

The Human Side of Genomics: Designing Tools for Better Research Partnerships

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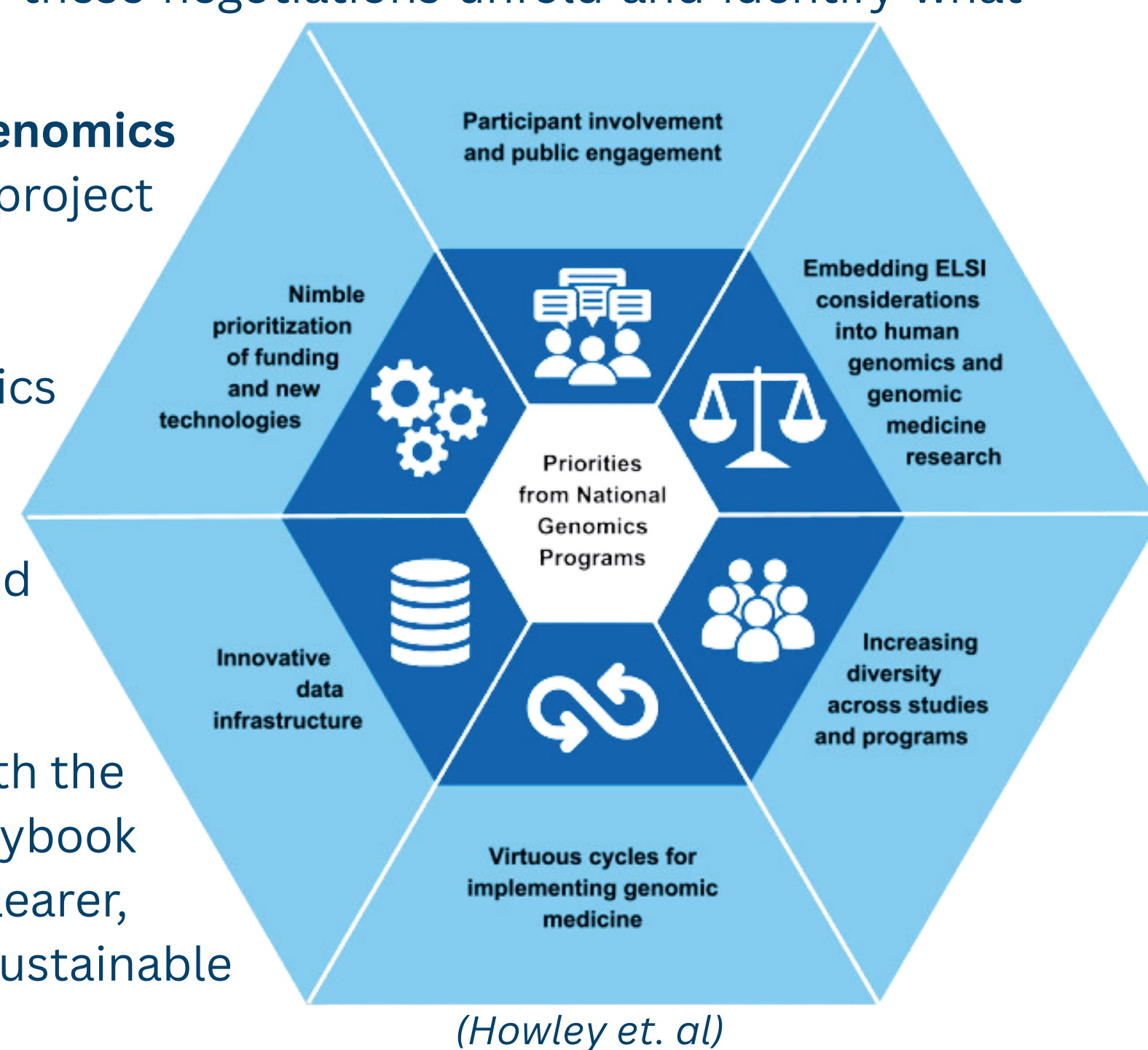
Project Background

Genomics is the study of an organism’s complete DNA. Over the past two decades, this field has grown dramatically. More than 96 national genomics initiatives have launched worldwide, with efforts like COG-UK’s 2 million viral genomes, All of Us’s 747,000+ participants, and H3Africa’s 3 million variants.

But as genomics becomes embedded in healthcare and public infrastructure, **the negotiations behind the science, including data governance, ethics, equity, public engagement, and cross-institutional collaboration, remain inconsistent and unclear.** This has quickly become a roadblock to continuing the field’s momentum, and so it has become a priority to understand how these negotiations unfold and identify what supports them.

Pathways to Negotiating Genomics

Research Partnerships is a project that aims to fill this gap by gathering input from stakeholders across genomics relationships (including researchers, funders, universities, institutions, and community members) to identify the most crucial moments in negotiation, with the goal of creating a global playbook that can be used to guide clearer, more equitable, and more sustainable partnerships.



My Project

My project focused on the technical aspect of translating these insights into a playbook. I reviewed and analyzed several existing negotiation playbooks from other fields including economics, data-governance, and artificial intelligence to synthesize the most practical and useful structures, features, and design strategies that could inform the development of our own genomics-specific playbook.

Method

Reviewed 30+ Playbooks

Included toolkits and guidance documents on public health, cross-sector collaboration, data sharing, viral genomic surveillance, health equity, and artificial intelligence governance. These materials were identified through targeted searches, recommendations from the research team, and references in existing literature.

Selected 7

Based on:

Prescriptive or descriptive: Does it give users explicit instructions or helps them understand a topic and make decisions?

Audience: Who is it for, how many audiences, how much background knowledge is needed?

Interface/ease of use: How easy is it to navigate, is the design engaging and accessible, how does one moves through it?

Structure: How is the content organized is it meant to be read continuously or does it allows users to jump between section?

3 Leading Contenders

Results

DataSharingPlayBook

Innovative Health Initiative and EFPIA

This is a web-based, discussion-driven toolkit with modular exercises designed to help diverse stakeholders reflect on the social and ethical dimensions of biorepository research. It was chosen for its flexible navigation, multi-audience guidance, and interactive design that supports engagement across different roles



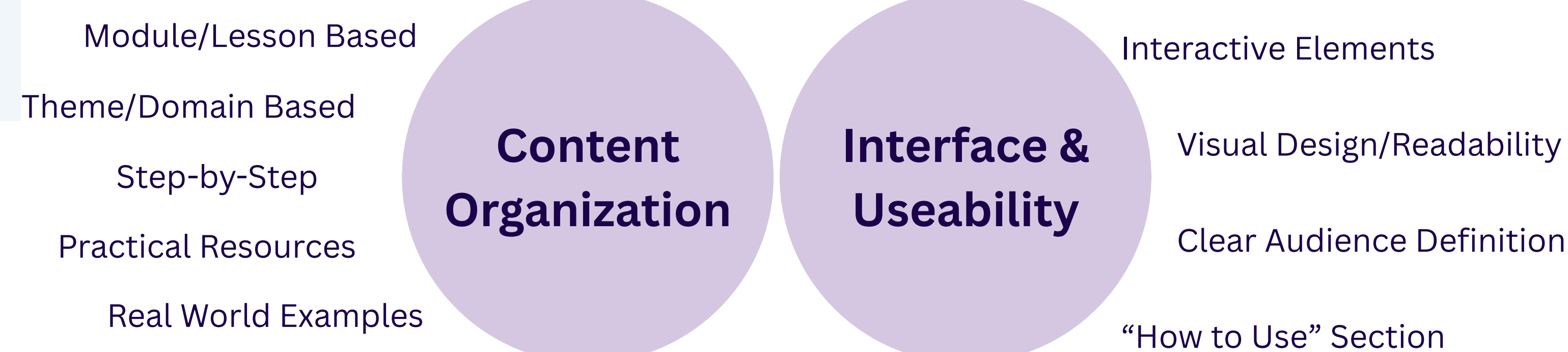
The Whitehall & Industry and Government Outcomes Lab

This is a prescriptive, strategy-focused guide for cross-sector partnerships, organized around thematic domains such as trust, power, leadership, culture, and learning. It was chosen for its clear structure, actionable “plays,” and use of real-world case studies that make negotiation strategies concrete and easy to apply.



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Across the playbooks, several design features consistently shaped how well users could navigate complex collaboration challenges, and they can be grouped into two main categories:



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Next Steps

Moving forward, the project will bring together the insights from ongoing interviews and field observations to better understand how people actually negotiate genomics partnerships in practice. These real-world experiences, combined with legal and policy analysis, will guide the development of a first draft of the negotiation playbook. Using the structural ideas drawn from CHIRON, the Collaboration Playbook, and the Data Sharing Playbook, the team will outline a framework that highlights key decision points, common challenges, and practical strategies for building more transparent and mutually beneficial partnerships. This draft will then be refined through a collaborative process with stakeholders, who will help shape the content, examples, and design features to ensure the playbook works for different roles and institutions. As the structure becomes clearer, the team will begin creating early prototypes to test usability and accessibility. Together, these steps will move the project toward a practical, easy-to-use resource that supports stronger, more equitable genomics research partnerships.

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Further Information

Scan below to learn more about my Laidlaw Scholars experience and the Pathways to Negotiating Genomics Research Partnerships project.

Pathways Project Info



Laidlaw Info

