

Non-Invasive Prenatal Testing

Facilitating Autonomy or Complicating Decision Making?

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Introduction

The context of this presentation is the UK RAPID* evaluation study on non-invasive prenatal testing (NIPT) for Down's syndrome and the possible future public funding of such a regime. This research seeks to identify from recent literature:

- The aims and purposes of a publicly funded NIPT regime?
- How those aims and purposes might be realised?
- How increased information about a possible future child might impact on the complexity of parental and clinical decision-making during pregnancy?
- Whether further research is required before the scope of NIPT is widened?

Methods

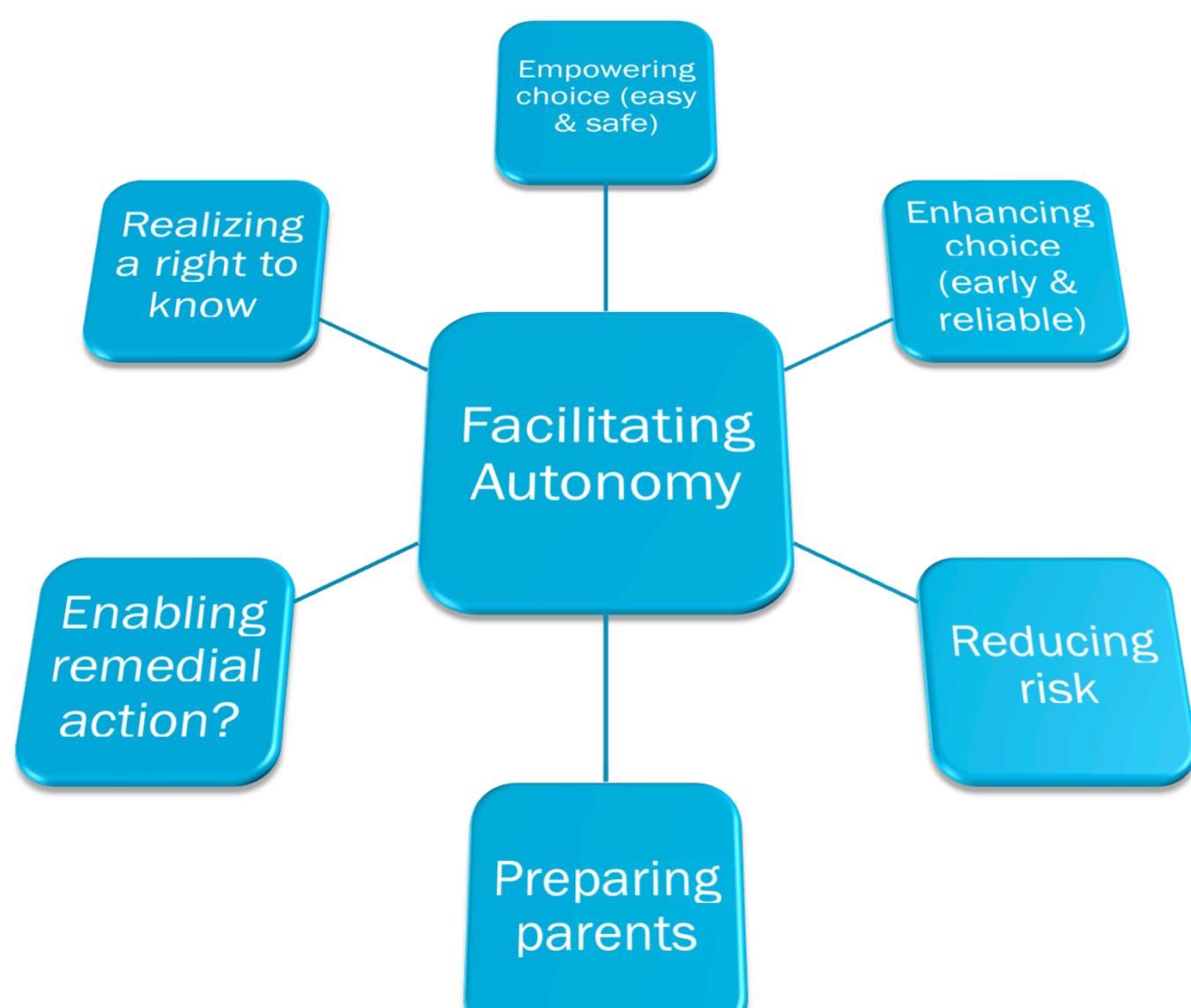
Narrative literature review – this is critical narrative overview synthesizing the findings of relevant literature retrieved from searches of computer databases and authoritative texts:

Inclusion criteria: non-invasive prenatal testing; decision making; consent.

Exclusion criteria: Invasive and ex-vivo embryo testing; literature pre 2013

Results

(1) **Aims and purposes of NIPT**: enhancing and facilitating reproductive autonomy are explicit purposes of NIPT for fetal anomaly and non-health related features. However, public health considerations may also apply to the former (eg reducing risks/ adverse outcomes and enabling parental preparation).

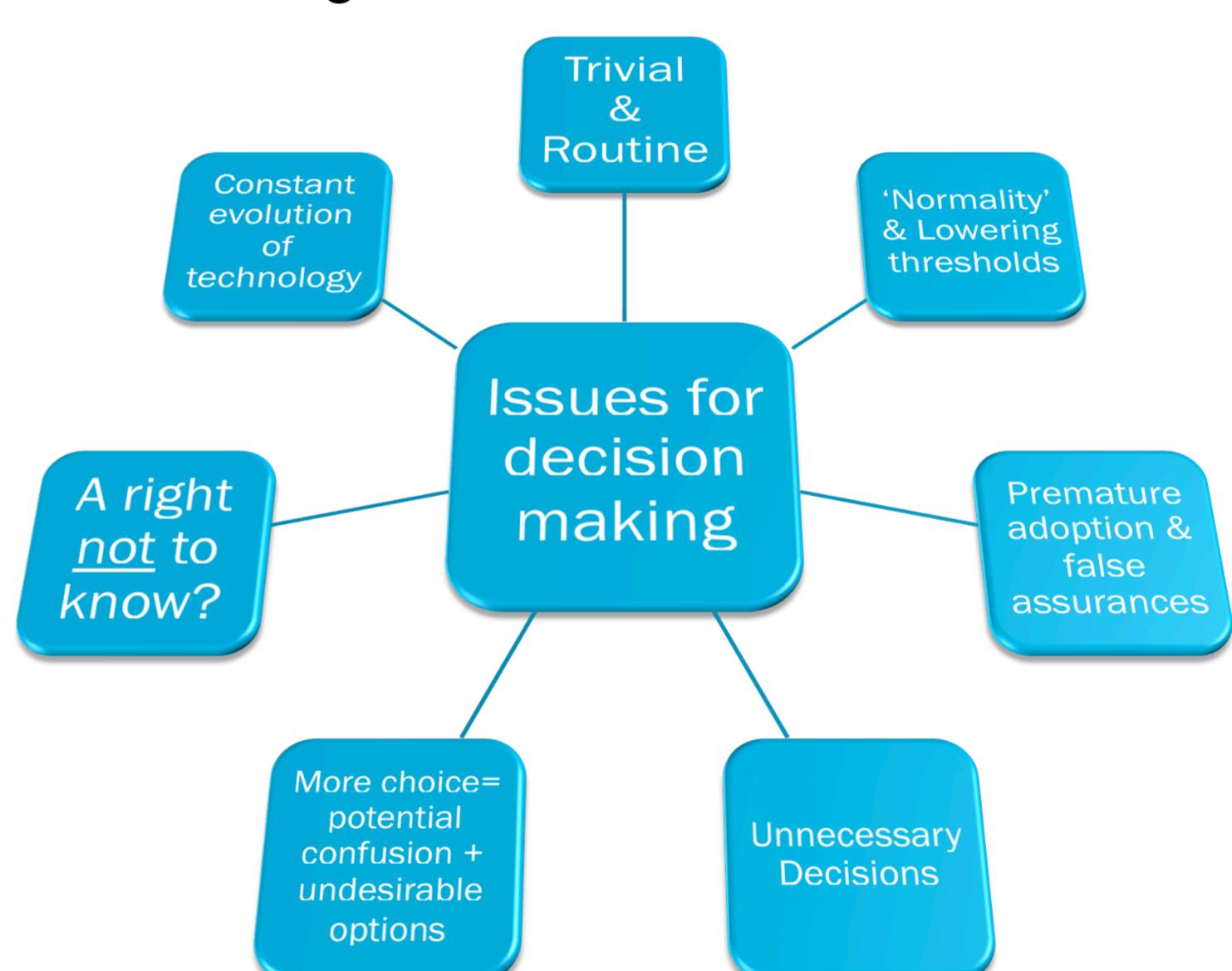


(2) **Realisation**: any resulting choices need to be real, meaningful and lawful and should align to the purposes of any testing regime.

Issues:

- Contingent testing and non diagnostic outcomes
- Grey (non reportable) results
- Mixed purposes
- Post test formulation of purpose(s)
- Concealment & enforcement of any pre test promise

(3) **Increasing Information and providing ‘the means to choose well’**: NIPT may increase the availability of unclear/ uncertain information. More information does not necessarily equate with more choice or better choices. Parental decision making is likely to be complicated unless supported by targeted and adaptable counselling **before** and **after** testing. The provision of suitably adaptive counselling may have significant resource implications for any state funded regime:



(4) **Widening scope**: research is needed to assess:

- Future reproductive choices: what information do we want and what should we have access to?
- Evaluation: what are we capable of processing?
- Evaluation: costs and priorities; benefits and burdens
- Handling advances: incrementalism or broader expansion?
- Informed choice: observational studies & interviews
- Public narration of the purposes and the choices presented

Conclusions

This research identifies the particular benefits and issues generated by advances in non-invasive prenatal testing. It also outlines possible lines of enquiry around decision-making before States incorporate and widen the scope of these tests within national screening programmes.

Limitations: This study does not include any new data from human participants.

KEY REFERENCES

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4. L Chitty et al., '*RAPID Non-Invasive Prenatal Testing (NIPT) Evaluation Study: Executive Summary*', May 2015 (ISBN 978-1-907198-17-5)
5. Nuffield Council on Bioethics, Note of Roundtable Meeting on Non-Invasive Prenatal Testing on 18 January 2016, available from <http://nuffieldbioethics.org/wp-content/uploads>Note-of-meeting-NIPT-meeting-18-Jan-2016-FINAL.pdf> (accessed 22 April 2016)
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See working paper for full references.