Towards Human-Precision Medicine Interaction

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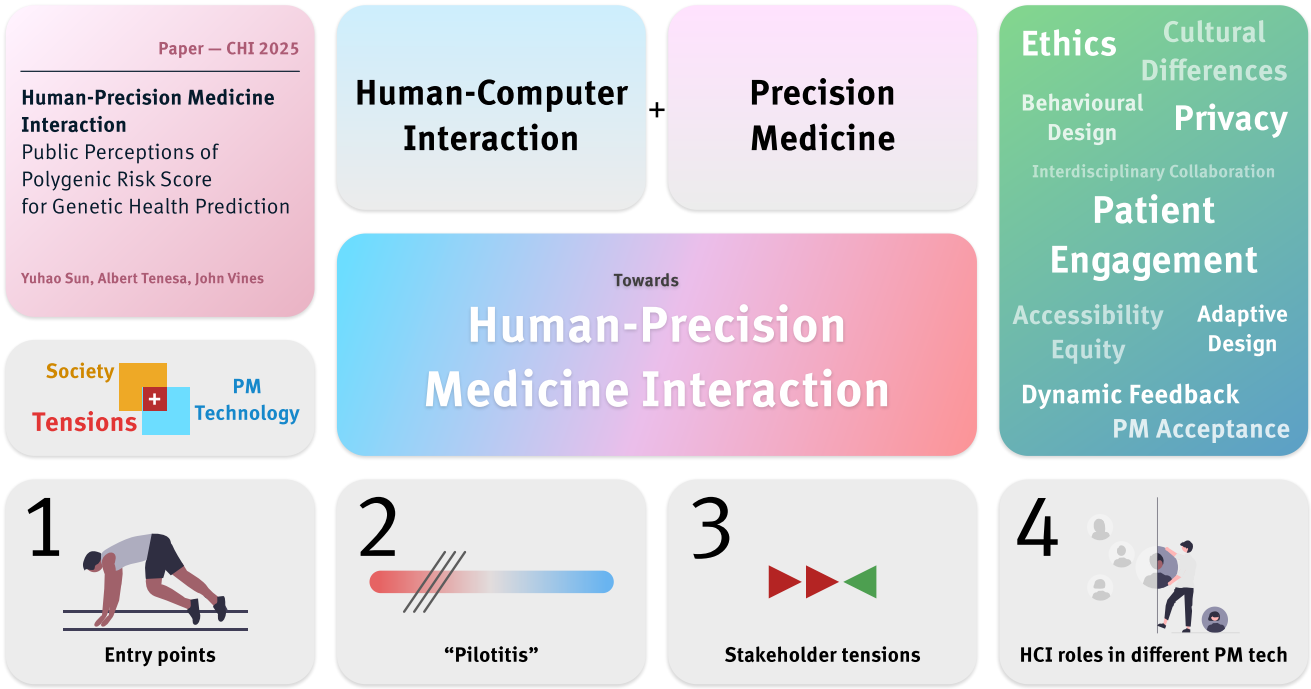

Figure 1: Teaser Bento: Introducing Human-Precision Medicine Interaction (HPMI). HPMI was first introduced in our CHI 2025 paper, as noted in the top-left corner, drawing inspiration from the tension between socio-technical considerations and the advancing technologies of Precision Medicine (PM). HPMI, which integrates HCI with PM, highlights several key challenges at the intersection of technology and human experience in healthcare. The four main challenges discussed in this paper are listed below, while the top-right corner highlights additional topics for further exploration. Some design elements of this figure are adapted from Figure 1 of our CHI 2025 paper.

ABSTRACT

In this paper, we introduce the term Human-Precision Medicine Interaction (HPMI) to explore the convergence of Precision Medicine (PM) and HCI in advancing personalised healthcare. Building on our CHI 2025 paper titled *Human-Precision Medicine Interaction: Public Perceptions of Polygenic Risk Score for Genetic Health Prediction*, this work further examines the challenges and opportunities at the intersection of PM technologies and HCI. While PM technologies like Polygenic Risk Scores (PRS) have the potential to empower individuals, they also present significant challenges, including privacy concerns and anxiety induced by uncertainty. We argue that the successful realisation of PM's potential requires a careful integration of technological innovation with human values. This paper, thus, focuses on four key areas: identifying entry points for HCI contributions, addressing challenges in pilot implementations, managing stakeholder tensions, and understanding the roles of HCI in different PM technologies. We invite the CHI and wider HCI communities to engage in a dynamic dialogue on fostering a more human-centred approach to interactive PM and wider health.

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CCS CONCEPTS

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

KEYWORDS

Human-Precision Medicine Interaction, HPMI, Precision Medicine, Polygenic Risk Score, Digital Health

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1 INTRODUCTION

The landscape of healthcare is more than just evolving – it is undergoing a profound transformation that touches every aspect of our lives. The era of one-size-fits-all treatments is over; today, Precision Medicine (PM) celebrates our individual differences. Technically, PM is a rethinking of how we interpret vast, multi-dimensional healthcare data to craft treatments that resonate with each unique individual [4, 6, 9]. Although PM found its early roots in the late 1990s with breakthroughs in breast cancer treatments [3], its true momentum surged in 2015 with the launch of the U.S. Precision Medicine Initiative [1]. More recently, digital health research in HCI has begun to grapple with this transformation, exploring how technology can and should support a more personalised approach to care – here, the field of HCI could play a crucial role [8].

In our CHI 2025 work titled *Human-Precision Medicine Interaction: Public Perceptions of Polygenic Risk Score for Genetic Health Prediction* [12][1], we explore public perceptions of Polygenic Risk Scores (PRS) in the context of PM through an HCI lens. PRS is an emerging PM technology that predicts human beings' future health conditions by comparing the genotype data in the cohorts with and without the disease [7]. While much of the existing literature focuses on PRS as a technical tool, there is limited research on how people perceive PRS. We uncovered that while PRS holds remarkable promise for informing personal healthcare strategies, it also brings with it a spectrum of challenges for the public. For example, the uncertainty embedded in risk predictions can inadvertently fuel anxiety or even trigger adverse mental health outcomes. Reflecting on these findings, we realised that the future of PM must be a harmonious blend of technological innovation and human values. This realisation, thus, led us to coin the term Human-Precision Medicine Interaction (HPMI), which aims to bridge the gap between technological advancements and the complexities of human experience in healthcare. Figure 2 shows the original text in our CHI paper towards the introduction to HPMI.

2 TOWARDS HUMAN-PRECISION MEDICINE INTERACTION (HPMI)

Our exploration into public perceptions of PRS [12] has illuminated a pathway towards what we call HPMI – a natural convergence of terms "precision medicine" and "human-computer interaction". Within HPMI, we call to integrate technological advancement with the nuanced realities of human experience in healthcare. HPMI invites us to ask: **How might we design and implement PM tools that are not only data-driven – which is what dominates much research and development around PM technologies thus far – but also deeply respectful of the human condition, including emotional, psychological, and cultural factors, in a responsible way?** In this section, we explore four main areas and challenges within HPMI:

(1) identifying entry points for the field of HPMI,
(2) avoiding "pilotitis,"
(3) addressing stakeholder tensions, and
(4) understanding the roles of HCI in different PM technologies.

2.1 Entry Points to HPMI

The integration of PM into everyday healthcare presents several clear entry points for further research and collaboration, especially when considering HPMI. These entry points refer to key areas where HCI researchers can intervene, such as interface design, user comprehension, and data presentation. In our paper [12], we chose not completely to define the term "HPMI"; at the forefront is the recognition that emerging technologies like PRS require not only technical refinement but also thoughtful consideration of how complex health data is communicated and interpreted by diverse users. HCI researchers, for example, are uniquely positioned to bridge the gap between data-intensive PM applications and their end users by designing intuitive interfaces and interaction models, to ensure that genetic and probabilistic health information becomes accessible and meaningful to both healthcare professionals and the public who have no relevant knowledge. A critical question, however, remains:

- What design strategies can best facilitate user comprehension and engagement with complex health data while maintaining clinical accuracy?

2.2 "Pilotitis"

Alongside these promising entry points, there are notable pitfalls that must be carefully navigated to avoid common challenges observed in wider digital health innovations. One significant risk is the tendency for these projects to remain perpetually in a pilot phase, often referred to as *pilotitis* [2], due to the reasons including delayed or insufficient stakeholder engagement. Early and continuous involvement of all relevant parties – ranging from patients and healthcare professionals to data scientists and policymakers – might prevent the disconnect that often arises when technological capabilities outpace public understanding and clinical applicability. Without such engagement, misalignments may occur between the technical design of PM tools and the practical constraints of healthcare settings, including limited time for comprehensive data interpretation by busy healthcare professionals [5]. To counteract these issues, design and implementation processes should remain iterative, incorporating ongoing feedback and adaptive governance structures that bridge the demands of transparency, privacy, and clinical utility. Therefore, we ask:

- How might we develop research frameworks and evaluation strategies that ensure HPMI studies translate into tangible, lasting improvements in healthcare delivery, rather than remaining confined to academic exercises?

[1] An arXiv version of this work is available: https://arxiv.org/abs/2501.19405. A preliminary version of this work has also been reported in an extended abstract [11].

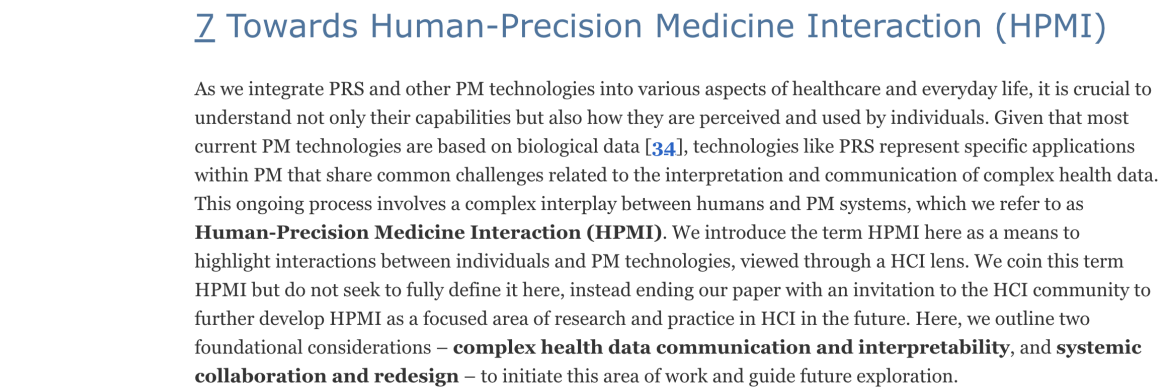

Figure 2: Introduction to HPMI in Our CHI Paper [12].

2.3 Stakeholder Tensions

The third challenge within HPMI is balancing diverse stakeholder priorities further complicates the integration of PRS and broader PM technologies. In any multidisciplinary effort, tensions are likely to emerge, as different groups bring their perspectives and priorities to the table. However, it is particularly pronounced in healthcare HCI and specifically, HPMI research. For example, while HCI researchers might advocate for user engagement and iterative design processes, healthcare professionals often emphasise clinical accuracy, evidence-based practice, and operational efficiency. These differing priorities can create challenges in aligning user-centred design with the strict standards of medical practice. Moreover, managing the inherent trade-offs between data transparency and privacy regulations adds another layer of complexity. Patients may expect clear, transparent communication about their genetic information and the ability to control its use, yet the operational realities of healthcare systems and regulatory frameworks can limit such flexibility. The divergence in expectations calls for careful, proactive public engagement from the outset, ensuring that all stakeholders are informed and their concerns addressed before the technology becomes fully embedded in clinical workflows. Ultimately, the success of PM technologies will depend on establishing shared frameworks that allow for deeper interdisciplinary understanding instead of surface-level compromises, thereby fostering trust and ensuring that technological innovations are both ethically sound and practically applicable. The two questions here are:

- How might HPMI research be adapted to balance user-centred design with the stringent requirements of clinical practice and regulatory compliance?
- How might interdisciplinary methods, such as design thinking and participatory design, be applied in the context of PM to improve the user experience and ensure the usability of PM tools, while considering the diverse perspectives of stakeholders from healthcare, technology, and ethics?

2.4 Roles of HCI in Different PM Technologies

Furthermore, it is important to recognise that not all PM applications require the same level of HCI involvement. Some PM technologies, such as PRS or medical imaging systems [13], rely heavily on direct user interaction, where clear communication and intuitive design are critical to patient and healthcare professional engagement. These high-interaction technologies, thus, require HCI researchers to design user-friendly interfaces and decision-support tools that facilitate comprehension and usability. Meanwhile, some PM technologies, like genomic sequencing pipelines or the delivery of drugs and cells *in vivo* [10], may not involve direct user engagement and primarily function through backend processes. In these cases, HCI may be less central, but its role in the interpretation, communication, and ethical considerations of these technologies remains potentially crucial. As such, different PM technologies necessitate varying degrees of HCI involvement, and it is vital to understand how to tailor HCI frameworks to address the specific needs of each in the field of PM. Here, we ask two questions:

- How might HPMI be adapted to varying levels of user interaction across different PM technologies, ensuring that usability concerns are appropriately addressed?
- What role does HCI play in ensuring ethical transparency and interpretability in low-interaction PM technologies, and how might it support their integration into clinical practice?

3 COMPLEXITIES IN HPMI: BEYOND THE CORE ISSUES

While the four primary topics discussed above are crucial to the development of HPMI, several additional issues warrant further exploration. In addition to complementing the existing discussion, eight topics here offer significant opportunities to shape the future of HPMI, addressing challenges that arise from the interdisciplinary and ever-evolving nature of PM. Below, we outline eight directions for HPMI for further discussion.

3.1 Ethics and Privacy Concerns

The integration of PM technologies, such as PRS, introduces significant ethical dilemmas, particularly related to privacy, informed consent, and data ownership. As personal health data becomes more central to healthcare decisions, there is an urgent need to balance innovation with the protection of individual rights. **How might HPMI address ethical concerns, particularly regarding data**

privacy, informed consent, and transparency, while fostering trust among stakeholders?

3.2 Cultural Differences

Cultural differences play a critical role in healthcare preferences, decision-making processes, and the acceptance of medical technologies. In a globalised healthcare environment, understanding how different cultural groups interpret medical information, health risks, and privacy concerns is essential for ensuring the widespread adoption of PM technologies. **How might HPMI be adapted to account for cultural differences in healthcare practices and patient expectations, ensuring that PM tools are effective across diverse populations?**

3.3 Enhancing Patient Engagement and Health Behaviour

A key challenge in PM is ensuring that patients are not only passive recipients of individual health data but active participants in managing their health. Empowering patients to take control of their health through informed decision-making is central to the success of PM. HPMI has the potential to bridge the gap between data-driven medical insights and meaningful patient action, enhancing the overall healthcare experience. **How might HPMI enhance patient engagement in PM, and what role do patient empowerment and health behaviour play in improving outcomes?**

3.4 Ensuring Accessibility and Equity

As PM tools become more advanced, there is a risk that access to these technologies will be limited to certain socio-economic groups, exacerbating existing healthcare inequalities. HPMI offers a future framework for ensuring that PM tools are designed to be inclusive and equitable, promoting accessibility for underserved populations and addressing systemic barriers to healthcare. **How might HPMI contribute to making PM more accessible and equitable, particularly for underserved populations or those with limited access to healthcare technologies?**

3.5 Addressing Technology Acceptance and User Experience

Despite the transformative potential of PM, widespread acceptance of new technologies remains a challenge. Patient and healthcare provider acceptance of PM tools is often hindered by concerns over usability, trust, and perceived benefits – as we introduced above. A key role for HPMI is to bridge the gap between PM technology and user-friendly interfaces, ensuring that PM tools are not only clinically effective but also widely adopted. **How might HPMI be used to improve user experience and address barriers to the acceptance of PM technologies, such as trust, usability, and perceived benefits?**

3.6 Fostering Interdisciplinary Collaboration and Innovation

HPMI itself is an interdisciplinary field, merging insights from including but not limited to healthcare, technology, social sciences, and ethics. The future of PM will require close collaboration between diverse disciplines to ensure the successful integration of human-centred design and cutting-edge PM technology. **How might HPMI foster interdisciplinary collaboration between healthcare professionals, technologists, and social scientists to drive innovations in PM?**

3.7 Incorporating Dynamic Feedback and Adaptive Design

As medical knowledge evolves and individual health data becomes more nuanced, there is a need for PM tools to adapt continuously to changing circumstances. HPMI can support the development of dynamic feedback loops that ensure PM tools evolve in response to new insights and individual patient needs, offering personalised care over time. **How might HPMI integrate dynamic feedback loops to enable continuous adaptation of PM tools, ensuring they remain responsive to the changing needs of patients over time?**

3.8 Behavioural Design and Personalised Interventions

One of the strengths of PM is its ability to offer highly personalised interventions based on personal health data. For example, genetic data. However, the success of these interventions depends on how well they are tailored to individual behaviours and lifestyles. HPMI has the potential to incorporate behavioural design principles, encouraging healthier behaviours and improving patient adherence to medical recommendations. **How might HPMI leverage behavioural design to create personalised interventions that improve patient outcomes and adherence to medical advice?**

4 CONCLUSION

In summary, we invite our communities to collaboratively examine actionable entry points, navigate "pilotitis," reconcile the often-competing priorities of multiple stakeholders, and understand the HCI roles in different PM technologies through the introduction and shaping of Human-Precision Medicine Interaction (HPMI). Just as HCI has long championed human-centred innovation, HPMI urges us to rethink the interaction between technology and the complex dimensions of human health. We hope that the discussions here will not only deepen our understanding of HPMI but also spark innovative approaches that transcend traditional disciplinary boundaries.

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REFERENCES

[1] 2016. Precision Medicine Initiative | The White House. https://obamawhitehouse.archives.gov/precision-medicine. (Accessed on 08/16/2024).

[2] Ann Blandford, Jo Gibbs, Nikki Newhouse, Olga Perski, Aneesha Singh, and Elizabeth Murray. 2018. Seven lessons for interdisciplinary research on interactive digital health interventions. *Digital health* 4 (2018), 2055207618770325.

[3] Ruggero De Maria Marchiano, Gabriele Di Sante, Geny Piro, Carmine Carbone, Giampaolo Tortora, Luca Boldrini, Antonella Pietragalla, Gennaro Daniele, Maria Tredicine, Alfredo Cesario, et al. 2021. Translational research in the era of precision medicine: where we are and where we will go. *Journal of Personalized Medicine* 11, 3 (2021), 216.

[4] Joshua C Denny and Francis S Collins. 2021. Precision medicine in 2030–seven ways to transform healthcare. *Cell* 184, 6 (2021), 1415–1419.

[5] Marie-Pierre Gagnon, Marie Desmartis, Michel Labrecque, Josip Car, Claudia Pagliari, Pierre Pluye, Pierre Frémont, Johanne Gagnon, Nadine Tremblay, and France Légaré. 2012. Systematic review of factors influencing the adoption of information and communication technologies by healthcare professionals. *Journal of medical systems* 36 (2012), 241–277.

[6] Kevin B Johnson, Wei-Qi Wei, Dilhan Weeraratne, Mark E Frisse, Karl Misulis, Kyu Rhee, Juan Zhao, and Jane L Snowdon. 2021. Precision medicine, AI, and the future of personalized health care. *Clinical and translational science* 14, 1 (2021), 86–93.

[7] Cathryn M Lewis and Evangelos Vassos. 2017. Prospects for using risk scores in polygenic medicine. *Genome medicine* 9 (2017), 1–3.

[8] Leonardo Rundo, Roberto Pirrone, Salvatore Vitabile, Evis Sala, and Orazio Gambino. 2020. Recent advances of HCI in decision-making tasks for optimized clinical workflows and precision medicine. *Journal of biomedical informatics* 108 (2020), 103479.

[9] Arabella L Simpkin and Katrina A Armstrong. 2019. Communicating uncertainty: a narrative review and framework for future research. *Journal of general internal medicine* 34 (2019), 2586–2591.

[10] Yuhao Sun. 2021. *Microrobots for Precision Medicine.* Master's thesis. Imperial College London. Available at http://dx.doi.org/10.13140/RG.2.2.18499.94246.

[11] Yuhao Sun. 2024. Design for Debate: Exploring Public Perceptions of an Emerging Genetics Health Prediction Service 'Polygenic Risk Score' Through Design Methods. In *Companion Publication of the 2024 ACM Designing Interactive Systems Conference*. 11–14.

[12] Yuhao Sun, Albert Tenesa, and John Vines. 2025. Human-Precision Medicine Interaction: Public Perceptions of Polygenic Risk Score for Genetic Health Prediction. In *Proceedings of the CHI Conference on Human Factors in Computing Systems*. 1–26.

[13] Yuhao Sun, Yamei Zhao, and Junsheng Sun. 2020. Subjective Image Quality Assessment: A Pre-Assessment on Visual Distortion of Medical Images by Clinicians and Radiologists. In *2020 7th International Conference on Information Science and Control Engineering (ICISCE)*. IEEE, 1367–1370.