

Our Views on **Participant engagement**

Paul Zimmer-Harwood
29th of Sept 2026



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- Grassroots effort for people who WANTED to be in Covid-19 human challenge studies



Thousands of people want to be exposed to Covid-19 for science

The New York Times

Britain Infected Volunteers With the Coronavirus. Why Won't the U.S.?

Science

Controversial 'human challenge' trials for COVID-19 vaccines gain support

Volunteers line up, and labs set to work on viral strains for controlled infections

LA PRESSE

S'infecter délibérément pour la science

nature

These volunteers want to be infected with disease to aid research – will their altruism help?

The Guardian

The volunteers lining up for Covid-19 challenge trials

Non-profit organisation 1Day Sooner has attracted over 38,500 willing participants

The Atlantic

Let Volunteers Take the COVID Challenge

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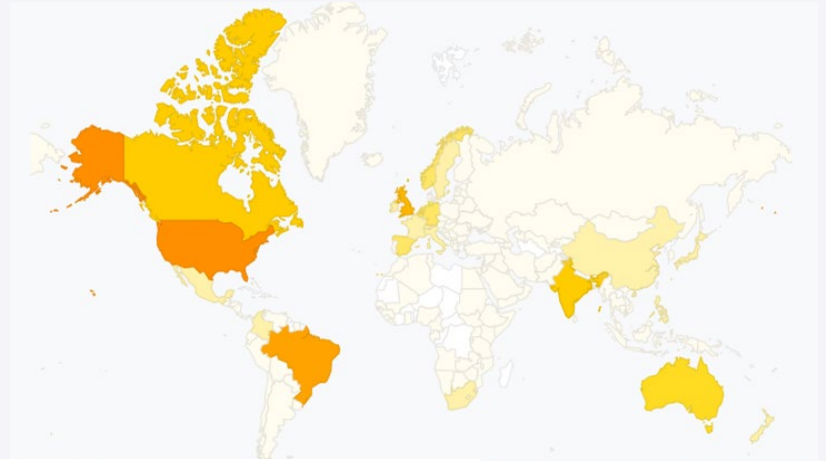
争鸣 | “人体挑战试验”是人类为终结大流行必须付出的代价？

The Washington Post
Democracy Dies in Darkness

I had the coronavirus dripped into my nose. On purpose. For science.

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- Founded in early 2020 in response to the pandemic
- Grassroots effort for people who WANTED to be in Covid-19 human challenge studies
- Over 40'000 people signed up with 1Day across the world



	Country	Total registrations -
1.	United States	20,041
2.	Brazil	9,482
3.	United Kingdom	4,878
4.	Canada	2,399
5.	India	1,483
6.	Australia	624
7.	Germany	454
8.	Spain	382
9.	Belgium	381
10.	Netherlands	309
11.	Norway	294
12.	France	234
13.	Italy	214
14.	Ireland	209
15.	South Africa	209

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Our perspective

Representing people who want to participate means we generally start from a presumption in favour of enabling participation.

About the Cooperative Participant Organization

1Day Sooner envisions challenge trial participation becoming as universally recognized and valued as blood and organ donation.

- We **organize volunteers** who are in studies and people who want to be in studies and reach out to participants in trials
- We strongly believe in the **autonomy** and agency of informed, consenting adult volunteers
- We engage in **advocacy** with regulators, lawmakers, and other stakeholders globally.
- We assist in communications and outreach to **elevate the voices** of research participants in public discourse
- We provide a **platform** to advocate and take part in discussions that affect them



COOPERATIVE
PARTICIPANT
ORGANIZATION

1. There is an issue with Healthy volunteer representation

- Healthy volunteers are stakeholders in research
- Patient communities often have established representation - healthy volunteers do not
- Research participants are often one-shot actors in a system of repeat institutional players

Participants are important, but usually stand alone in the research system.



1. There is an issue with Healthy volunteer representation

- Healthy volunteers are stakeholders in research
- Patient communities often have established representation - healthy volunteers do not
- Research participants are often one-shot actors in a system of repeat institutional players
- Persistent councils and advisory boards for trials can fix that

A Participant Council / CPO provides an independent, collective participant voice.



2. Engage participants while decisions can still change...



- Engagement should start before the protocol is fixed
- Ask prospective participants about risks, burdens, procedures and practical constraints
- Engagement after all major decisions are made risks becoming consultation rather than influence

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

Jake D Eberts¹, Paul Zimmer-Harwood^{1 2}, James W B Elsey³, Alastair Fraser-Urquhart¹, Thomas Smiley¹

THE LANCET Gastroenterology & Hepatology

CORRESPONDENCE • Volume 8, Issue 11, P967-969, November 2023

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Joint statement in support of hepatitis C human challenge studies

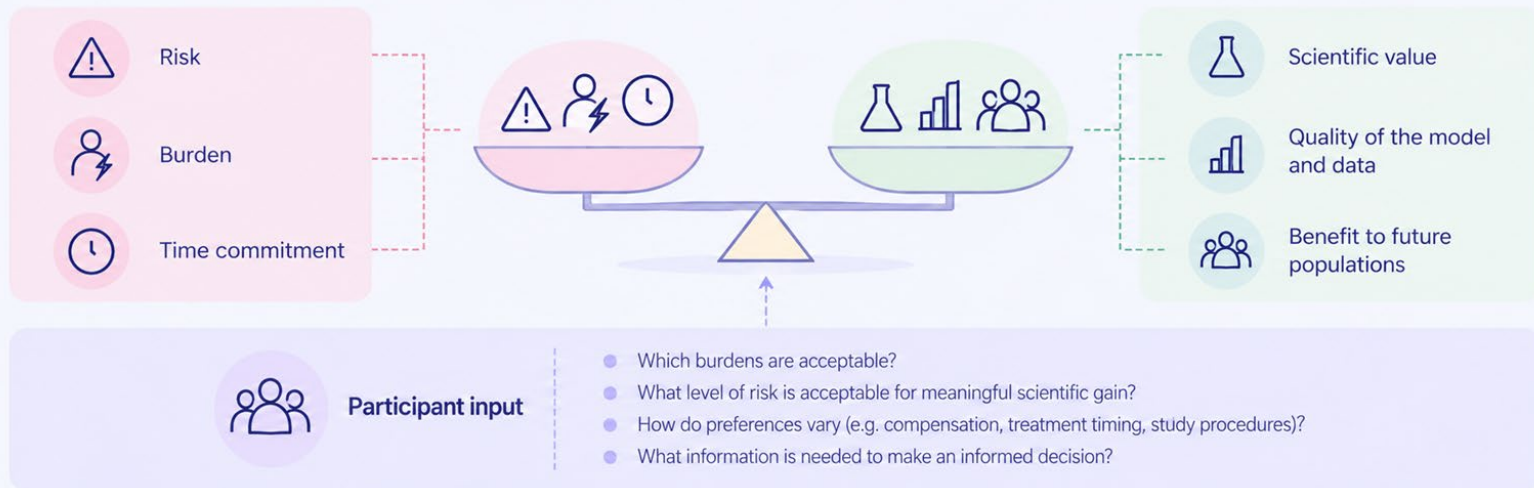
Harvey J Alter^a · Eleanor Barnes^b · Mia J Blondj^c · Andrea L Cox^d · Jake D Eberts^e · Jordan J Feld^f · T Jake Liang^g · Josh Morrison^h · Charles M Rice^{ij} · Naglaa H Shoukry^k · David L Thomas^d · Jennifer Van Gennip^l · Charles Weijer^m · on behalf of other signatories[†] Show less

2. ...And close the loop

Ask for input, listen throughout, act on it where possible, and show what happened.

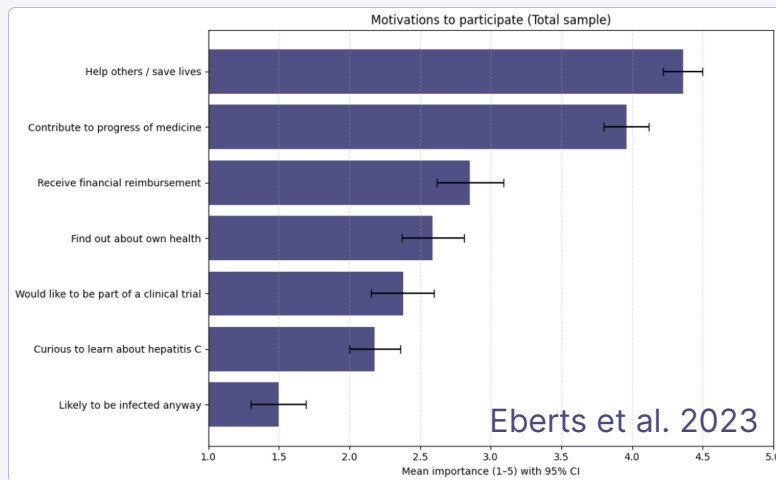
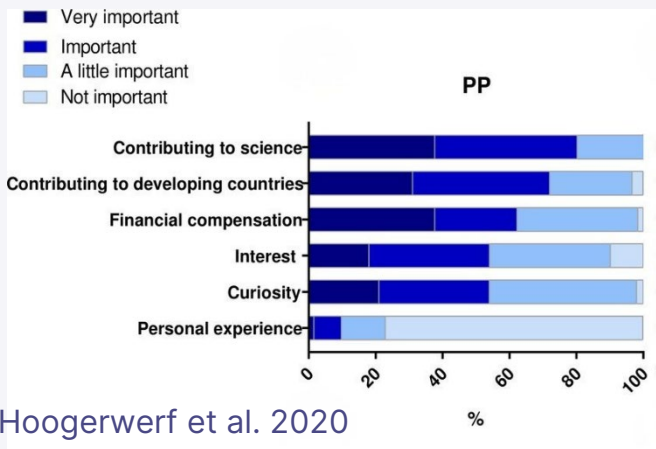


3. Ask about trade-offs instead of “acceptability”



- “Would you participate?” is not as informative as it could be
- Instead, ask what participants value enough to justify additional burden.
 - Reducing risks at a high cost to scientific value may reduce attractiveness
- Scientific value, burden, risk and compensation are trade-offs - participants should help inform them

3. Ask about trade-offs instead of “acceptability”



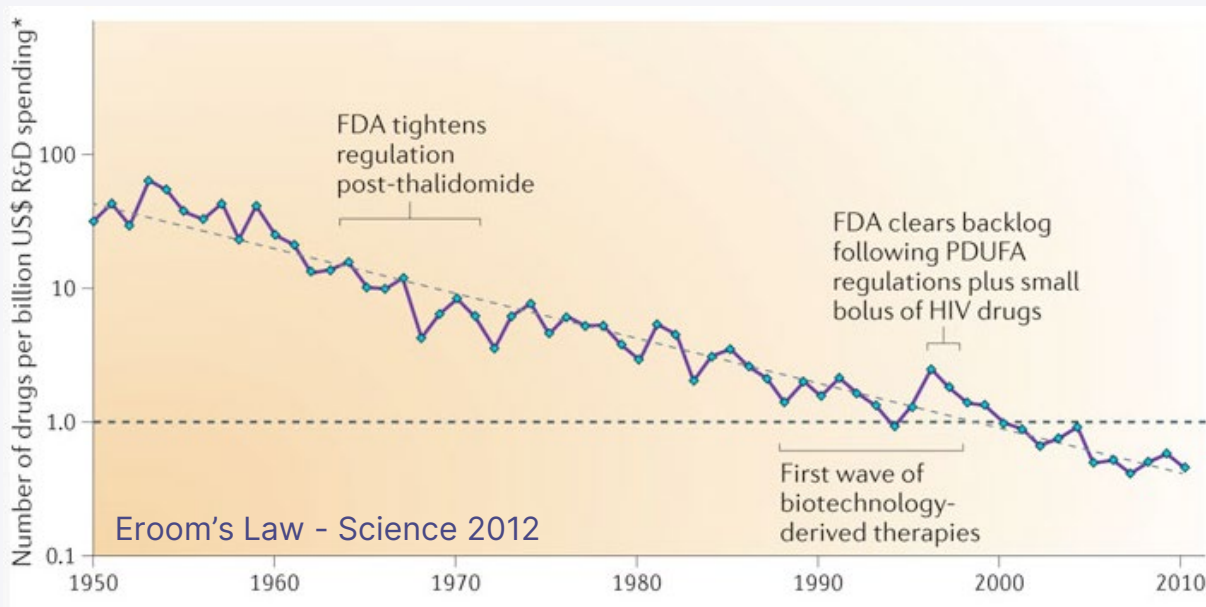
- Purpose & Impact are key motivations -> but unlike financial compensation this is hard to assess
 - Inform about the bigger picture goal that a study has and where reasonable include the possible impact

4. Participant engagement ≠ recruitment

- The purpose of engagement is influence - not persuasion
- Independence matters
 - Engagement works best when participants are not dependent on the study team for their voice (this is an opinion)
- Better participant recruitment may be a consequence - but participant matching is the goal
- Medical progress depends on people agreeing to participate in research

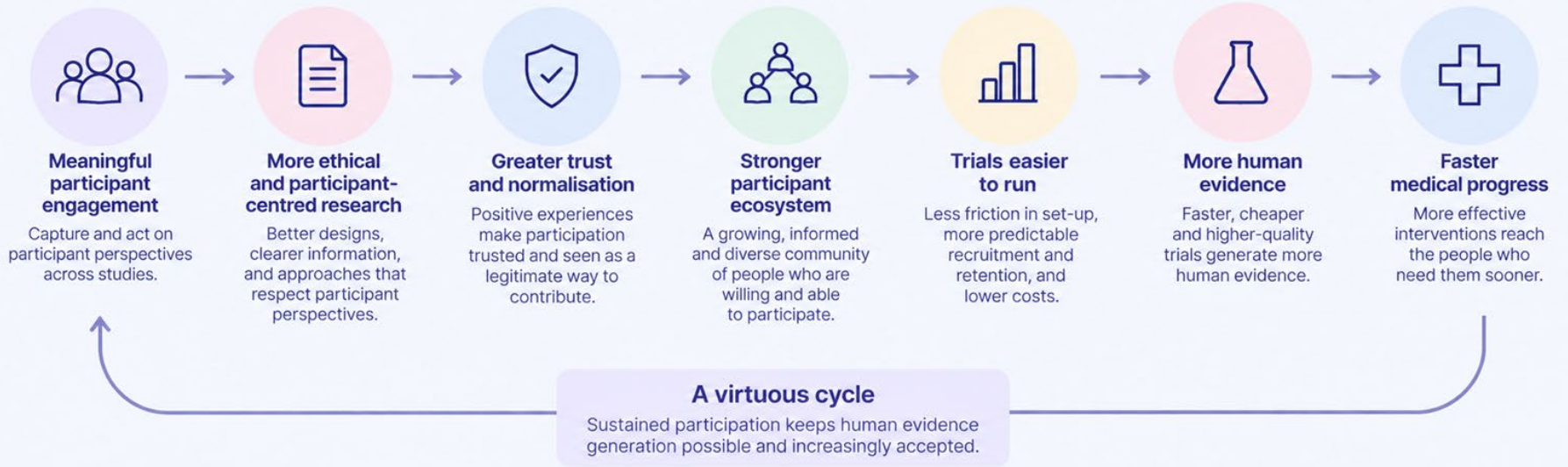
5. Why do this?

- Human evidence generation is the key bottleneck in medical progress



5. Why do this?

- Human evidence generation is the key bottleneck
 - Participant engagement should be infrastructure, not ad hoc extra
 - Build repeatable systems that can be reused across studies and institutions
 - Learn systematically, as a field, what makes participation acceptable and worthwhile
- Make research participation trusted and normal
 - Participation should be seen as legitimate way to contribute to medical progress - not a fringe activity
 - Good experiences and trustworthy institutions make continued participation socially sustainable
- Our theory of change: Over time, a stronger participant ecosystem should mean
 - Less friction, more predictability
 - Easier, faster, cheaper and ultimately more trials



Thank you!