Development of the NC NEXUS Decision Aid

Implications for parental education and newborn screening

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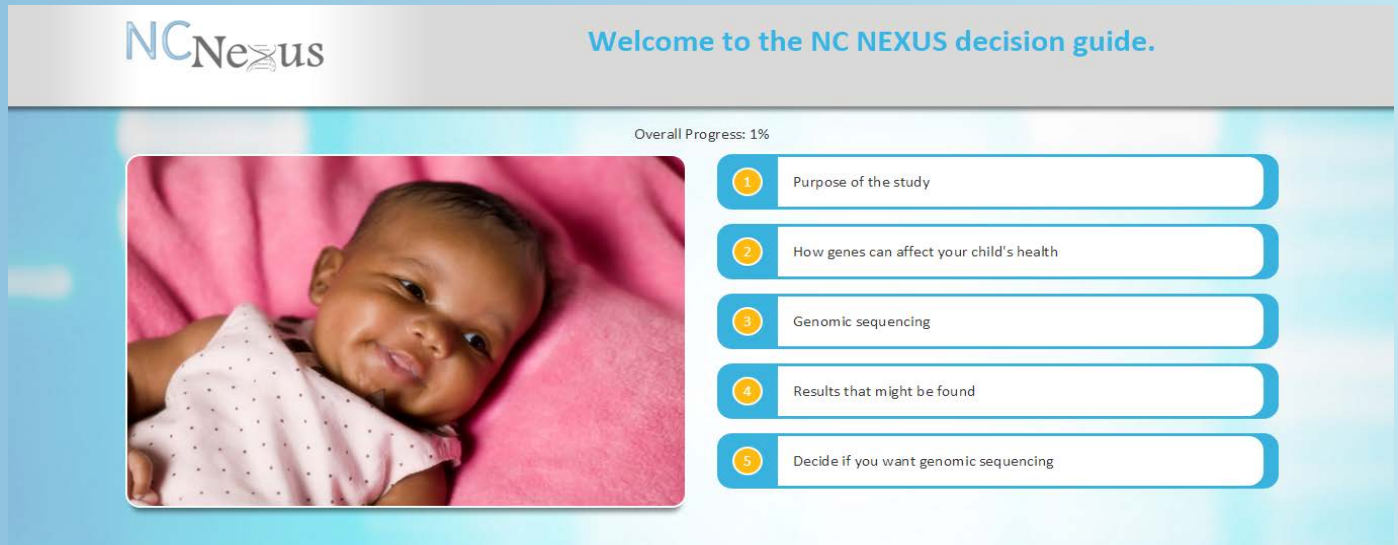

Project Team

Team Members

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Combined Areas of Expertise

- Health communication
- Health literacy
- Informatics and computing technology
- Human computer interaction
- Graphic design
- Pediatrics
- Genomics

NC NEXUS Decision Aid Overview

The Problem:

- Typical consent forms:
  - Often more than 10 pages long
  - Contain medical terminology and concepts beyond average health literacy
  - Require lengthy individual interactions
  - Do not provide knowledge or help people clarify values
- Traditional consent models will be problematic as NGS becomes more pervasive in research and practice for population studies

Our Approach – the *NC NEXUS Decision Aid*:

- Explains genomic information at a lay level
- Applies communication science strategies including principles of plain language, clear communication, and health literacy
- Uses text, graphics, and audio to convey challenging concepts
- Includes values clarification exercises

How it meets participant's needs:

- Facilitates informed decision making
- Eases the enrollment process
- Reduces decision making burden

The Value of Decision Support Tools/Decision Aids

*“Decision aids differ from usual health education materials because decision aids make explicit the decision being considered, and provide detailed, specific, and **personalized** focus on options and outcomes for the purpose of preparing people for decision making.”*

– Cochrane Review (2014)

Decision aids are

- evidence-based tools
- intended to help patients be an active participant
- assist in making specific and deliberated healthcare choices among various options.

Development – How Did We Gather and Use Parental Input?

Formative Interviews with Parents

- Recruited 33 couples who were married or in committed relationship
- Examined how couples communicate with each other and make decisions about genomic screening results for their child
- Revealed importance of letting couples complete the decision aid together
- Showed that different results categories evoked distinct decision processes–informed how content was organized around multiple decision points

Discrete Choice Experiment

- Online experiment with 1,289 parents of young children (ages 5 or younger)
- Stratified by race and gender
- Demonstrated how the characteristics of genetic disorders influence parental decisions about which sequencing results are most important to know
- The information helped select disorders to use as examples in the decision aid

Lewis et al. *Pediatrics* (2016)

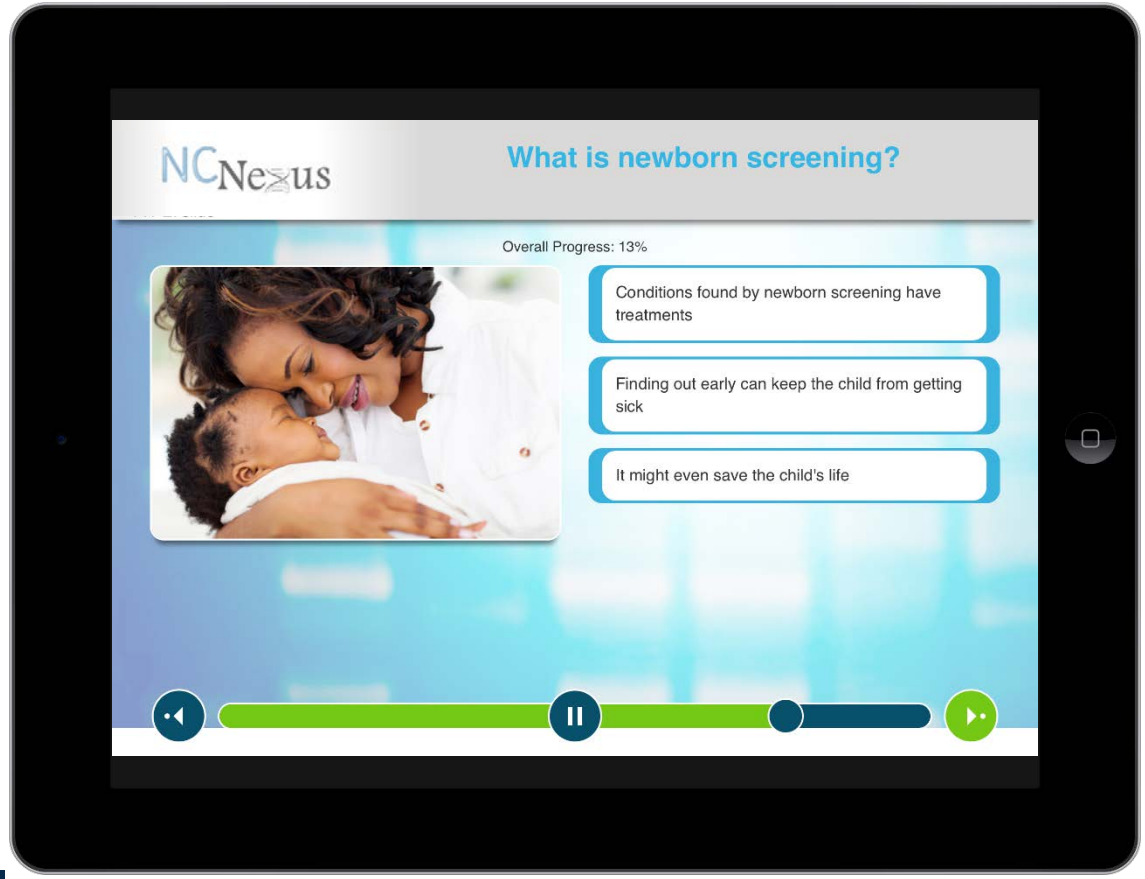
Development – How Did We Gather and Use Parental Input?

User-Centered Design

- Used best practices, theory, and guided by international decision aid standards
- Followed iterative process to develop, test, and refine the decision aid
- Applied plain-language principles to address differences in health literacy
- Conducted user testing to understand areas of confusion related to content and navigation
- Interface allows users go at their own pace, repeating and reviewing information as needed

Lewis et al. *Pediatrics* (2016)

Decision Aid – contains 4 “sections”



Traditional Newborn Screening and Similar Conditions

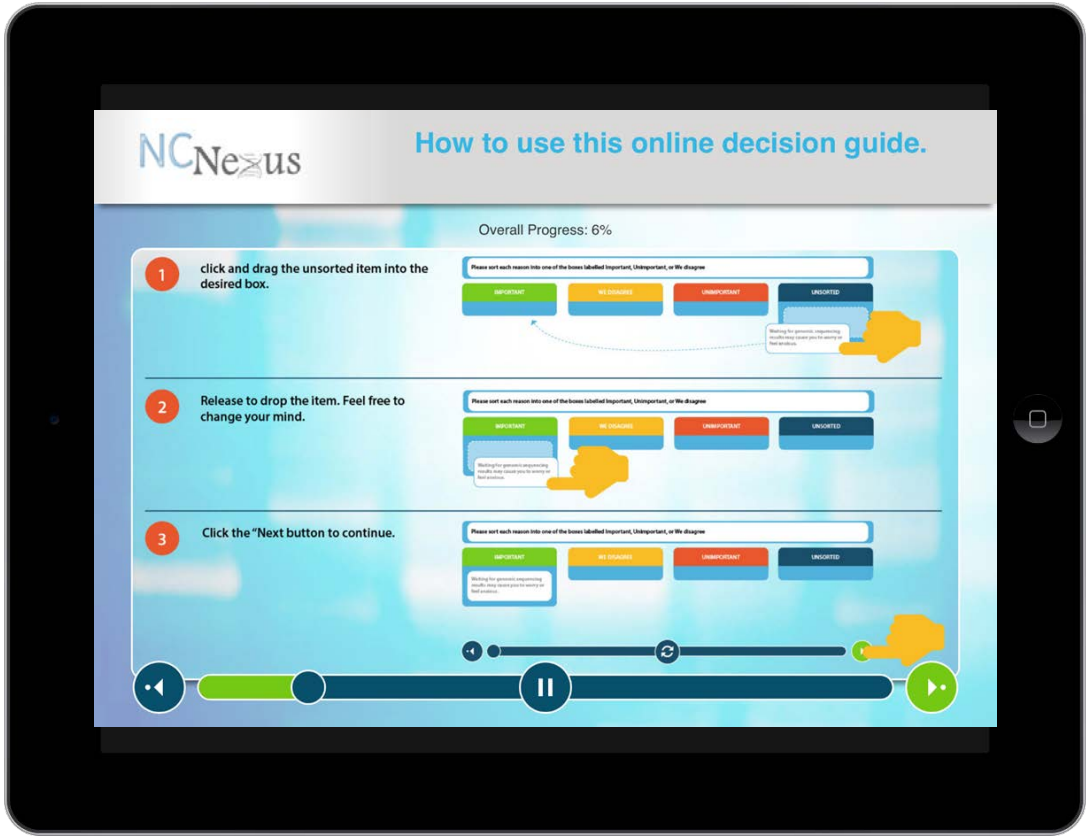
Non-Medically Actionable Childhood Conditions

Medically Actionable Adult Onset Conditions

Carrier Status

Topics Covered in Decision Aid

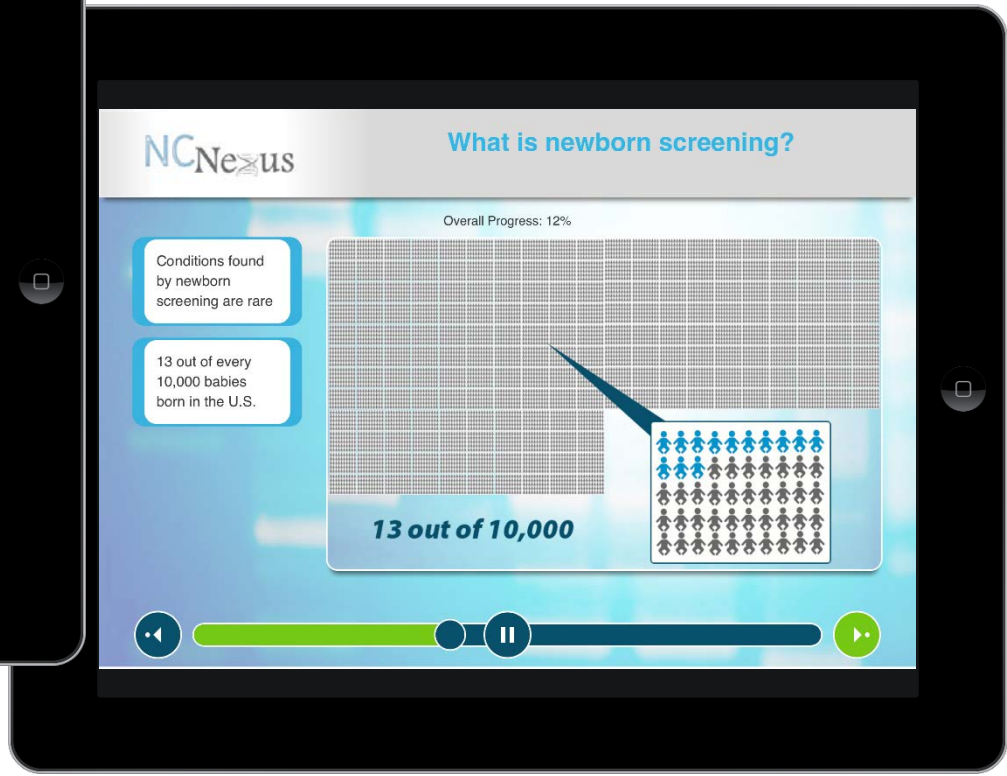
- How to use decision guide
- What is newborn screening?
- What is genomic sequencing?
- What is the NC Nexus Study?
- Reasons for and against participating
- Decision and next steps



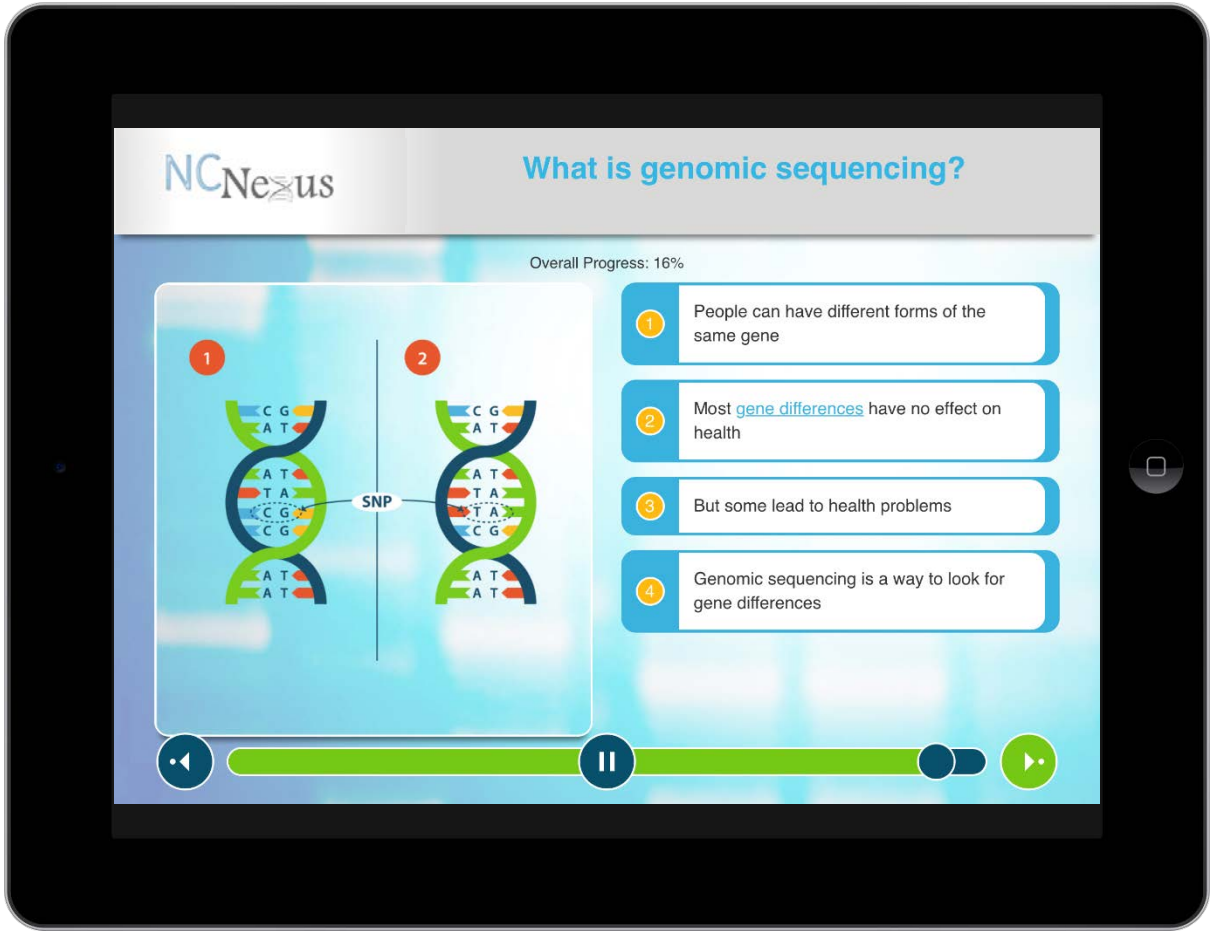
What Makes Our Tool Unique?

- Interactive, can be deployed on multiple platforms
- Theory-driven
- Input from users and clinicians
- Plain language as much as possible
- Interactive sorting exercise (shown here)
- Iterative user-centered design and testing process

Screenshots – Condition Category Description and Risk Array



Screenshot – Addressing Difficult Terminology and Concepts



Screenshot – How the Study Works

Question to Help Parents Make a Decision

Screenshot – Values Clarification

Screenshot – Decision about Genomic Sequencing

Next Steps – How Do We Know if it Works?

NC NEXUS Randomized Trial

- 400 parents will participate and use the aid to make decisions about categories of information
- 1/3 will be randomized to ‘control’ only meaning they make decision about conditions like those on current NBS panel, 2/3 to additional ‘decision’ categories
- Decision confidence, conflict, distress, and other outcomes will be monitored over four month follow-up
- Will allow us to evaluate the extent to which the decision aid supports informed decision making

For more information:

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