

Indigenous Communities and the Genome: Lessons for the Microbiome

Paul Spicer
University of Oklahoma

Or Here We Go Again

- Genomic knowledge has proven intensely controversial in indigenous communities
- And I would argue that genomic fantasies are to blame
- But these fantasies arise as much on the scientific side as they do from communities
- And my take-home message today is that we are all better served by getting real about what this knowledge may mean
- And what we can actually expect from each other

Questions of Trust

- Onora O'Neill suggests that our current approaches to trust are wrong-headed
- that we emphasize accountability and transparency
- When instead we should be emphasizing our duties and responsibilities
- Especially relevant here, I think, is the duty to be honest

Lessons from the Genome

- We began work in native communities as part of the ELSI efforts funded with the development of the PDR
- Aware of the controversies regarding population genetics, we focused instead on medical research
- Most of which was led directly by NIH investigators
- We also invited representatives from as many emerging tribal research review entities as we could
- with the intent of generating a discussion about how this work should be done

What Happened Instead

- A very intense and difficult two days
- The anger from tribal communities was overt
- One prominent native scholar literally left the meeting in protest
- And questions of procedure were all but impossible to focus on
- Tribes were keenly sensitive to the “value” of this work
- which was not very much in evidence
- and so the question became not how to but why?

The Standard Line

- Researchers are accustomed to small gains, the hope of eventual significance
- Indeed, in my new liberal arts environment, I meet people who are literally focused simply on advancing their discipline
- And I'm enough of an intellectual to appreciate the beauty of that
- Problems arise, though, when we attempt bridge to other questions
- especially in response to community concerns

But There Is Intense Pressure to Do So

- Indigenous communities confront dramatic health disparities
- And have many basic needs for public health and health care infrastructure
- Let alone persistent problems of poverty more generally,
- including a significant failure to provide appropriate and valuable education

This Mismatch Causes Problems

- Given these needs, there is an obvious pressure to try to address them
- But the knowledge we are developing often has little direct relevance
- One unfortunate tendency is to act as if it could (or worse that it does)
- which raises serious credibility issues
- and generally leaves communities disappointed

Community Perspectives on Science

- A persistent criticism of scientists concerns their preoccupation with the data
- and with the limited fame we may enjoy
- So our protests about being misunderstood,
- and actually caring about suffering often lack credibility,
- and the sheer remoteness of the questions we ask
- often underscores this disjuncture

But Certainly That's Not Fair

- We've all ended up doing the work we do for mysterious reasons we're often called on to (re)construct
- But most of us recognize our shared humanity with the participants in our studies
- at least those of us who have human participants
- And emphasizing only our pursuit of knowledge would literally be indifferent to suffering,
- which I think is not generally true

Echoes of the HGDP

- I suspect that much resistance to genetic knowledge in native communities arises because of its apparent indifference to suffering
- But simply recognizing this and professing to care is insufficient
- We likely have these problems because communities need more than we have
- and we wish we had more than we do

We're Talking About Research, People!

- This was not lost on the tribal leaders I visited
- Who stopped me 5 minutes in to my ELSI presentation
- To clarify the utter irrelevance of research on research from their perspective
- And we certainly do not need research to identify many of the most pressing concerns in indigenous communities

So What Can We Do?

- The economic benefits of research are not lost on communities
- Indeed a persistent criticism of researchers concerns the benefits they get
- in contrast to what communities get
- And recent years have seen some notable experiments in broader distributions of the research enterprise
- Several US tribes are and will be taking an increasingly entrepreneurial approach in this area

Investments in Education

- But their ability to do so depends on the development of human capacity
- And here we certainly can do much much more
- In our second ELSI project, we focused on CU and its relationship to CO communities
- Indigenous and otherwise
- And many of us were struck by one critique especially
- That, from where community members sat, the University seemed to care much more for minority tissue than for minority minds

Which Brings Me Back to Village Schools

- Post-doctoral training programs are nice, to be sure
- And I understand they are central in many sciences
- But they do nothing to engage students with science and research
- The native-focused programs I've been involved with confront serious pipeline constraints
- and the problems are even more severe internationally

And Then Clinics, Sanitation, and Food

- Why are we surprised when our community consultations suggest that people need doctors?
- and clean water?
- and adequate nutrition?
- While we cannot expect the HMP to address these needs
- And I certainly have advised us not to pretend it can
- I'm not sure that this work is entirely irrelevant

Relationships

- Our work on trust consistently emphasizes the value of relationships
- Indeed our earliest relationships often form the substrate on which our notions of trust are based
- But O'Neill's persistent criticism underscores the impossibility of legislating trust
- While there is certainly much we can and should be thinking about in terms of research policy
- those of us who work in indigenous communities also need to answer these questions personally

Too Busy To Care

- A graduate student of mine shared with me this quote from the African village where he lived
- Clearly, our preoccupations show in our interactions with the world
- And are not lost here at home either

A Non-Scientific Conclusion

- While we may have very good reasons for the work we do,
- it seems clear we will not get where we want to,
- until we take the time to honestly understand the communities where our samples come from,
- to form lasting partnerships with them,
- just as they try to do with us,
- for work that is of value to them,
- even if it has nothing to do with the HMP!

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