



FOR BIOMEDICAL ETHICS

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*Hospital & Clinics • School of Medicine*

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# Citizen Science and Emerging Ethical Issues

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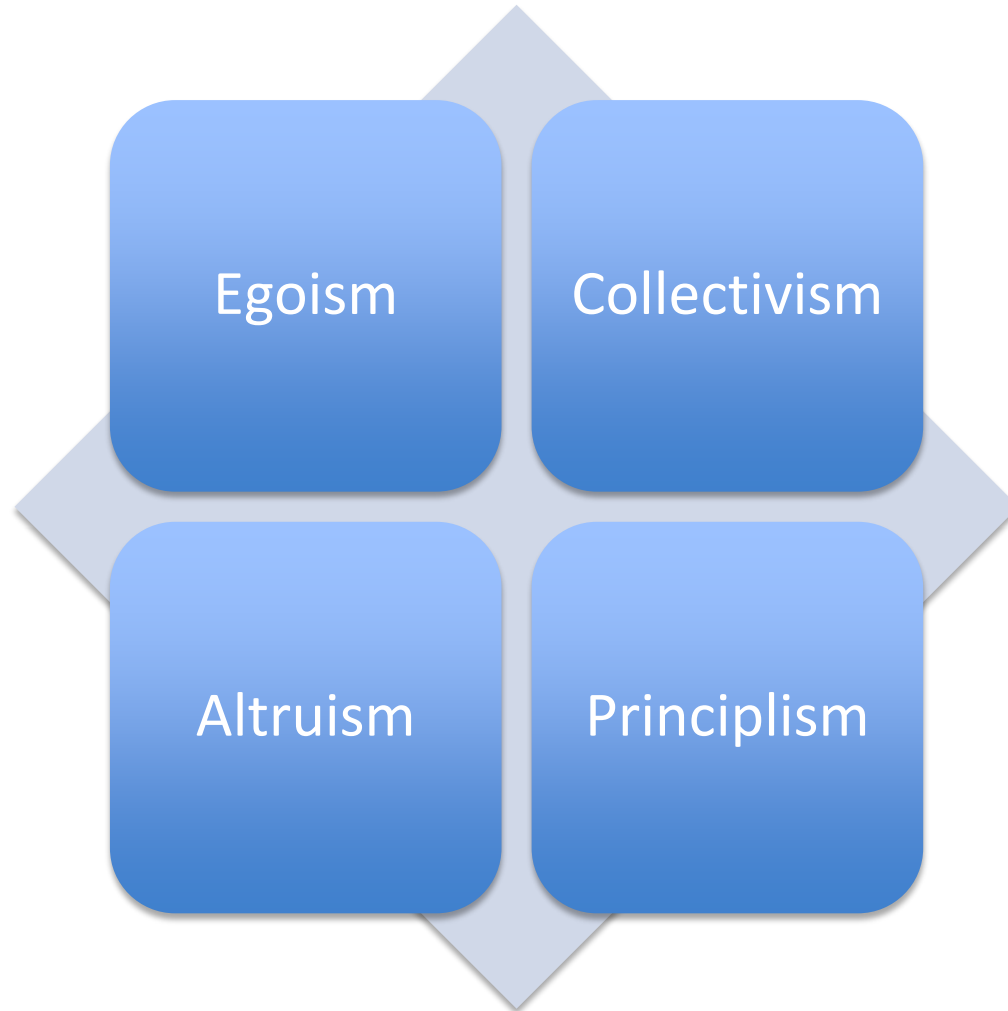
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# Motivations for Participation



# Egoism



The data volunteers provide  
enhance my research



Collaboration with scientists  
enables me to open my horizons  
to new ideas and knowledge

# Collectivism



Collaboration with volunteers can be helpful to others in the scientific community



Collaboration between scientists and scientific volunteers is beneficial for the volunteers

# Altruism



Collaboration with volunteers helps educate them about scientific methods



Collaboration between scientists and scientific volunteers is beneficial for scientists

# Principlism



Collaboration with volunteers is worthwhile because I believe that all scientific knowledge should be accessible to everyone, regardless of their expertise



Collaboration with scientists is worthwhile for making scientific knowledge accessible to the public and outside the scientific community

# Emerging Relationships

## Contributory projects

- the public are recruited into projects conceived and designed by scientists

## Collaborative projects

- scientists work with the public to collaborate on research design in addition to enabling the public to contribute data

## Co-created projects

- scientists and the public are involved in each phase of the research, beginning with its conception and following through to co-publication

(Rotman et al. 2012)



# Educative Dividend/Self Discovery

Learning  
something  
new and  
valuable

Who is able to participate? What level of expertise?  
Who curates the data? What is the nature of quality control?  
How are standards created?  
What are the limits for “repurposing” and mining shared data  
in the name of “discovery”?



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## 2014 Biennial PXE Research Meeting



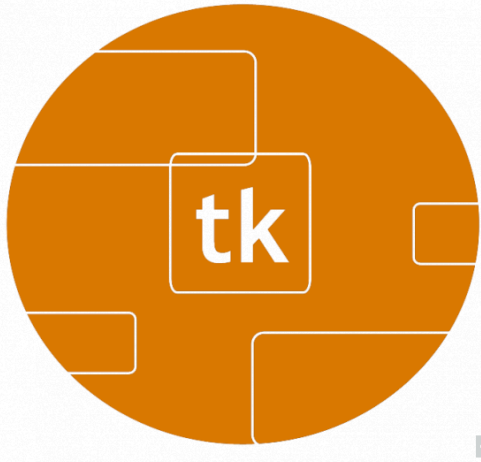
The 2014 Biennial PXE Research Meeting took place in Bethesda, Maryland on September 22-23, 2014. This was a very exciting meeting because the last year saw some very **meaningful breakthroughs in translating basic science into potential clinical applications**. Experts in many disciplines convened to determine the plans for future research and clinical studies. This workshop also helped to determine the fundraising strategy for the next several years.

# Goals and Tasks

Participants not only undertake tasks but help set goals

How are goals determined? Who sets the agenda?  
Who participates in research design?  
Who determines what the results mean?  
How are results published? What constitutes acknowledgment and responsibility?

## TK Licenses and Labels



Cultural Protocols  
Open to all users

Communities  
Features

Category  
General

Log in to post comments  
Sharing Protocols (group content visibility)  
Use group defaults

Author  
admin

11/28/2012 - 16:32

Description

Mukurtu CMS makes it possible for you to share your digital cultural heritage using a set of innovative licenses and labels specifically designed for the unique needs of Indigenous cultural materials. Mukurtu CMS provides several TK (Traditional Knowledge) license options for Indigenous creators, custodians and beneficiaries to manage their community-owned and generated cultural content with third-parties and external-community users. The TK labels recognize and have been designed for the large amounts of culturally sensitive materials that are in the public domain. The TK Labels provide additional or missing information and help users make an informed decision about the best and most appropriate way of using this material. Traditional knowledge licenses and labels ask all new users of this special material to respect Indigenous protocols and to gather, create, and share responsibly and respectfully.

Read more: <http://localcontexts.org>

### Related Items



Mukurtu Mobile



Roundtrip



Cultural Protocols

# Resource Control

Participants get to control (own or use) resources, not merely produce them.

Who owns pooled resources? Are institutional interests apparent?  
How does the ethos of open sharing impact the desire for control?  
How is data protected and secured?  
What rights do third party platforms have to resources?

Connected + The Quantified  
devices self

What problem  
are you solving for?



I want to control my own  
WELL BEING.

## Exit

Capacity to leave  
without penalty  
and with resources

Is exiting possible?

What assurances can be made that one has exited?

How to exit without some loss of data, access to network  
and other resources?



# Voice

Opportunities  
to 'speak back'  
in order to  
influence use of  
data

What are the rules of engagement?  
What are effective models for “speaking back”?  
What is the obligation to hear?  
Whose voices? How diverse and representative are  
participants?

foldit BETA  
Solve Puzzles for Science

23:18:45 GMT

PUZZLES BLOG CATEGORIES FEEDBACK GROUPS FORUM PLAYERS WIKI FAQ RECIPES ABOUT CONTESTS CREDITS

### Top Evolvers Directory

RANK	PLAYER	GLOBAL EVOLVER SCORE
#1	Galaxie 1 3	4261
#2	gmn 2 6	4067
#3	jamiexq 3 38	3981
#4	LociOiling 4 10	3763
#5	alwen 5 78	3600
#6	phi16 6 47	3355
#7	retiredmichael 7 2	3343
#8	Bruno Kestemont 8 4	3324
#9	gloverd 9 23	3303
#10	brgreening 10 217	3202
#11	Angus 11 34	3098
#12	mimi 12 16	3070
#13	mirp 13 11	2956
#14	reefyrob 14 43	2926
#15	Bletchley Park 15 18	2807
#16	gitwut 16 14	2722

OPTIONS

- Players with pictures
- Players with profiles
- Top Evolvers
- Top Evolvers this month
- Top Evolvers this week
- Soloist Hall of Fame
- Top Soloists
- Top Soloists this month
- Top Soloists this week

GET STARTED: DOWNLOAD

Win Beta Mac Beta Linux Beta

Windows (XP/Vista/7/8) OSX (10.7 or later) Linux (64-bit)

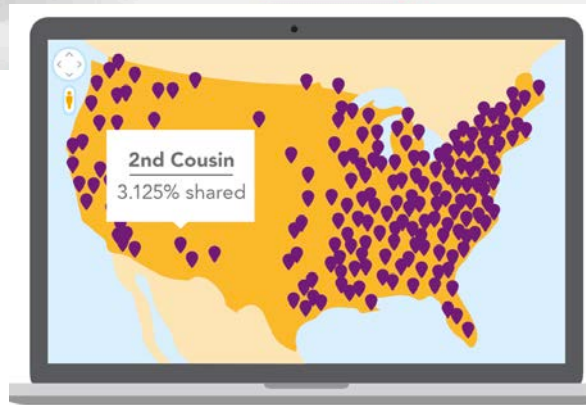
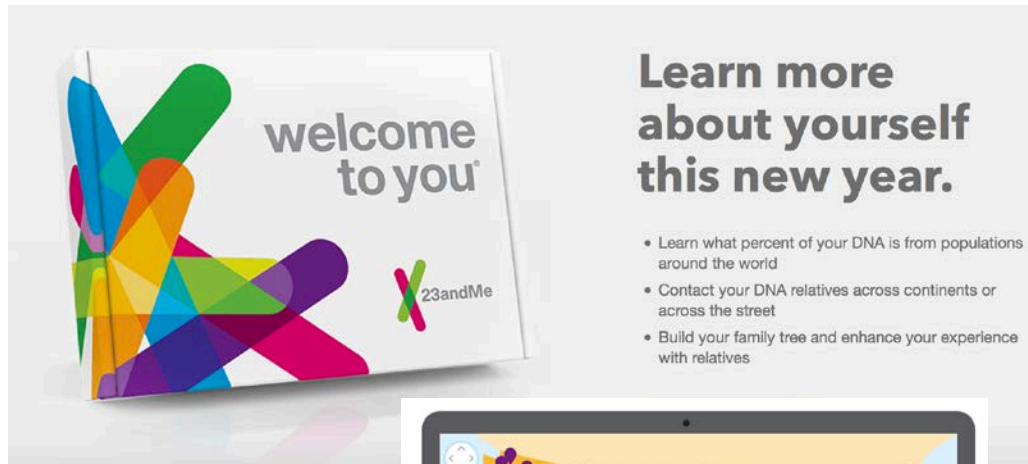
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# Visible Metrics/Gaming

Empirical demonstrations of the connection between participation and outcomes

What constitutes compensation for “participation”?  
 Are there issues with blurring of “work” and “play”?  
 Should we care whether it is a corporate entity or non-profit sponsoring the games?



# Affective/Visible Communicative Capacity

Participants have opportunities to to produce affect, affiliation, and sociability

What are expectations in the flow of information?  
What should participants know about the limits of privacy and data security?  
Should there be oversight of dissemination of “expertise” and self-research activities?

# Discerning what is new

Democratization



Bottom up disruption



Open sharing and  
transparency



Empowerment

Science per usual



Institutionalization



“Evolving” terms of  
engagement



Data, without  
information

# References

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