2010
• Knight: phenotypes vary, but are highly similar at genetic level. “You are not a beautiful, unique snowflake” #GET2010
• Knight: from Dawkins, van Leeuwenhoek to the Human Microbiome Project. We know there as many e.coli in your gut as ppl on earth #GET2010
• Agreed. RT @phylogenomics: Anne West, high school student at #GET2010, is remarkably polished presenting before nobel winners, CEOs, etc
• Now up at #GET2010, Rob Knight (Boulder) discussing the BioWeatherMap for microbial communities: mapping what we are all exposed to
• Lipkin: next steps: sample prep, Dx & surveillance platforms, sequencing, bioinformatics, serology, gene-env-timing interactions #GET2010
• Lipkin: “it’s not the pathogen, per se, but the host-response” / genomics in isolation is not enough #GET2010
• Lipkin touching everything from Poe to cryptography to linguistic hierarchies, all in the name of virus ID. #GET2010
• IL’s description of his WHO work re: virus identification sounds like something straight out of Hollywood. #GET2010
• IL: now describing research investigating rapid, mysterious decline of bee population #GET2010
• IL: important not to focus on a single genetic/ neoliberal universe to understand how they cause disease #GET2010
• IL: showing examples of identification of novel disease-causing agents using genomic sequencing #GET2010
• IL: shows a tourism slide just prior to SARS: “Hong Kong: It will Take Your Breath Away” #GET2010
• Bit of misinformation RT @23andMe: @genomicslawyer @phylogenomics @dgmacarthur our SAB is still there, no changes to report
Back for the "Prototypes of the Future" sessions at GET2010. Ian Lipkin (Columbia) now speaking about infectious disease.

Jim Watson, IP session: "I hate Myriad the way some people hate Goldman Sachs." GET2010

That's it for the GET2010 breakout pitches. Now we disperse to learn, discuss. Back in a few hours for the afternoon sessions.

TG: discussing the idea that genetics is information - like so many other types - and has the potential to help make better choices.

Moderator & presenter @tgoetz from @Wired on Personal Health. How genetics illuminates the life path we take, the choices we make.

DD: what are possibilities, problems as personal genomes produces info re: behavioral genes. How to understand, use that info?

Journalist @David_Dobbs on Predicting Temperament. Looking at recasting "risk genes" in a more nuanced light.

RD: topics incl. how genetics changes nutrition, what we eat (and where), and what health benefits are available.

Richard Delerins (French Chef, UCLA genetics researcher) on Nutrition & 21st Century Cuisine.

JC: patents help display the always challenging intersection between law and science. Law lags behind, as usual.

John Conley, RBH on IP: boils pitch down to 2 wrds: Myriad Genetics. How will Myriad, etc. impact development of personal genomics?

RP: new data suggests genotyping can reduce hospitalization due to drug usage by 30%. How do we implement this in healthcare?

Ryan Phelan, DNA Direct on Genes & Drugs. Topic: translating actionable genomic info into the practice of medicine, today.

DW: genetics can become more accessible. Question is what are best strategies to make genetics relevant, accessible?

Great idea for GET2011 RT @andrewhessel, @phylogenomics $100 vs $1 metagenomes would be terrific. Would help with funding too!

Dana Waring, Personal Genetics Education Project on Education. Preparing next generation for intro of genetics into daily life.

Jason Bobe (PGP) on DYT Genomics. If you like DTC genomics, you'll love DIY. If you hate DTC, you'll hate DIY even more.

PR: topics for discussion: ID recessive risk alleles, prenatal diagnosis, newborn screening, PGx, etc.

Philip Reilly, Third Rock Ventures on Disease. Remember: 1/6 of world's ppl does not have access to clean water. How do we improve?

GI: going to be describing BioWeatherMap, microbiomic sequencing of dollar bills.

Gerard Irzyk, Roche/454 on Desktop Sequencing & Analysis. Looking for feedback on how to make sequencing available to more ppl.

JT: investigating how genetics gives a better picture of the consumer, and how it will lead to novel consumer products.

JT: why consumer genetics? Cos like P&G are inherently involved in manipulating biology at individual level.

(Won't be able to live-tweet the breakout sessions; 10 happening simultaneously. Incentive to come in person to GET2011)

Getting started w/ the afternoon at GET2010. Breakout session "pitches" are beginning, starting with Jay Tiesman, P&G on Consumer Products.

That's it for the morning session from GET2010. Tweeting will be lighter in the afternoon during the breakout sessions.

Maxey: points out that genotype-phenotype associations require vastly improving our ability to describe, record phenotypes.

West: doesn't think it's a bad thing if people have patents and want to charge for it. If I could get a medical benefit I'd pay.

Church: discusses Myriad: whoever wins the court battle, the larger battle is being won by technology obviating (certain) patents.

Q: about genome sequencing and patent infringement (curious to see what the panel will say).

Church (going back to Bob Green's comment), agrees that there needs to be constant reevaluation of info based on outcomes.

Q: how will culture change through personal genomics? Will it be like private investigators being replaced by Google searching?

Green: we need ways to stratify information, determine what is useful vs. not useful.

Green: not all information is necessary beneficial to human health. Concerned about raiding of the medical commons.

Bob Green: science of discovery vs. science of disclosure, linked by science of health outcomes.

West: wishes his MD would take advantage of looking at his genome. It's only become more complicated.

John West: methylation is an important, natural extension of the technology. Will be part of rich datasets necessary to advance.

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● Church/Lucier: sees adoption of EHRs as a separate issue. Sequencing is fundamentally digital, will develop along parallel path #GET2010
● Q from @carlzimmer: is healthcare ready for personal genomes? Can you drop that data into a patient’s traditional medical record? #GET2010
● Lucier: understanding genomes is fundamental to science, & a viable biz. There are many applications beyond what we’ve discussed #GET2010
● Kruwilch: sees personal genomes as a slog - through public acceptance, privacy issues, science, etc. Why is this perception wrong? #GET2010
● West: preventative medicine fundamentally lowers costs, improves outcomes. #GET2010
● Q: are we going to just be generating needless medical workups, tests, etc. Will we overburden doctors? #GET2010
● John West: don’t sequence to find out about diseases we already knew we have. Learning new information that is actionable #GET2010
● Wests: MD didn’t find anything, but now they can monitor over time and detect - and treat - at early stage. Ex of why to sequence #GET2010
● Wests: talking about “exfoliation glaucoma”. No reason to suspect risk of this, but learned it from genotyping. Went to see MD #GET2010
● Changing the panel one last time: back on stage: George Church, Anne and John West, Greg Lucier #GET2010
● Gill: enthusiasm & investment) created technologies, progress we could have never imagined. So there is reason for excitement #GET2010
● Dyson: discussing @23andMe SAB, and how attitudes changed (opened) about what data could be returned #GET2010
● Dyson: scientific progress proceeds one funeral/investigator at a time. Getting the public engaged speeds this #GET2010
● Lupski: science is hard; anybody who doesn’think that is fooling themselves. Will take time to separate signal from noise #GET2010
● Q for panel: “is there a disconnect between enthusiasm at #GET2010 and how complicated/hard this is?” #GET2010
● Kim: has also sequenced wife and two kids as well. Interested in whether kids share the same genetics risks he does #GET2010
● Kim: based on genotype, phenotype data (temporary vision loss) he is taking preemptive steps to try to address risks #GET2010
● Seong Jim-Kim now talking about learning of his own risk for macular degeneration, usefulness of his own sequence #GET2010
● Lupski as Columbo for genetics. Moving from SNPs to gene panels, and soon will simply do whole-genome once #GET2010
● Lupski: we’ve learned an incredible amount over the past years. It’s not all in the base pairs. We need sequencing #GET2010
● Lupski: now discussing his exp (and that of his family) w/ Charcot-Marie-Tooth disease #GET2010
● Lupski: as MDs, we should not be paternalistic & control what info ppl can have access to. Should instead tell them what it means #GET2010
● Flatley: we have abstracted those which creates actionable information; we need to do the same for whole-genome sequences #GET2010
● Flatley: remember that genetic tests are done every day; in most cases neither MD nor patient understands underlying technology #GET2010
● Lupski: but complications, fear, should not stop us from learning (and he is most interested in medically actionable variants) #GET2010
● Lupski: it is hard. We don’t understand function of 90-95% of human genes. That is humbling #GET2010
● Angrist: if we focus solely on individual understanding/value we lose sight of the value this contributes to science #GET2010
● Q: are the stories our genes tell us simply too hard for (some) individuals to understand? #GET2010
● Gill: emphasizing that understanding neither starts nor stops at the genome. You have to focus on environmental components as well #GET2010
● Dyson: we are helping people understand their own genetics. If they can understand the Red Sox, they can understand @23andMe #GET2010
● Dyson: it will take a long time to understand personal genomes. So there is value in starting now #GET2010
● Dyson: thinks MDs are good when you need them. But shouldn’t be required for ppl to look at their own data. #GET2010
● Flatley: philosophically agree that no MD should be necessary, but thinks involving one is most robust regulatory / safety approach #GET2010
● Flatley: my MD refused to write a prescription for full genome sequence (required by $ILMN) b/c he knew nothing about it #GET2010
● Lupski: says @23andMe just disbanded their scientific advisory board? (Did I hear that correctly?) #GET2010
● Dyson: “Can’t talk to god yourself; you need a priest. But we are heretical, just like Gutenberg” #GET2010
● Dyson: @23andMe also received letters from states, and adapted to comply. States like MDs as gatekeepers. #GET2010
● Dyson: @23andMe has a slightly different story, but the same basic issues exist. Give information, not advice #GET2010
● Gill: received cease & desist letters from CA, NY and MD. Thought regulations didn’t apply; regulators didn't. Uncertainty is tough #GET2010
● Gill: challenge Sciona ran into was access to capital, not regulatory hurdles. But we need is greater clarity in what is allowed #GET2010
● Panelists, including Gill and Dyson now being asked about regulatory enforcement / hurdles. Are they worried about this? #GET2010
● Flatley: still trying to get the iPad app right internally. Plenty of underlying issues, but this is where we see the future #GET2010
● Flatley: have ported application from iPhone to iPad. Allows sharing of genome with MD, pharmacist, family, etc. App still internal #GET2010
● Krulwich asking Flatley about his prototype illumina iPhone app. Is instantaneous analysis the future? #GET2010
● Transition now from the burdens of genomic sequencing to the benefits - for individuals, as well as the cos, investors #GET2010
● Stepping down: Maxey and Gates. Coming back up: Flatley, Gill, Jim Lupski, @MishaAngrist, @edyson, Seong Jim-Kim #GET2010
● Maxey: not all donors want to be found; but that’s a minority. Most find it a great experience to reconnect w/ donor-conceived kids #GET2010
● Maxey: no reason/value for denying ppl access to their genetic information, including sperm donor children seeking to locate him #GET2010
● Maxey: my identification was made much easier by being in the PGP (participant #5); Maxey understood and was in favor of this #GET2010
● Maxey: donated sperm numerous times in the 80; years later he was located by his children. It was a “wonderful day” #GET2010
● For background on Maxey's story, see this Newsweek feature: http://bit.ly/4Dh5aO #GET2010
● Gates handing it over to Kirk Maxey to talk about re-identification with genetic information (in the form of sperm donation) #GET2010
• Gates: there are cultural diffs, but everyone shares the impulse to understand one's ancestors. Just need to tie in genetics #GET2010
• Gates: the world values genealogy (aside: Mormons are "the Borg of genealogy - eat up all the records we can find") #GET2010
• Q: is this a peculiarly American set of values? Would the same story resonate in France or in China? #GET2010
• Gates: this allows us to see ourselves as a genetic bouillabaisse, which is what we are. A new measure of identity #GET2010
• Gates: this was the first time he ever saw white people being disappointed that they didn't have white ancestry #GET2010
• Krulwich: this is a celebration of "mutt-dom" that is fantastic. Gates: yes, and people don't mind" #GET2010
• Gates: expected emotional peak to be genetic ancestry; instead it was locating genetic relatives by name That made it relevant #GET2010
• Gates: has had to raise $21M for his various genealogy secrets. Now describing how he landed Oprah #GET2010
  • (Skip Gates has landed at least one joke every 90 seconds on stage. Playing the crowd at #GET2010 even better than Jim Watson)
• Gates: you get greater breadth and depth of information. Helps tell the larger identity narrative #GET2010
• Q: is whole-genome sequencing important for genealogy? Does it add much that genotyping, Y DNA, mtDNA doesn't? #GET2010
• Gates: it is tough to get informed consent. Considers himself reasonably informed, but took him a long time. #GET2010
• Gates: that was irresponsible science. They should have been asked, provided informed consent. Admires PGP model #GET2010
• Q: what happens when the story that is shared isn't one that you want to hear (e.g., Havasupai Indian) example? #GET2010
• Gates: comparing genealogy to photography. Both are representations. We need to learn how to read a genome way we read a photograph #GET2010
• Gates: just a bunch of bands and colors, but it was a tremendously emotional moment. "Like my mother coming back from the grave" #GET2010
• Gates: first father-son to have genome fully sequenced, as well as first African-Americans #GET2010
• Gates: every day his brother calls, he worries his dad has died. Wanted to immortalize his father and make the genome public #GET2010
• Gates: high point of Faces of America was showing unexpected relatedness to the guests. Putting faces, timelines to haplotype grps #GET2010
• Gates: describing how he put together Faces of America: took the Noah approach to genealogy - 2 from each background #GET2010
  • Break over. Now on stage, Skip Gates (PGP#12) and Kirk Maxey (PGP#15) talking about tracing relatives through genetics #GET2010
• Quake: qualifies that anybody with employer-sponsored healthcare will have $0 cost. Dyson points out that isn't everybody. #GET2010
• Dyson: disagrees. Nothing is cost-free. Who is investing, and what is returned on that investment. #GET2010
• Dyson: the cost is $0, George is right. Thinks not just sequencing, but also interpretation will go to $0 as well. #GET2010
• Dyson (in question to response of whether S99 is good enough, why pay $48K) in 2-3 years we won't do SNPs. "Why bother?" #GET2010
• Flatley who will have access? Goal is to make it integrated part of healthcare (eg every child born is seq). Still 10 years away #GET2010
• Flatley: we need 100s, 1000s of genomes in a single place. We're still ramping up to that. Need to sequence first. #GET2010
• Break over. Now on stage, Skip Gates (PGP#12) and Kirk Maxey (PGP#15) talking about tracing relatives through genetics #GET2010
• Dyson: @23andMe will be offering a whole genome sequencing service "some day," but ancillary services will remain critical #GET2010
• Dyson: more than pure sequencing (eg what @23andMe is doing) is important to consumers; saw a "huge response" to DNA Day $99 sale #GET2010
• Flatley: if the price drops to $0, as Church says, then we have a problem #GET2010
• Flatley: thinks the market is "incredibly elastic"; concerns about commoditization, but volume will expand rapidly #GET2010
• Dyson: one reason Chinese market is growing is that they are not as worried about the ethical / privacy issues #GET2010
• Watson back on stage to talk about collaboration between Cold Spring Harbor & China #GET2010 Still believes US is better at technology
• Flatley: bioinformatics means: storage of data, sequence alignment, interpretation of data. Need all 3 to have something meaningful #GET2010
• Dyson: China is becoming the dominant market. Flatley: we have one customer who will be end of year have capacity of entire US #GET2010
• Flatley: bioinformatics, sample prep are becoming the dominant component of cost #GET2010
• Flatley, Quake, Dyson and Seong-Jim Kim discussing price of sequencing #GET2010
  • (Apologies for temporary darkness. Twitter thinks I'm a robot - too many tweets from #GET2010)
• Anne West: not planning to publish her own data, possibly at 21, probably not until later. Her brother also keeping data private #GET2010
• JW: Anne will be talking this afternoon about what the family has learned, but first lesson is data is complicated; takes time #GET2010
• JW: in our family, the information is medically actionable today #GET2010
• JW: talking about the risks of sequencing, but what about the risks of NOT sequencing; not having access to actionable information #GET2010
• John West: he's not sick, but he's still at risk (embolism as an example). #GET2010
• John West: first point: why are we talking about risks of genome sequencing when @edysdon is talking about being shot into space? #GET2010
• AW: first genotyped by @23andMe, which led to Illumina sequencing. Prompted by father's embolism. Treatable, but need to know. #GET2010
• AW: thinks what is acceptable to talk about publicly changes with generations, although it's not as if there are no distinctions #GET2010
• Anne West talking about the Facebook generation's privacy preferences #GET2010 AW thinks her generation is much more open, public
• Angrist: if genomic science has taught us anything, it is that this information is not powerfully predictive #GET2010
• Angrist: helps that daughters will only receive probabilistic knowledge (mother's genome not public) #GET2010
• Angrist: tries not to think about the fact that, in time, new knowledge will crop up. Daughters will learn plenty from the internet #GET2010
• Angrist: biggest concern was daughters were finding out they were at risk from the internet; wanted them to find out from parents #GET2010
• Angrist: daughters are aware of the PGP (recommends "Here Comes Science" by They Might Be Giants for explaining DNA to kids) #GET2010
• Angrist: pre-tested for BRCA1/2 common mutations. Once those came back clean, his greatest fear was removed #GET2010
Angrist: his concern was BRCA status, given family history and his two daughters. Long family discussion before joining PGP

RK: What about "the Cassandra problem": learning something about future development of children that perhaps should not be known? #GET2010

Now coming on stage at #GET2010, @MishaAngrist, John West and Anne West #GET2010 to talk about sequencing and families

Flatley: makes a point that genomic sequencing is like credit cards online: uncomfortable at first, but pros outweigh the cons #GET2010

Flatley: worrying about theoretical bad sequencing is understandable, but need to tip the balance so costs outweigh the cons #GET2010

Dyson: disease is clearly important. But seemingly frivolous things (e.g genealogy) are important to the growth of the field #GET2010

Lucier: focus of why people should get sequenced is to solve disease. Not to dismiss consumer aspects, but priority to disease #GET2010

RT @tgoetz: Fwiw I'm on @npr's here&now today w @edyson talking DNA & health. Natl showtimes here: http://bit.ly/j445q #GET2010

RK: what about identifying which parent supplies certain alleles/trait? Has this created any interest among marriage counselors? #GET2010

GC: we encourage family enthusiasm and discussion around participation in the PGP #GET2010

GC: what about if you have a twin and they disagree? GC: PGP policy is that identical twins cannot join unless both join #GET2010

TW: became concerned once she became a mother. Thinks her daughter should make the decision for herself. GC went ahead, TW did not #GET2010

TW: their family treats sequencing as a matter of personal choice. Describing her own reservations about publishing her own seq #GET2010

Ting Wu (George Church's wife) talking about how genomic sequencing has been discussed in their family. #GET2010

RG: raising awareness of the value of DNA as information is important. "guess what, it didn't kill me to find out about my DNA" #GET2010

JW: lack of concern reflects his age. At 20 he would have worried. At 80, what is there to worry about? #GET2010

JW: "I didn't think about sequencing because I have other things to think about" #GET2010

Watson stepping down. Now on stage at #GET2010: Esther Dyson, Rosalynn Gill, George Church & Ting Wu #GET2010

JF: biggest argument against sequencing was implications for children. But it is a personal choice (Flatley's wife not interested) #GET2010

JF: similarly unconcerned about privacy issues. For me, sequencing was really not a question. #GET2010

GL: thinks the privacy issues will simply be handled. Wants to lead by example for personal genomics #GET2010

GL: for his family, because of his biz, this has become a very familiar conversation. Sequencing the family is "next logical step" #GET2010

JF & GL: both discussed with their families, and not with their boards of directors #GET2010. Lucier going to sequence his whole family nxt

Q: should an executive of a multi-billion dollar company publish their genome? #GET2010 Flatley's is up, Lucier's is coming up soon

Watson stepping down. Now on stage at #GET2010: Jay Flatley and Greg Lucier to talk about biz of genomics

JW: limiting factor at this point is intelligence of scientists, not $. Encourage ppl to put genomes online ("send them a pie...") #GET2010

JW: the ethical objections to genomic sequencing are just "crap" - a minor blip on the radar screen #GET2010

JW: "I am very happy that we can do it. Don't have to talk about $. Just whether humans are bright enough to get its act together." #GET2010

Q: for Watson: are you amazed that we are now at a point that we can do intimate investigations of an individual's inheritance? #GET2010

JW: thinks PGD will be very important in the future (e.g., for bi-polar disease) People will have diff opinions re: nasty traits #GET2010

JW: is lowering the price of genomic sequencing enough? JW: it should be. Immoral not to pursue it #GET2010

JW: the argument for sequencing is the same as for motherhood: why wouldn't you just do it? #GET2010

JW: we should sequence 100,000 genomes. Cost will be nothing, interpretation will be everything. Goal is to find pathways #GET2010

RK: does sequencing complicate parenthood? JW: why should it? It's an absurd sentence. It's just genetics #GET2010

JW: we should sequence 100,000 genomes. Cost will be nothing, interpretation will be everything. Goal is to find pathways #GET2010

What did he learn? JW: lactose intolerance, cytochrome P450 (which changed my beta-blocker medication). That was very useful #GET2010

JW: "I didn't think about sequencing because I have other things to think about" #GET2010

JW: lack of concern reflects his age. At 20 he would have worried. At 80, what is there to worry about? #GET2010

JW: at this stage of my life, I tend to say yes. Willing to be sequenced (other than APOE)(and we know how that worked out) #GET2010

Now coming up on stage: @MishaAngrist, John West and Anne West #GET2010 to talk about sequencing and families

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● GC: oldest PGP volunteer is PGP #11 - Skip Gates, Sr. Demonstrating allele identification, interpretation tool #GET2010
● GC: if we act as a community, we can improve genomic interpretation. http://evidence.personalgenomes.org #GET2010
● GC: “how many complete genomes are there?” (Putting aside the missing 7%), probably around 17 #GET2010
● GC: now discussing specifics of PGP. For more visit personalgenomes.org #GET2010
● GC: even if you can encrypt data, controlling access to the material itself is difficult #GET2010
● GC: on re-identification: we can promise privacy, but that would be disingenuous. And what about cell lines? #GET2010
● GC: “Who to sequence?” Need to embrace non-experts. Families are the best non-experts to embrace. Amazing what you can from family #GET2010
● GC: “Why public GET datasets?” Remove barriers to research & serendipity. We want to encourage imagination. #GET2010
● GC: “What if there is no cure? Do we not want to know?” GC wants to know. Inspired by Odone, Fox, Rienhoff, Heywood, Melton, etc. #GET2010
● GC: Genetests: 1770 genes: highly predictive & medically actionable. Why don’t they show up in DTC tests? #GET2010
● GC: “Are rare diseases so rare?” Add them up and 10% of us have a rare disease, and more are carriers #GET2010
● GC: “Should we cure genetic diversity?” Tricky question comes with trade-offs. Depends on the gene in question. #GET2010
● GC: “what if the gov’t started testing babies for intelligence genes?” This already happens: PKU #GET2010
● GC: #GET2010 more than just cheerleading. Imagine the unintended consequences of personal genomes - positive & negative
● GC: $0 genome comes w/ strings: ex: data sharing. What are other ways that the cost will be covered? Inspect your genome's label #GET2010
● GC: the endpoint is the $0 genome. Cost somebody something, but costs the individual nothing. #GET2010
● GC: “who is my choice for the seq technology winner?” Answer: "yes" (Puts up a list of 20 companies) #GET2010
● GC: over 200M base pairs still missing - that's a huge gap. #GET2010
● GC: "mission accomplished...except 7%" We haven't finished a single human genome yet. E.g, 20M base pairs missing on chromosome 1 #GET2010
● GC: history of DNA Day from 1953 to 2010. Focus on DNA structure, HGP and GINA. Interesting to see GINA elevated to that level #GET2010
● GC: beginning with a Q&A of himself. First question: when is the next personal genomes meeting? #GET2010
● And we're off at #GET2010. George Church delivering intro keynote. Starts with a slide of nudibranchs...
● #GET2010 getting ready to begin. Agenda here: http://bit.ly/anBDd6 Morning will be free-flowing convo w/ genomic pioneers