



# “A cohort of pirate ships”: Biomedical citizen scientists’ attitudes towards ethical oversight

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In qualitative interviews, 35 stakeholders in biomedical citizen science endorsed ethical oversight of projects that is voluntary, advisory, community-driven, and respectful of the fierce independence that characterizes these “pirate ships” communities.



- Introduction**
- Ethical oversight of “bottom-up” biomedical citizen science projects is attracting policy attention.
  - Participants’ perspectives on proposed oversight models have not yet been systematically examined.

- Methods**
- Candidates with relevant knowledge were identified from the literature, media reports, and snowball sampling.
  - Semi-structured interviews were conducted at Biohack the Planet in Las Vegas, NV and the Global Community Bio Summit in Cambridge, MA.
  - Interviews were audio-recorded with permission, transcribed, and coded for themes.

- Results**
- Thirty-five interviewees identified 10 ethical priorities, including autonomy, diversity, and safety.
  - They generally endorsed mechanisms that are voluntary, community-driven, and offer guidance.
  - They rejected mechanisms that are mandatory, hierarchical, and inflexible.
  - Expert consultation and community review models appear to align well with expressed priorities and preferences, but there is no “one size fits all” solution and local conditions should guide oversight for specific projects.
  - Implementation barriers include time and money to build infrastructure and governance challenges.



**Characteristics of interviewees (N=35)**

Characteristic	n (%)
<b>Gender</b>	
Male	21 (60%)
Female	11 (31%)
Gender non-conforming	1 (3%)
Declined to answer	2 (6%)
<b>Age</b>	
18-19	1 (3%)
20-29	9 (26%)
30-39	12 (34%)
40-49	11 (31%)
Declined to answer	2 (6%)
<b>Residence*</b>	
U.S. Northeast	10 (29%)
U.S. Midwest	1 (3%)
U.S. South	6 (17%)
U.S. West	9 (26%)
International	6 (17%)
Multiple residences	2 (6%)
Declined to answer	1 (3%)
<b>Conference attended</b>	
Biohack the Planet only	15 (43%)
Bio Summit only	17 (49%)
Both	3 (9%)

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Percentages may ≠100% due to rounding.  
\* U.S. regions defined by U.S. Census Bureau.