

On the Role of Human-Precision Medicine Interaction in HCI-for-Health

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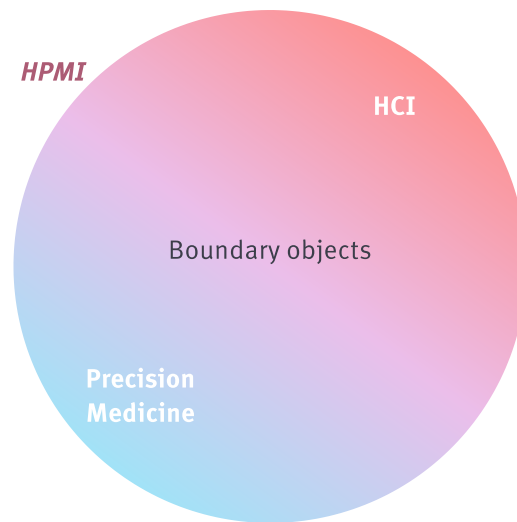


Figure 1: Visualising how carefully chosen boundary objects mediate between Human-Computer Interaction (HCI)’s human-centred concerns and Precision Medicine (PM)’s technical and clinical requirements, enabling interdisciplinary dialogue and ultimately realising Human-Precision Medicine Interaction (HPMI).

Abstract

Precision Medicine (PM) is increasingly adopted in clinical and consumer health contexts, with a growing body of HCI research engaging with PM-related technologies and practices. In this paper, we adopt a reflective and critical stance to examine how PM technologies may unsettle interactional assumptions commonly held in HCI-for-health. Building on recent discussions of Human-Precision Medicine Interaction (HPMI), we consider the role such a lens may play when probabilistic, model-derived evidence resists experience-based validation, when personalised prediction carries long-term psychological implications, and when trust and accountability are distributed across stakeholders. We identify five provocations that surface recurring interactional tensions in PM systems, alongside minimal criteria for recognising when HPMI-level attention may be needed. We outline a set of directions for HCI research in PM, and position these contributions as a basis for reconsidering how HCI

engages with uncertainty, responsibility, and long-horizon health risks in data-driven medicine.

CCS Concepts

• **Human-centered computing** → **Interactive systems and tools**; • **Applied computing** → **Life and medical sciences**.

Keywords

Human-Precision Medicine Interaction, HCI-for-Health, Precision Medicine, Polygenic Risk Scores, Provocation, Contestability

ACM Reference Format:

Yuhao Sun, John Vines, and Albert Tenesa. 2026. On the Role of Human-Precision Medicine Interaction in HCI-for-Health. In *Interactive Health Conference (IH '26)*, July 05–08, 2026, Porto, Portugal. ACM, New York, NY, USA, 7 pages. <https://doi.org/10.1145/3786579.3804909>

1 Introduction

Precision Medicine (PM) promises to transform healthcare by tailoring prevention, diagnosis, and treatment to individual characteristics, moving beyond the traditional “one-size-fits-all” paradigm [2, 8]. We have previously proposed Human-Precision Medicine Interaction (HPMI) as a conceptual call to integrate and extend



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ACM ISBN 979-8-4007-2422-0/26/07
<https://doi.org/10.1145/3786579.3804909>

HCI approaches for this emerging domain [40, 42, 44]. Since the Precision Medicine Initiative in 2015 [15], PM technologies, particularly those based on genomics and AI-driven risk prediction, have become increasingly visible in both clinical and consumer-facing contexts [25, 28, 36].

In this paper, we take a reflective and critical stance. We ask a core question: What breaks when PM technologies are treated as ‘just another’ health system? We argue that PM systems challenge several common assumptions in much existing HCI health research, and that these assumptions may lead to recurring interaction problems with ethical, psychological, and social consequences. Our goal is not to defend HPMI as branding or as a settled subfield, but to use it as a way of examining where established HCI-for-health approaches may need future development. We suggest that without a deliberate shift, there is a risk that PM technologies may become normalised as technically precise yet interactionally fragile.

This paper contributes (i) a set of minimal criteria for when an HPMI lens becomes necessary and (ii) five provocations that help structure discussion within the IH community. We position this paper as an analytic synthesis. The five provocations and minimal criteria were developed through an iterative process of abstraction across multiple sources. These include: (a) empirical findings from prior work on public perceptions of polygenic risk scores (PRS), (b) recurring tensions identified in recent HCI-for-health and precision medicine literature, and (c) design-oriented reflections emerging from prototyping and speculative engagements with PM service ecosystems. Rather than being derived from a single dataset, the provocations were formulated by comparing and consolidating patterns across these sources. As such, they should be understood as theoretically-informed analytic constructs rather than empirically validated categories or exhaustive taxonomies. Here, their purpose is to surface recurring interactional tensions and make them available for discussion, critique, and further empirical examination.

2 HCI and Health: Where Common HCI Assumptions May Not Hold in PM

The field of HCI has a long history of engagement with health, care, and medicine. Research in the fields of digital health, health informatics, and personal informatics has produced user-centred designs for wellness apps [34, 46], chronic disease management tools [4, 5], clinical decision support systems [31, 35], and patient portals [12, 20]. Foundational work, such as Consolvo et al.’s studies on fitness tracking, demonstrated how interactive systems can support behaviour change and self-reflection [7].

In this paper, we focus on a set of interactional assumptions that still commonly shape the design and evaluation of many HCI-for-health systems, but which may not hold as reliably in the context of PM. Here, we use the term “Precision Medicine (PM)” to refer to data-intensive, model-driven approaches that tailor prevention or treatment using biomarkers and genomics, increasingly surfaced through clinical and direct-to-consumer services – for example, PRS aggregate many genetic variants into a population-calibrated probabilistic estimate of disease susceptibility [42]. In such services, individuals submit genetic data (e.g., saliva samples) and later encounter risk evidence through service touchpoints such as online reports, dashboards, and counselling sessions. What they receive

is typically a risk score (often framed as a percentile or relative risk) that may shape screening, prevention, and life planning under uncertainty [42]. When PM technologies, such as PRS services, are treated as direct extensions of common HCI-for-health framings, they may be approached as if:

- Users can validate system outputs through lived or embodied experience (e.g., “I walked more today, so my step count increased”).
- Personalisation generally increases user agency and understanding.
- Health data, while sometimes complex, can be meaningfully interpreted through familiar metaphors or longitudinal self-tracking.

While critical and sociological scholarship has long questioned some of these assumptions built into behaviour-change technologies and personal informatics, including their focus on individual responsibility, normative expectations, and uneven consequences [18, 23, 24], PM can make these assumptions more difficult to sustain in practice. Technically, PM systems frequently generate probabilistic, model-derived outputs [17, 37] that users cannot readily validate or contest through lived experience (e.g., PRS) [19, 32]. These outputs may inform decisions with long-term consequences, including clinical treatment choices or reproductive planning [33, 48]. As a result, interaction problems in PM can influence trust, anxiety, and moral judgment over time.

While few HCI papers explicitly label themselves as PM research, related work is emerging [6, 11, 42]. For example, Calisto et al. showed how adaptive AI interfaces can reduce diagnostic errors in radiology [6], and Mitchell et al. integrated machine learning with expert knowledge to personalise nutrition advice for people with diabetes [11]. These PM-related studies suggest that HCI can play an important role in making complex biomedical data more actionable, while also highlighting tensions around transparency, trust, and human oversight – tensions that PM contexts may amplify.

3 What Is HPMI, and Why Revisit It Now?

We initially introduced the term “Human-Precision Medicine Interaction (HPMI)” at CHI 2025 as an invitation rather than a finished framework [42]. Building on this initial work, we have since explored these challenges across different contexts and methods. While some of this work predates the formal introduction of HPMI, it can be understood as collectively engaging with similar interactional questions in PM. This includes empirical studies of public perceptions of PRS [42, 44], where we observed adoption barriers that could not be fully addressed through conventional HCI design implications. These observations contributed to the development of HPMI as a way of bringing together and extending HCI approaches to address the distinctive challenges of PM.

Furthermore, this line of work includes design-oriented prototyping of PM service ecosystems [39, 43], and conceptual discussions of responsibility, actionability, and contestability in PM [40, 41]. Taken together, these contributions form a coherent research trajectory that HPMI makes more visible.

To initiate this area of work and guide future exploration, we previously outlined two guiding considerations, which we rephrase slightly for clarity here:

- communicating and interpreting complex, probabilistic health data, and
- redesigning systems and workflows across heterogeneous clinical and non-clinical stakeholders.

Building on this trajectory, we propose a minimal set of criteria that abstract the structural conditions recurring across the five provocations presented in this paper. The provocations and criteria were developed through an iterative process of abstraction across multiple sources, including prior empirical work, recurring tensions identified in HCI-for-health and PM-related literature, and design-oriented reflections from provotyping engagements. Rather than representing validated thresholds, these criteria serve as a compact analytic lens for identifying when an HPMI perspective becomes especially salient. Intentionally, they function as a boundary object for discussion [38], as shown in Figure 1. A system may involve HPMI-level attention when it simultaneously:

- (1) Produces probabilistic, model-derived evidence that users cannot validate through everyday experience,
- (2) Supports decisions with significant clinical, psychological, or life planning consequences under uncertainty, and
- (3) Requires coordination across stakeholders with unequal expertise, authority, and accountability.

4 Provocations

As previously mentioned, we propose these minimal criteria as cross-cutting trigger conditions that repeatedly surface across the five provocations below. These provocations do not function as isolated claims, nor are they intended as a checklist of design failures. Rather, they describe a set of interrelated interactional breakdowns that emerge when PM technologies are approached through HCI-for-health framings. Table 1 summarises each provocation alongside a minimal argument, a plausible counterargument, and a trigger condition indicating when HPMI-level attention becomes necessary. In the subsections that follow, we expand each provocation through possible PM scenarios and HCI consequences. Together, these five provocations reflect a set of interrelated tensions that might co-occur when PM systems are approached through conventional HCI-for-health assumptions.

4.1 Provocation 1: Probabilistic Outputs Weaken Experience-based Validation

First, PM challenges the assumption that users can iteratively validate system outputs through experience-near feedback loops. Many HCI-for-health systems support interaction through short feedback loops. Users can relate system outputs to experience-near signals and iteratively calibrate their engagement (e.g., walking more leads to a higher step count, improved sleep metrics, or lower resting heart rate). This is not to suggest that such systems allow users to directly verify long-term disease outcomes (e.g., diabetes). Rather, they provide proximal, measurable proxies that make system feedback contestable and adjustable over time.

PM systems often weaken this feedback structure. For example, a PRS condenses hundreds or thousands of genetic variants into a probabilistic estimate, typically framed relative to a population baseline [42]. Unlike experience-near metrics, users cannot iteratively validate or recalibrate such risk evidence through everyday

action, and the consequences of acting on it may unfold over years. As a result, the interactional challenge is both comprehension and calibration: users may understand what the risk score means yet remain uncertain how much weight to place on it, under what conditions, and with what accountability. In practice, people may seek alternatives – comparing family members, consulting clinicians, or selectively attending to outputs that align with prior beliefs [13, 16, 45]. When evidence remains population-derived and difficult to calibrate through lived experience, trust formation shifts from an individual cognitive task to a relational and institutional process.

4.2 Provocation 2: Personalisation Can Amplify Psychological Harm

Second, PM challenges the assumption that personalisation is primarily empowering, by introducing long-term psychological implications that extend beyond immediate interaction. Personalisation has often been associated in the field of HCI with increased relevance, engagement, and user agency. In PM contexts, however, personalised predictions can carry disproportionate psychological weight. Learning about elevated genetic risk for conditions such as cancer or Alzheimer’s disease may reshape how individuals imagine their future selves, their family roles, or their perceived control over health outcomes [14, 26, 42]. By comparison, this may be less pronounced for conditions such as type 2 diabetes, where risk information is often interpreted as more behaviourally actionable and experience-near [42].

In addition to the moments of initial disclosure, PM outputs can linger, resurfacing during unrelated life decisions such as career planning, insurance considerations, or reproductive choices. Even when interfaces are carefully framed, optional, or accompanied by disclaimers, the personalised nature of the information can render disengagement difficult. Unlike self-tracking data that users can stop collecting or disengage from, genetic information is perceived as enduring and difficult to ‘turn off’ – even though the risk estimates derived from it may change over time as models, evidence bases, and contextual factors evolve [42]. Relatedly, this complicates HCI strategies that rely on user choice or opt-in engagement to mitigate harm. Designing for comprehension alone is insufficient. Therefore, PM systems must account for long-term emotional trajectories that unfold over time. When personalisation concerns irreversible futures rather than modifiable behaviours, its psychological consequences persist even in well-designed systems, marking a boundary where personalisation ceases to be a purely empowering design move.

4.3 Provocation 3: Interfaces Can Normalise Misapplied Evidence

Third, PM challenges the assumption that model outputs can be treated as broadly applicable, by exposing how interfaces may obscure population scope, uncertainty, and limits of validity. PM models are only as robust as the data behind them. One notable case is that many genomic datasets and biorepositories remain heavily skewed towards populations of European ancestry, resulting in reduced predictive validity for underrepresented groups [27]. Importantly, the issue is not simply a limitation of

Table 1: Five provocations for HPMI: minimal arguments, counterarguments, and triggers for HPMI-level attention in PM.

Provocation	Minimal Argument	Counterargument	Trigger for HPMI-Level Attention
Probabilistic outputs weaken experience-based validation	PM systems produce probabilistic risk outputs that users cannot iteratively calibrate or contest through experience-near feedback loops, weakening assumptions of experience-based interaction.	Improved explanations, visualisations, and risk communication techniques may sufficiently support user understanding and trust.	When risk evidence cannot be iteratively calibrated through experience-near feedback loops, the core challenge shifts from explaining outputs to designing for relational trust, endorsement, and accountability across people and institutions.
Personalisation can amplify psychological harm	Personalised predictions in PM may reshape how users perceive their future selves, eliciting anxiety, fatalism, or distress beyond typical self-tracking feedback.	Psychological impact varies by individual and context, and can be mitigated through careful framing, optional engagement, or supportive design.	When predictions are interpreted as having long-term implications for life planning and persist beyond moments of use, design must shift from “personalisation-as-empowerment” to supporting long-term affective trajectories, including opting out, revisiting, and psychosocial support.
Interfaces can normalise misapplied evidence	PM interfaces may present model outputs as broadly applicable while obscuring population scope, calibration limits, and uncertainty, enabling misapplication to become routine.	Bias is primarily an upstream modelling issue, and presenting detailed caveats may confuse users or reduce confidence.	When predictive validity is uneven across populations and outputs may be treated as universally applicable, interfaces cannot treat uncertainty and limitations as optional details. HPMI-level attention is needed to make representativeness, caveats, and uncertainty clear and actionable without offloading interpretive burden onto users.
PM interaction is inherently multi-stakeholder	PM interactions span patients, clinicians, counsellors, and institutions, with model-derived risk evidence often circulating across settings and time, challenging single-user models of interaction and accountability.	Multi-stakeholder workflows are already addressed within CSCW and health IT research.	When interpretation and responsibility are distributed across stakeholders over time – especially for upstream, model-derived evidence that is difficult to validate at the individual level – interaction must be designed beyond a single user-system encounter. HPMI-level attention requires shared artefacts and workflows for joint sensemaking, clarifying who can act, who explains, and who is accountable.
Design choices in PM are never value-neutral	PM interfaces necessarily require designers to resolve tensions between incompatible values (e.g., transparency vs. protection, autonomy vs. clinical responsibility) in order to function at all.	Value conflicts can be managed externally through regulation, ethical guidelines, or professional norms, allowing interfaces to remain neutral.	When interface defaults enact value trade-offs around uncertainty, autonomy, and responsibility, neutral design becomes weak. HPMI-level attention requires making value choices explicit and designing mechanisms for contestation, consent, and governance at the interaction layer.

the modelling technology in the abstract. Rather, interaction breakdowns arise when model outputs are presented or used as broadly applicable evidence without making their population scope and limitations visible. In other words, interfaces and service workflows can normalise misapplication.

At the interaction layer, for example, risk scores may be rendered through clean, authoritative visuals that encourage interpretation as precise and universal [29, 42]. In particular, caveats about representativeness, calibration, and uncertainty may be relegated to secondary screens or omitted altogether. For users whose demographic background is poorly represented in training data, this can produce a false sense of precision and fairness. Therefore, the design challenge is not ‘how much to disclose’ in the abstract, but ‘how to make applicability actionable’: who the score is most valid for, when it should be interpreted with caution, and what alternative pathways are appropriate (e.g., clinical referral or additional testing). Without such interactional support, PM systems risk normalising health inequity while maintaining an appearance of neutrality.

4.4 Provocation 4: PM Interaction Is Inherently Multi-Stakeholder

Fourth, PM challenges the assumption of single-user interaction by introducing distributed interpretation, responsibility, and decision-making across multiple stakeholders over time. PM interaction typically extends beyond a single user engaging with a standalone system. Given the interdisciplinary nature of PM [47], it unfolds across stakeholders such as patients, clinicians, genetic counsellors, data scientists, and sometimes family members, with information circulating over extended periods and across institutional boundaries [22]. A result generated in one context may later be interpreted, reinterpreted, or contested in another [21].

CSCW and health IT (e.g., electronic health record and clinical point of care technology) research have long addressed multi-stakeholder coordination [1, 3, 9]. While uncertainty is not unique to PM – many chronic diagnoses involve ambiguity and evolving evidence – PM can intensify coordination challenges by introducing model-derived, population-based risk estimates whose evidential

basis often lies outside the clinical encounter and can be difficult to interrogate or validate through routine follow-up. On one hand, clinicians may be responsible for communicating upstream outputs (e.g., lab- or vendor-generated risk score reports) without stable interpretive conventions comparable to those surrounding many clinical tests (e.g., medical images). On the other hand, patients must interpret evidence that cannot be independently evaluated or iteratively calibrated through symptom change. In such a context, accountability becomes distributed, yet interfaces often assume linear handoffs and stable roles. These dynamics foreground sustained human-machine-human relations rather than discrete interactions. Without shared artefacts and interfaces that support joint sensemaking, PM systems risk amplifying misalignment between stakeholders.

4.5 Provocation 5: Design Choices in PM Are Never Value-Neutral

Finally, PM challenges the assumption that interface design can remain value-neutral, by requiring explicit trade-offs between competing values such as autonomy, responsibility, and uncertainty. PM systems need to make interactional decisions in contexts where core values are in tension and cannot be simultaneously satisfied. In PM contexts, interfaces and workflows can shape how uncertainty, responsibility, and future health risks are interpreted and acted upon across people and institutions. For example, deciding whether to foreground uncertainty (e.g., confidence ranges, population caveats) or to simplify risk estimates entails a trade-off between making uncertainty visible and limiting psychological burden. Similarly, choices about default data sharing settings, result visibility, and the timing or pathway of disclosure can implicitly prioritise certain values over others, such as clinical authority, patient autonomy, or precaution. In these settings, neutrality is difficult to sustain: designing the interaction necessarily enacts particular value trade-offs [10].

What is distinctive in PM is not that values matter in designing interfaces – HCI research has long shown that they do – but that these trade-offs may be played out repeatedly through routine interaction mechanisms. Users encounter them through interface and workflow decisions such as default visibility (who sees results first), opt-in versus opt-out sharing, thresholds for highlighting elevated risk, and the presence or absence of action prompts (e.g., screening recommendations or referrals). Treating ethics in PM as an external concern addressed solely through regulation or professional guidelines risks obscuring how values are enacted and normalised in everyday use [30].

5 An Agenda for HPMI in HCI

One year after the introduction of HPMI, revisiting it is valuable less for naming a new subfield than for sharpening what it makes newly visible: interactional assumptions that may become unstable in precision medicine contexts. What is new in this short form beyond the initial articulation of HPMI is a minimal, actionable basis for critique and discussion. We offer two elements: (i) a set of minimal criteria that help identify when PM systems benefit from HPMI-level attention, and (ii) five provocations that surface

recurring interactional tensions and clarify when conventional HCI-for-health framings may break down.

Importantly, these contributions are not intended as empirically validated thresholds or an exhaustive account of PM interaction. Rather, they function as a compact analytic abstraction that surfaces structural tensions warranting further empirical testing, design experimentation, and theoretical refinement. In this sense, the value of this paper lies less in settling boundaries than in making them visible and contestable.

Building on these provocations, we outline a set of directions for how HCI research may respond to these tensions in practice. These directions highlight areas where conventional approaches may require extension, and are summarised alongside corresponding design opportunities in Table 2.

- **From comprehension to relational trust and accountability.** HCI work may need to examine how trust is established, negotiated, and maintained across stakeholders. This includes designing shared artefacts that support joint interpretation (e.g., clinician-patient interactions), making institutional endorsement visible, and clarifying who is responsible for explaining and acting on model-derived evidence.
- **From one-off disclosure to long-term engagement.** PM information persists beyond moments of interaction and may resurface in future decisions. This suggests a need to move beyond designing for initial result communication, towards supporting revisiting results over time, enabling reinterpretation as evidence evolves, and providing mechanisms for disengagement or re-engagement.
- **From generic transparency to actionable uncertainty.** Interfaces may need to make the applicability and limitations of model outputs actionable. This includes communicating population scope, calibration boundaries, and when alternative actions (e.g., clinical consultation) are appropriate.
- **From single-user interaction to multi-stakeholder workflows.** PM interaction spans patients, clinicians, and institutions over time. Designing for HPMI may therefore require shared artefacts, coordination mechanisms, and interfaces that support distributed sensemaking and accountability.
- **From implicit values to explicit contestability.** Interface and workflow design in PM inevitably enact value trade-offs. This suggests a need to make these choices visible, support user contestation, and enable negotiation of responsibility across stakeholders.

In summary, these directions suggest that interaction design in PM is inseparable from questions of responsibility, governance, and value trade-offs enacted through everyday interface decisions. We invite the IH community to engage critically with, refine, and empirically examine these directions in future work.

Acknowledgments

We thank the anonymous reviewers for their helpful comments.

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Table 2: An agenda for HPMI in HCI: key shifts and design opportunities.

Shift	Design Opportunities
Comprehension → Trust	Design shared artefacts, support joint interpretation, clarify accountability
Disclosure → Long-term engagement	Enable revisiting results, reinterpretation, and disengagement
Transparency → Actionable uncertainty	Communicate applicability, population scope, and limits
Single-user → Multi-stakeholder	Support coordination across patients, clinicians, institutions
Implicit values → Contestability	Make value trade-offs visible, enable user negotiation and control

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