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Human brain organoids and stakeholders' attitudes: evidence, gaps, and governance

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We review 13 empirical studies examining attitudes toward human brain organoid (HBO) research. Stakeholders tend to emphasize practical concerns—worries about commercialization, reproductive cloning, informed consent, and uncertainty about consequences—rather than issues related to consciousness. Based on these findings, we identify three priority areas for future ethical and policy discussions.

Background, aims, and scope

Human brain organoids (HBOs)—3D structures derived from human stem cells that self-organize to recapitulate aspects of early neurodevelopment—are now used across disease modeling, drug discovery, and exploratory integrations with animal brains or artificial intelligence/computer chip interfaces. As their capabilities expand, evaluation must move from technical feasibility to ethical legitimacy: not only what HBOs can do, but how research into HBOs can be responsibly carried out given the risks and values at stake. Public or stakeholder attitude research can inform ethical debate and governance. We therefore synthesize empirical findings to identify which problems stakeholders expect governance to solve and where evidence-sensitive policies should be enacted.

A growing empirical literature asks what different stakeholders think about HBOs (Table 1). To our knowledge, there are 13 studies on this issue, all of which indicate broad—but qualified—support for HBO research. They also suggest that ethical concerns extend beyond 'consciousness of HBOs' to practical issues such as the validity of donors' consent. The evidence base spans patients, lay public, donors, and scientists. Methods include semi-structured interviews, large-scale surveys with questionnaires, experimental studies using hypothetical vignettes, and deliberative workshops. Studies have been conducted in Europe, East Asia, and the USA. A tabulated overview of these investigations, including methodological details and information on sampled populations, is presented in Table 1.

It should be noted that the 13 studies differ substantially in participant groups, sample sizes, and research methods, and their findings are sometimes inconsistent. In the remainder of this review, we focus on three key issues that warrant closer attention.

Consciousness, consent, and methodological limits

Consciousness has dominated headlines, with many popular articles stressing that HBOs might be or become conscious, which could afford them an intrinsic moral status (https://www.meer.com/en/93818). Scientifically, however, present-day HBOs are widely considered not to have consciousness (subjective experience) of any sort, much less sentience (the ability to feel pleasure or pain) or to have other ethically significant experiences. Nevertheless, credible markers of sentience would raise the stakes (e.g., requiring animal-style research protections) [14]. Empirically, lay participants still worry about possible consciousness [1,2,7,11,12], while surveyed scientists tend to remain skeptical that it will ever occur or that it would change moral status [4,5,8]. However, a survey of Japanese citizens, comparing the intensity of various concerns, found that potential consciousness is not the top-rated concern: a broad category labeled 'unanticipated risks' (what organoids might do, reveal, experience, or imply under uncertainty), 'commercialization', and 'reproductive cloning' were all rated higher than 'consciousness', in that order [11]. Thus, potential consciousness is salient but should not overshadow nearer-term governance needs—especially around consent, commercialization, and uncertainty (e.g., risk of misuse, misinterpretation of findings, or premature clinical or commercial applications).

A central ethical concern in HBO research has to do with consent. Because re-consenting cell donors for every downstream protocol is not feasible, broad consent is widely used. That is, consent is obtained in advance for a wide range of possible future uses of cells, which may include the creation of HBOs. The empirical findings on the perceived permissibility of broad consent are mixed. Many qualitative studies report preferences for greater transparency and limits on downstream use, which are in opposition to broad consent [6,9], whereas MacDuffie *et al.* found that participants often accept broad consent in health-related research [3]. Views among HBO researchers themselves are divided on its ethical acceptability [4]. Quantitatively, a Japanese public survey found that 36% of participants declined broad consent when told that their cells might be used to create HBOs, citing the need for prior explanation, a desire for self-determination over downstream uses, and distrust of researchers or institutions [13].

If broad consent is deemed unacceptable by stakeholders, a revised consent architecture may be needed. Two frequently proposed alternatives aim to balance scientific flexibility with donor autonomy.

Table 1. Overview of empirical studies on HBOs

Participants	Method	Sample size	Region	Key findings	Refs
Patients and laypersons	Semistructured interviews	28	Netherlands	Primary concerns are HBO consciousness and other potential misuse such as creating human life.	[1]
Adult patients and parents of pediatric patients	Semistructured interviews	60	USA	Expressed general support for HBO research, with concerns about potential consciousness.	[2]
Adult donors and parents of child donors	Semistructured interviews	67 (11 adult donors and 56 parents)	USA	Donors generally accept broad consent for health research; desire for ongoing engagement.	[3]
Researchers on HBOs	Semistructured interviews	21	Not documented	Scientists' primary concerns are donor consent and communication to the public, not consciousness.	[4]
Molecular systems engineering scientists	Semistructured interviews	24	USA and Europe	Ethical concerns are premature; primary issues will arise in clinical trials.	[5]
A diverse group of stakeholders (public, patients, donors, civil society organizations, representatives, and vulnerable individuals)	Deliberative workshops	Three workshops (19, 12, and 20 participants)	Italy, Greece, and Denmark	Support for research with oversight/consent; concerns about commercialization, access, and cerebral organoid consciousness.	[6]
Laypersons	Mixed methods (survey with experimental vignettes and in-depth interview)	2095 (survey) + 35 (interview)	USA	Most supported HBO research; support linked to views of Nature (e.g., Conservationism vs. Preservationism) but not to the assumed levels of HBO consciousness.	[7]
Researchers at a conference on organoids	Survey	184	China	Researchers have diverse views on consciousness; prefer consent for governance over broad consent.	[8]
Patients with neurological disorders	Focus groups	19	Netherlands	Participants generally accept commercial involvement but strongly concerned about excessive profit, trust, and loss of control.	[9]
Laypersons	Survey	964	USA	Public opposition linked to conservative ideology/religiosity; support linked to deference to science and to risk–benefit perceptions.	[10]
Laypersons	Survey	326	Japan	High expectations for outcomes; concerns about unanticipated risks and commercialization; support linked to understanding of HBOs.	[11]
Laypersons	Experimental vignettes	357	Residents in UK, USA, etc.	Moral judgments influenced by potentials for pain/visual experience in HBOs.	[12]
Laypersons	Survey	326	Japan	36% disapproved of broad consent for HBO creation; 37% had a stance dependent on specific circumstances.	[13]

Consent-for-governance asks donors to authorize rules and oversight structures rather than preauthorizing discrete studies or granting a blanket 'any research' permission [15]; however, in the HBO context, it may not satisfy donors who want study-specific explanations before their tissues are used [13]. Notably, Boers and Bredenoord also recognize that the prospects of particularly controversial research warrant additional explanation and more substantive participant engagements [15]. By contrast, dynamic consent enables two-way, ongoing communication (e.g., scope updates, interim results, opt-ins); participants in several studies welcomed reciprocal information flows and, in some cases, recognition or compensation [1–3,6]. Both approaches raise infrastructure and equity questions (e.g., digital access, participant burden). A pragmatic path, therefore, would be hybridization: governance-level authorization plus concise, plain-language

general briefings at key decision points in HBO research.

Additional donor-facing issues further complicate the picture. One concerns the duration of consent: while many adult donors accept postmortem use of the donated cells [2], parents of child donors often favor reconsent once the child reaches adulthood [3]. Another relates to compensation, where views vary widely—from gift analogies (e.g., blood donation), to proposals for nonmonetary benefits such as research updates or discounted care, to direct monetary rewards [1–3,6,13]. This heterogeneity underscores the need for flexible consent architectures and for clearer upfront commitments regarding information return, data governance, and any benefits or acknowledgments that donors may reasonably expect.

Methodological limits matter. Most studies are qualitative, and quantitative work remains scarce, constraining generalizability and subgroup analysis. There may also be comprehension barriers: for example, when Ota *et al.* asked lay English speakers to imagine conscious HBO scenarios, roughly a quarter failed comprehension checks and were excluded [12]. In addition, inconsistent results have been reported among studies of citizens (e.g., what forms of consciousness are morally important; see [7,12]). Laypeople's responses may change depending on the relevant information researchers provide. Laypeople may also conflate 'consciousness' with other properties, such as neural activity, and may not understand what being conscious does and does not entail. Finally, the corpus is regionally concentrated (Europe, East Asia, and the USA). The attitudes of stakeholders toward HBO research are not well understood in many regions. These gaps should motivate the refinement of survey methodology, including the incorporation of plain language and validated comprehension checks, and suggest the necessity of investigating the robustness of responses across different framings and cultures.

Concluding remarks

What, then, should ethics and governance take from stakeholder opinions we currently know? Empirical attitudes offer input for ethical and regulatory deliberation but must be balanced against other considerations and goals; some may need to be set aside, where appropriate. Moreover, stakeholders occupy different epistemic positions, so the robustness of findings, including heterogeneity across groups and cultures, warrants further scrutiny. Still, the empirical literature on HBOs provides provisional yet meaningful insights. As one of us (J.S.) has argued elsewhere, Collective Reflective Equilibrium can integrate stakeholder values with ethical concepts and principles for public policy. Reviews like this help by clarifying what the evidence does (and does not) show (Box 1).

Across 13 studies, the overall pattern is one of broad yet qualified support for HBO research. Although the possibility of consciousness attracts public attention in news media items, the empirical record suggests that it is not the strongest concern among survey participants. By contrast, stakeholders consistently emphasize other, more immediate and practical issues. While governance structures should embed adaptive mechanisms that can escalate protections if validated indicators of sentience or pain emerge in HBOs, they should not overlook nearer-term domains. Especially, concerns around consent emerge as a recurring theme across stakeholder groups. Given the repeatedly observed resistance to broad consent, alternative models should be considered in the context of HBO research. Evidence also indicates that commercialization and misuse generate sustained worries across the public and donors; however, some of these worries are unfounded (e.g., unscientific beliefs that HBOs might be used for thought transference) [1,11]. In those cases, the concerns would be better addressed through communication rather than governance mechanisms.

Empirical limitations should be reiterated: much of the evidence derives from small-scale qualitative studies, with regional concentration. Survey and vignette-based experiments show substantial framing sensitivity and comprehension barriers, limiting the generalizability and interpretability of much existing data. Methodological refinements should be a priority for this field.

On the basis of available evidence, three provisional priorities can be identified: (i) the redesign of consent architectures toward greater transparency, relationality (i.e., an ongoing donor–researcher relationship with two-way updates, options to modify or withdraw consent, and clear communication), and auditability (i.e., end-to-end traceability and verifiable audit trails linking each downstream use to the valid

Box 1. Implications of existing studies and provisional priorities

Concerns about broad consent in HBO research are shared across stakeholder groups, including researchers, donors, and laypeople. These findings point to the need to revisit and possibly redesign current frameworks for cell donation.

While the potential consciousness of HBOs has dominated ethical debates, it is neither the most urgent nor the most salient concern expressed by stakeholders. This discrepancy suggests that the ethical discussions may need to shift their focus to better reflect stakeholder priorities.

Scientists broadly agree that current HBOs are unlikely to possess consciousness. Accordingly, while continued vigilance is warranted, ethical and regulatory attention should be proportionate to the current scientific understanding of HBOs' consciousness capacities.

consent); (ii) the redirection of near-term policy attention to commercialization, data governance, and misuse; and (iii) the incorporation of adaptive mechanisms that respond to validated markers of consciousness in HBOs. To achieve these ends, practical policy implementation is required, and empirical studies can play a role in evaluating the effectiveness of any such measures. Iterative evaluation—through experimental survey designs and crossjurisdictional monitoring—will be essential to determine whether such measures enhance trust, legitimacy, and willingness to donate. In this way, governance of HBO research can remain responsive to evolving evidence while avoiding overreliance on speculative futures.

Author contributions

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Declaration of interests

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