

# Using qualitative research methods to solicit patient experiences and values for health technology policy-making

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# Disclosure

I have no actual or potential conflict of interest in relation to this topic or presentation

# Agenda

- Why is it important to include patient perspectives?
- Why use qualitative research methods? In what circumstances?
- Example of the type of patient information qualitative research can provide
- Example of how qualitative methods can be adapted for HTA





## Why do patient perspectives matter in HTA?

- Context in which technology is understood, implemented, used.
- Evidence for social, psychological, ethical, organizational assessments.
- Can also inform HTA value judgments, e.g. scoping, determination of appropriate outcomes and metrics.



## HTA Process Decisions

- What technologies will be assessed?
- Which related and comparator technologies are included?
- Which target populations are relevant?
- Which outcomes are important?
- What metrics will accurately measure those outcomes?

# Typical Methodological Approaches for Assessing Socio-Cultural Implications



Expert Checklist



Literature Review



Participatory



Primary Qualitative  
Research

# Typical Methodological Approaches for Assessing Socio-Cultural Implications



Primary Qualitative  
Research

## Advantages:

- Targeted, directly relevant information
- Capture dynamism of evolving technology use
- Offers privacy, confidentiality, accommodation of participants
- Tailor data collection to questions of interest

## Disadvantages:

- Special expertise required
- Significant time required for planning, design, conduct of research

# Two Questions

Can QR provide helpful information?



Example of the type of evidence that can be obtained through primary qualitative research

Can QR provide this information within the time and resource constraints of the HTA?



Resource requirements and potential for adaptation



# Type of information qualitative research can provide

- Specific to our jurisdiction
  - *Existing funding and implementation policies, social and healthcare context*
- Before social scientists have studied (and published) about this technology
- Differentiates between specific nuances of technology of interest vs. comparators
- Patients with personal experience and therefore, reasonable understanding of the specific technology, target condition, healthcare pathway etc.

# Example of info provided by qualitative research

*Grounded Theories: Policy*

## **Women's Experiences of Publicly Funded Non-Invasive Prenatal Testing in Ontario, Canada: Considerations for Health Technology Policy-Making**

**Meredith Vanstone<sup>1</sup>, Karima Yacoub<sup>1</sup>, Mita Giacomini<sup>1</sup>, Danielle Hulan<sup>1</sup>, and Sarah McDonald<sup>1</sup>**

### **Abstract**

Non-invasive prenatal testing (NIPT) via fetal DNA in maternal blood has been publicly funded in Ontario, Canada, for high-risk women since 2014. We solicited women's experiences and values related to this new health technology to describe how this test is currently being used in Ontario and to provide information about patient priorities to inform future policy decisions about the use of NIPT. Guided by constructivist grounded theory methodology, we interviewed 38 women who had diverse personal experiences with NIPT. Participants' accounts of their values for decision making about NIPT heavily relied on three mutually modulating factors: timing, accuracy, and risk. The values expressed by women conflict with the way that publicly funded NIPT has typically been implemented in Ontario. We offer recommendations for how NIPT might be integrated into prenatal care pathways in a way more consistent with women's values.

### **Keywords**

prenatal testing; prenatal screening; non-invasive prenatal testing; patient values; health technology; health policy; Ontario, Canada; qualitative research

Qualitative Health Research  
2015, Vol. 25(8) 1069–1084  
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sagepub.com/journalsPermissions.nav  
DOI: 10.1177/1049732315589745  
qhr.sagepub.com  
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Technology: Non-Invasive Prenatal Testing (NIPT)

- Rapid diffusion as a private-pay technology
- High patient demand: more sensitive, more specific, results available earlier in pregnancy
- Ethical issues (target conditions, pregnancy termination)
- Socio-cultural issues (equity of access, counselling and decision-making)
- Implementation/Organization issues (comparator technology, health professional involvement)

# Non-Invasive Prenatal Testing & Comparators

## NIPT

- > 10 weeks gestation
- Fetal sex, chromosome anomalies (e.g. T21) [No NTD]
- DR >98%, FPR <0.3%
- Results available 1-2 weeks

## Prenatal Screening

Ontario IPS:

Part 1: Bloodwork,  
U/S

Part 2: Bloodwork

- Results available Week 16-20
- DR 88%, FPR 1.9%
- Chromosome aneuploidy + Neural Tube Defects

## Amniocentesis & CVS

Weeks 15-20 (Amnio),  
Weeks 9-13 (CVS)

Risk of miscarriage: 0.6-1%

Diagnostic:

- DR ~100%
- FPR not reported
- Chromosome aneuploidy + Neural Tube Defects

# Why qualitative research? Contextual factors about technology



Sophistication of understanding: NIPT requires significant background knowledge, but women who receive it (in this instance) typically had access to genetic counselling, so were quite knowledgeable about the technology.

Rapid diffusion: Easy to find women with personal experience, but no published literature about this population

Jurisdictional variation: Each province has a different system of prenatal testing, Ontario had already started to offer publicly funded NIPT on a case-by-case approval basis

Sensitive topics: Talking about NIPT means talking about personal medical history, beliefs and views on sensitive and controversial topics e.g. abortion, disability, miscarriage

# Information we were able to provide through use of qual. research



Depending on comparator technology and integration into care pathway, NIPT requires a compromise on: timing of results, accuracy of test or risk of miscarriage

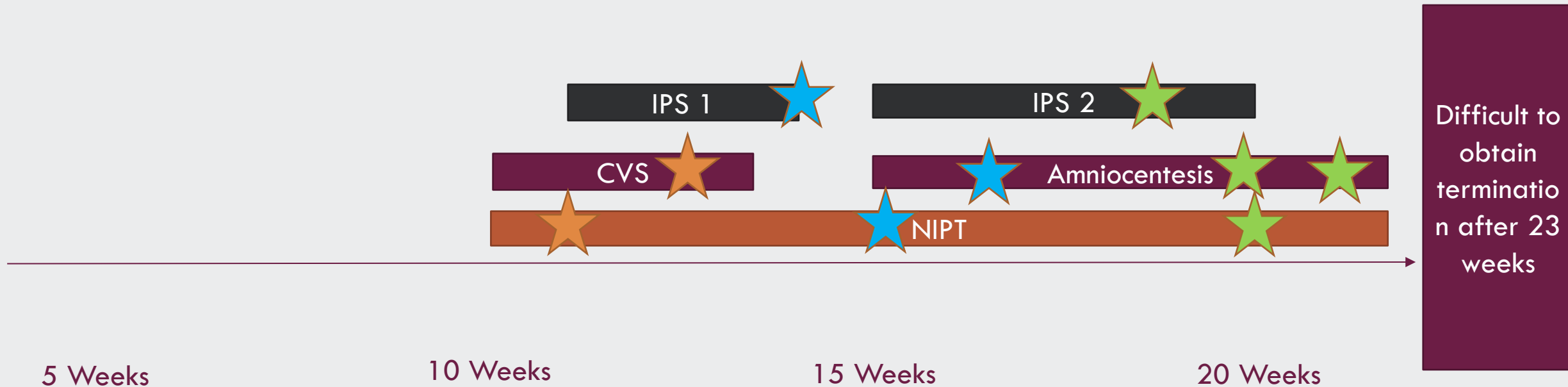
Women expressed clear priorities for accurate results, available as early in the pregnancy as possible, obtained with no risk to the fetus.

- Not yet possible with existing technologies
- Compromises and priorities depend on particular circumstances
- Demonstration of how priorities shift depending on the circumstances under which the test is considered

# Timing & Comparator Tests

Public Funding for NIPT in Ontario:

- Pre-conception if existing risk factor (previous trisomy pregnancy, maternal age > 40)
- After other testing which reveals high risk of trisomy



# Information we were able to provide through use of qual. research



Early access to NIPT was highly important to women

- Current ON policy grants access to most women in mid-late second trimester, which was unacceptably late to many women.

Women and clinicians understand “accuracy” of test differently

- Clinically, NIPT is considered a screening, not diagnostic test; Many women found the  $>98\%$  detection rate of NIPT to be “virtually the same” as the diagnostic test of amniocentesis.

Results also highlight key areas for future consideration

- Content areas for Patient/Provider education
- Values about public funding, equity of access
- Concerns about expansion of conditions tested for
- Misunderstandings (e.g. higher miscarriage risk from amniocentesis)

# Empirical Qualitative Research for Pt. Perspectives

Disadvantages: Time and resource intensive.

Advantages:

- Accommodate new, complex, and sensitive technologies.
- Provide very relevant, jurisdictionally-specific information.
- Can adapt to specific questions under consideration OR take a broader approach to gather information that may alert assessors to potential issues not yet considered.
- Can be used to supplement other types of patient information (e.g. reviews of published literature)



# Phases of research & resource use

	Personnel Requirements	Time	Financial Resources
Planning	High- Assessors, research staff		
REB approval	Medium-low	4-10 weeks	
Sampling/Recruitment	Low if strong support from experts, community groups	Highly variable depending on buy-in from participants	Mostly online, electronic recruitment, potential travel to meet with patient groups, small printing cost
Data Collection	3 hours/interview	Highly variable depending on buy-in from participants, flexibility of interviewer	Transcription, parking, mileage, participant honoraria = \$150-200/interview
Data Analysis	5-8 hours/interview		Data management software- one time purchase
Writing/Reporting	High for 1-2 researchers	2-6 weeks	

# Methodological Adaptations

Identify specific areas for inquiry:

- What can the literature not provide?
- Instead of building a general understanding of the phenomena, target specific questions.

Mobilize expert resources

- Help identifying gaps, areas primary research can fill
- Help with recruitment, patient contacts

# Methodological Adaptations

## Relationship with REB

- If conducting a series of similar projects, where specific technologies/conditions change, but recruitment methods and type of questions are consistent.

## Revise point in HTA process for qualitative research

- Scoping? Horizon Scanning?
- Inform development of HTA protocol, other evidence-based analyses

# Methodological Adaptations

Partner with qualitative researchers

- Mobilize expertise, collaborative teams
- Capitalize on work in progress
- Obtain access to timely information, without waiting for publication, critical appraisal, synthesis
  - *Make use of qualitative evidence for framing assessment questions and issues*

# Conclusions

## Primary qualitative research:

- Unique opportunity to emphasize and amplify patient voices
- Requires different skills, resources than typical HTA
- Unparalleled relevance: jurisdiction, current tech use, care pathway, involved HCP
- Contributes to social, ethical, organizational analyses
- Informs decisions made throughout HTA (outcomes, boundaries of tech, comparators)

# Funding and Acknowledgements

We acknowledge contribution of the co-authors and team members on the ongoing NIPT work: Jeff Nisker, Lisa Schwartz, Sarah McDonald, Danielle Hulan, Karima Yacoub, Leichelle Little.

We gratefully acknowledge our funders, CIHR (FRN 136734) and the Ontario Ministry of Health and Long-Term Care.

This work was supported by the Ontario Ministry of Health and Long-Term Care through a Health Systems Research Fund grant titled “Harnessing Evidence and Values for Health System Excellence”. The views expressed in the presentation are that of the authors and should not be taken to represent the views of the Ontario Ministry of Health and Long-Term Care.



CIHR IRSC

Canadian Institutes of Health Research  
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