

Volunteering for Infection

A Survey of Participant Perspectives

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About 1Day Sooner

- 1Day Sooner 1Day Sooner is a nonprofit advocating for healthy medical research volunteers, especially in human challenge/CHIM studies
- Independently collaborating on proposed HCV CHIMs
- Over 40,000 across the world who have expressed a specific interest in CHIM participation via 1Day

“Volunteering for Infection: Participant Perspectives on a Hepatitis C Virus Controlled Human Infection Model”

- 4 of 5 authors were former human challenge study participants
- Survey of 1Day membership base from US, CAN, AUS, UK (N = 117 passing comprehension Qs)
- Introduced HCV CHIM concept, asked questions on perceptions, concerns, etc.
 - Support for concept overall (median 6 on 1-7 Likert scale)
 - Generally receptive to idea of volunteering
- ☞ There appear to be a substantial number of altruistically-minded who might participate; how do we maximize engagement with this very nebulously defined group?

Risk tolerance and sources of concern

- Greatest concern was over long-term health effects
 - Strong desire to know measures of their health during study
- Lower enthusiasm about longer period of infection
- 53% of respondents at least somewhat agreed that they would consider participation “even if I were found to be at a slightly higher risk of complications”

Taking Altruism Seriously

- In general, altruism an important factor in healthy people's decision to volunteer in medical research
 - This was reflected in our survey — altruistic motives highest ranked
- Scientific utility/impact is thus morally relevant
 - Design decisions featuring fully explained risks for significant scientific benefit are not inherently objectionable — and may better align study with values of volunteers
 - Model quality – speed, adoption, capacity, regulatory pathway

Transparency

- Ethical obligation to ensure data generated from the bodies of volunteers is made useful and public to extent possible
 - 1Day Sooner's transparency pledge for HCV CHIM
- Ability to contribute to the greater good as a benefit of participation
 - Be upfront about *why a study is important*
 - Share results!
 - You can be much more specific than “help vaccine research”

Compensation: Altruism Doesn't Have to be Free!

- Survey respondents more concerned by underpayment than overpayment
- Factors seen as relevant to compensation: time & inconvenience, but also health risk, discomfort/illness, and potential benefit to society
- We proposed a target of \$20,000 for six-month infection period
 - Almost any arbitrary sum, \$2k or \$20k, is still a lot of money to *somebody*

Concluding thoughts

- A properly explained HCV CHIM is not outlandishly scary — many who might consider participation on altruistic grounds
 - Important background information — extreme difficulty testing vaccines in field trials among PWIDs, major global burden — helps altruistic volunteers decide why they might want to participate
- Ensuring studies are efficient and scientifically useful is an issue of respect for volunteers as well
- Valuable contributions should be recognized — higher compensation
 - Altruism and compensation are not mutually exclusive
 - 1Day Sooner's proposed challenge volunteer fund (e.g. 2x baseline compensation, with volunteer directing one half to a charity)

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