Co-Producing a Research Decision-Making Guide for Down syndrome with Caregivers and Self-Advocates.

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Introduction

Caregivers and self-advocates often face difficult decisions about research participation but may lack accessible information about:

- Research protections
- Participant rights
- Data privacy
- Funding Sources
- Risks and benefits
- Time commitments
- Informed consent
- Overall Research Process

Key Gap: No widely available decision-support tool exists to help caregivers and self-advocates make informed, values-based decisions about research participation.

Why This Study Was Needed

Interest in Research Exceeds Participation

High Interest in Research Participation

Low Participation Rates

Information and Education Barriers

Many families express interest in Down syndrome research, yet participation rates remain lower than expected. Limited access to clear, understandable information about studies, participant protections, and research processes may contribute to this gap.

Families were not simply asking, “Should I participate?” They were asking, “What will happen, how am I protected, and how will this help me or my community?”

Project Goal

Improving Access to Research Information

Accessible Information

Provide Education on Research Process

Support Decision Making

Participation

This project aims to provide clear, accessible information about research participation, participant protections, and the research process to support informed decision-making among caregivers and self-advocates.

Decision Guide Co-Production Process

Who Created the Guide?

- 2-5 People per Group
- Virtual Environment
- Initial Content Development

7 Focus Groups

Iterative Feedback

Facilitated Using Prompts
- Content
- Language
- Usability
- Relevance
- Trust and Transparency
- Decision Support

Participants evaluated:
- Can I understand it?
- Can I use it?
- Does it answer my questions?
- Does it support informed choice?

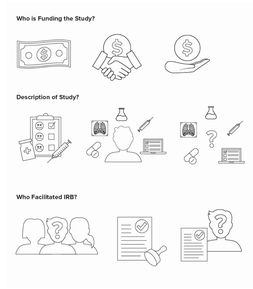
User Testing

Choosing not to participate in research is a valid and supported outcome.

Final Decision-Making Guide

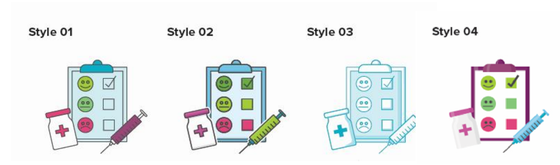
Co-Designing Process

Step 1: Icon Development



- Created draft icons for key research concepts.
- Gathered participant feedback on clarity and meaning.
- Refined designs based on stakeholder input.

Step 2: Style & Design

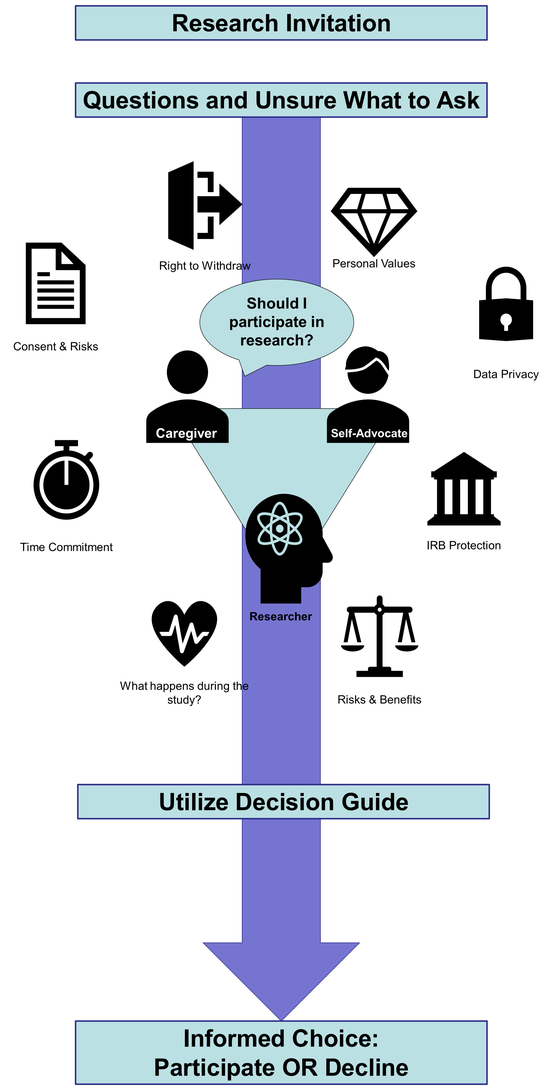


- Developed visual concepts with a media artist.
- Tested colors, fonts, and visual elements.
- Refined designs through participant feedback.

Step 3: Layout & Format

- Tested information layouts.
- Applied plain language principles.
- Revised structure based on participant feedback..

Research Participation Decision Process



Significance

By centering caregivers and self-advocates throughout development, this project is creating an accessible decision-support tool that promotes:

Accessible Information Plain-language content to support understanding of research studies and participation.	**Participant Understanding** Clear explanations of participant rights, protections, and research processes.
Research Engagement Reducing information barriers that may limit research participation.	**Stakeholder Engagement** Co-design with caregivers, self-advocates, and a media artist throughout development.

Acknowledgements

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