

# Collective Imaginaries for Intimate Health Data: Applications of Participatory Futures Methods for Consent and Control

PUSHPI BACGCHI\*, Edinburgh Futures Institute, UK

JENNIFER PYBUS, York University, Canada

ADAM JENKINS, King's College London, UK

KYLE MORRISON, Edinburgh Futures Institute, UK

Current consent mechanisms fail users of intimate health technologies. FemTech apps collect intimate personal data through "app events"—microdata points that fuel algorithmic profiling—yet users cannot meaningfully imagine what is captured, how it circulates, or how it may be repurposed. We adapted Voros's Futures Cone framework into participatory workshops (UK n=21; Canada n=23) where participants co-created personas and envisioned alternative futures of data practices for 2030. Our findings surface a productive tension with significant consequences for consent design: while participants articulated clear preferences for transparency, data minimisation, and user compensation, they remained pessimistic about systemic change. We argue that futures methods make preferred consent alternatives futures imaginable, challenging the inevitable—a distinction with important implications for how we design consent mechanisms that empower rather than merely inform.

CCS Concepts: • **Human-centered computing** → **Empirical studies in HCI; HCI design and evaluation methods.**

Additional Key Words and Phrases: Intimate health technologies, data practices, futures cone, imaginaries

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## 1 Consequences of Current Consent

Users of FemTech and mobile health apps face a fundamental consent problem: they are asked to make decisions about data sharing without any basis for imagining what is captured, how it circulates, or what consequences might follow. This opacity is not incidental but structural. Data collection by developers and third parties is embedded in mobile tracking infrastructures that deliberately obscure data flows across multiple actors and devices [3]. The consequences are particularly acute for intimate health data. Unlike formal healthcare settings where clinical protections apply [2], FemTech data—including information about sexual orientation, reproductive health, and bodily functions—remains largely unprotected. Marketing companies define "app events" as "anything a mobile marketer or developer determines is helpful to measure" [1], including identifiers, timestamps, and behavioural markers. The period-tracking app Flo, for

\*All Authors contributed equally

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Authors' Contact Information: Pushpi Bagchi, [pbagchi@exseed.ed.ac.uk](mailto:pbagchi@exseed.ed.ac.uk), Edinburgh Futures Institute, Edinburgh, UK; Jennifer Pybus, York University, Toronto, Canada, [jpybus@yorku.ca](mailto:jpybus@yorku.ca); Adam Jenkins, King's College London, London, UK, [adam.jenkins@kcl.ac.uk](mailto:adam.jenkins@kcl.ac.uk); Kyle Morrison, Edinburgh Futures Institute, Edinburgh, UK.

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instance, used sensitive app events labelled "R\_PREGNANCY\_WEEK\_CHOSEN" that were transmitted to third-party advertising platforms [4]. Users clicking "I agree" have no meaningful way to anticipate such consequences. This consent landscape produces three interconnected failures. First, users cannot assess potential privacy harms when intimate data is shared, aggregated, and repurposed for targeted advertising, profiling, and commercial risk scoring. Second, the temporal dimension of consent—agreeing now to unknown future data sharing and use by third parties—renders current mechanisms fundamentally inadequate. Third, individual consent frameworks cannot address collective harms that emerge from aggregated intimate data. We ask: can participatory futures methods enable users to imagine alternatives to this landscape, and what are the consequences—for users and for design—when these imaginaries are articulated?

## 2 Method: Adapting the Futures Cone for Consent Futures

We adapted Voros's Futures Cone [5, 6] into a participatory workshop format designed to surface user imaginaries about consent and control. The Futures Cone offers a framework for alternative futures, namely: between projected futures (business as usual), probable (likely if trends persist), plausible (possible within known constraints), possible (speculative), preferable (value-grounded desired outcomes), and preposterous (wildcards). We conducted two three-hour workshops—UK (n=21, August 2025) and Canada (n=23, October 2025)—with participants who predominantly identified as female, aged 20–25. Workshops followed four parts. First, we introduced how FemTech apps capture data, using illustrative app event examples to ground abstract concerns in technical specificity. Participants then co-created personas by inferring characteristics from an imagined digital footprint. Second, using the Futures Cone canvas and scenario prompts, groups explored potential data futures for their personas in 2030, responding to prompts such as: Who controls your persona's intimate health data, and how does that shape its collection, sharing, and use? Third, groups presented scenarios in a reflective discussion. Fourth, participants completed voluntary post-workshop surveys on learning outcomes and intended actions. This design differs from prior futures work by grounding speculation in concrete data practices. Rather than imagining abstract futures, participants worked from actual app event structures documented in FemTech audits [4], making the consequences of current consent mechanisms tangible before imagining alternatives.

## 3 Findings: Consent Futures for Madison

One UK group co-created "Madison," a 27-year-old middle-income woman with low privacy awareness who uses apps to track her period and sexual activity. Their responses illustrate how the method surfaces user priorities for consent and control. **Who should control intimate data?** The group identified three potential controllers: individual app companies, the UK's National Health Service (NHS), and large platforms such as Meta. They saw NHS integration as plausible because it could enable "responsive action" and support "evidence-based research." However, they considered corporate consolidation more probable, raising concerns that such companies "do not have the public's best intentions at their heart." **What would preferable consent look like?** Their preferred scenario envisioned: "no personalised ads, no sharing data with third parties," full transparency, and compensation for users in exchange for their data. The central notion was that apps should exist to benefit users "for their purpose" rather than as extraction mechanisms. Data sharing would be limited to anonymised scientific research, ensuring that "if your data is being shared, it's for a good cause." **Consequences for participants:** Post-workshop surveys (n=18) revealed that grounding speculation in concrete app event data heightened critical awareness. All respondents indicated they were likely to alter their FemTech practices—reviewing privacy policies, changing permissions, "being more conscious of what I am agreeing to," or deleting apps altogether. One participant described learning about data practices "in ways I haven't thought about."

**The empowerment-pessimism paradox:** Yet a tension emerged: while participants felt more informed and agentic, many remained "somewhat pessimistic" about systemic change, with one noting that "corporations will still do what they do best." Participants could clearly articulate preferable consent futures but doubted the likelihood of change.

#### 4 Anticipated Consequences and Contribution

Our findings have three consequences for rethinking consent and control. **For users:** Futures methods make consent alternatives imaginable in ways that current mechanisms do not. Participants moved beyond passive acceptance to articulate specific preferences: data minimisation, purpose limitation, transparency about third-party sharing, and compensation models. The method builds what one participant called preparation "to act"—even amid pessimism about whether action will matter. **For design:** User-generated preferable futures provide grounded starting points for consent redesign. Madison's group did not imagine exotic alternatives; they articulated pragmatic demands already present in regulatory frameworks (GDPR's purpose limitation, data minimisation) but absent from lived consent experiences. This suggests the gap is not user imagination but implementation—a design problem. **For the field:** The empowerment-pessimism paradox suggests that literacy-focused interventions are insufficient. Users who understand data practices and can articulate alternatives may still feel powerless against structural constraints. Consent mechanisms that merely inform—however transparently—cannot resolve this. The consequence is a design challenge: how might consent interfaces not only inform users but also demonstrate that alternatives are achievable? Our work differs from prior approaches by pairing futures methods with technical grounding in actual data practices, producing imaginaries that are simultaneously speculative and concrete. We offer this as a methodological contribution to the workshop's goal of envisioning consent "beyond clicks."

#### 5 Author Biographies

**Pushpi Bagchi** is Principal Designer in the *Futures and Design* team at the Edinburgh Futures Institute, University of Edinburgh. She specialises in participatory design and applied futures methodologies to support interdisciplinary collaboration. **Jennifer Pybus** is a Canadian Research Chair in Data, Democracy and AI and Associate Professor in Politics at York University. Her research examines data infrastructures and investigates how to best support more engaged, data-literate citizens who have greater agency to participate meaningfully in public debate around artificial intelligence. **Adam Jenkins** is a Research and Teaching Fellow at King's College London. His research focuses on privacy, security, and accessibility in digital systems. **Kyle Morrison** is a Design Technician at the Edinburgh Futures Institute, University of Edinburgh. His role involves combining creativity with technical skills to design products and services that are functional, aesthetically pleasing, and user-friendly.

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