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Considering Consent: Factors Influencing Parental Perceptions of Decision Quality When Accepting Newborn Screening



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Disclosures



Nothing to declare

Take home message

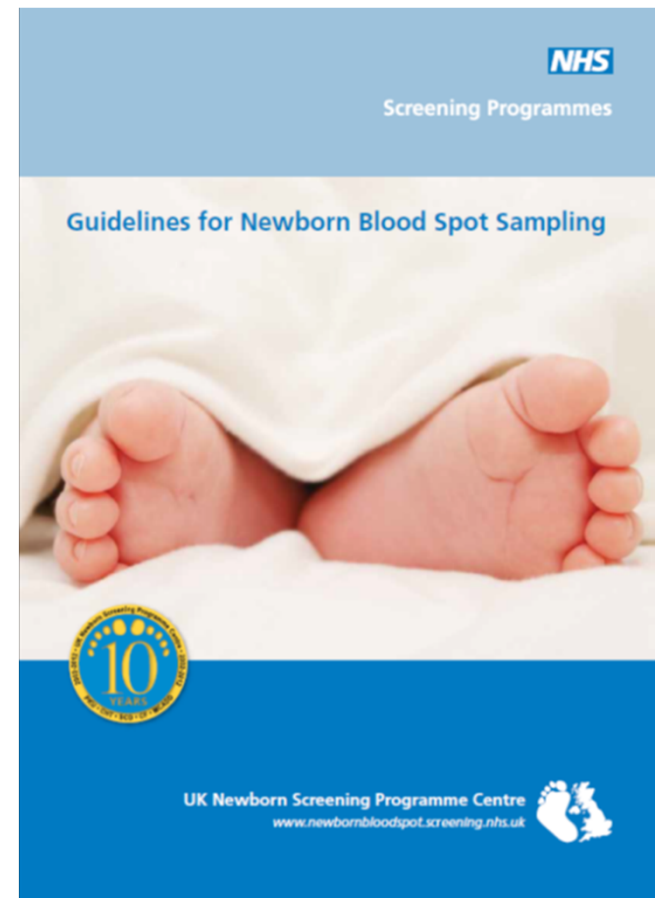
If we want to better understand parental decision making we need to consider the context in which screening is provided.

Overview

- Background: Screening in the UK
- Parental decision-making and newborn screening
- Methods: Measures and modeling
- Results
- Conclusions

Screening in the UK

- 3-5 days post-birth, usually at home
- (Community) midwife led
- Informed consent:
- *“Explain the procedure to parents and record in the maternity record that newborn blood spot screening has been discussed and recommended, the booklet given and consent sought.”*
- Verbal consent is adequate (written consent is required in Scotland).” [1]



Decision-making and NBS

- Knowledge – recall issues
- Education materials – use?
- Uptake rates – administration? Low level of refusal
- Decision quality
 - Decision-making process
 - Statistical variation

Aim

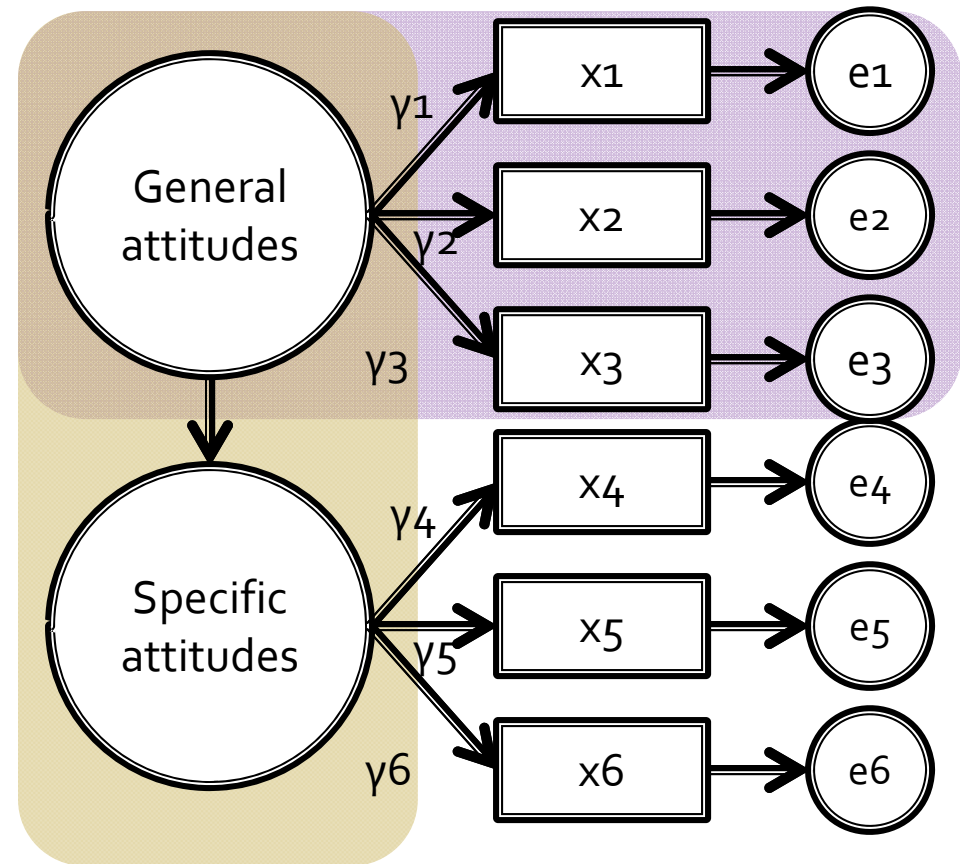
- To model identified factors that influence parental decisional quality within the context of newborn bloodspot screening

Methods

- Cross-sectional survey
- Survey items developed based on prior qualitative data and existing tools such as The General Trust in Physicians Scale [2,3] and Revised Susceptibility, Benefits, and Barriers Scale for Mammography Screening [4]
- Random sample (n=500) of parents from Merseyside and Cheshire
- Year 2008 (N=28348)
- Excluded if child subsequently died or severely ill

Methods

- Analyzed using:
 - Confirmatory Factor Analysis (**measurement**), and
 - Structural Equation Modeling (**structural**)
- Assessed using:
 - Satorra-Bentler χ^2 (seek n.s. χ^2)
 - Goodness of fit indices: RMSEA (<0.05), CFI (>0.9)
 - Parameter estimates (size, direction)



Methods

Latent variable	Indicator (scale)	Cronbach's alpha	Factor loading
Perceived knowledge (PCK)	Perceived understanding of motivation (Mot)	0.854	0.916**
	Perceived understanding of Procedural aspects (Proc)	0.816	0.805**
	Perceived understanding of Condition (Cond)	0.898	0.744**
Attitudes toward screening (ATTSCR)	Perceived Risk (Risk)	0.775	0.443**
	Perceived Benefits (Ben)	0.871	1.00**§
Perceived choice (CHOICE)	Ability to Make a Choice (Abch)	0.793	0.622*
	Availability of Choice (Avch)	0.730	0.593**
Attitudes toward medicine (ATTMED)	Trust in the Midwife (Mid)	0.831	0.659**
	Trust in the healthcare system (Trustsys)	0.629	0.782**
Decisional quality (DCQ)	Uncertainty Subscale of ODCS (Unc)	0.907	0.9**
	Effectiveness Subscale of ODCS (Eff)	0.898	0.935**

**p<0.01, § = item constrained to have error variances greater than zero

Results

- 154 respondents (32%)
- 3 surveys had large amounts of missing data.
- Multiple imputation (ANOVA n.s.)

Item	Number	%*
Age group: <30 years	50	32.5%
Number of children: 1	55	35.7%
Highest educational level: high school or below	31	20.1%
Ethnicity: White	147	95.5%
Household income: < £11500	16	10.4%

* Indicates valid percent from respondents completing the question

Results

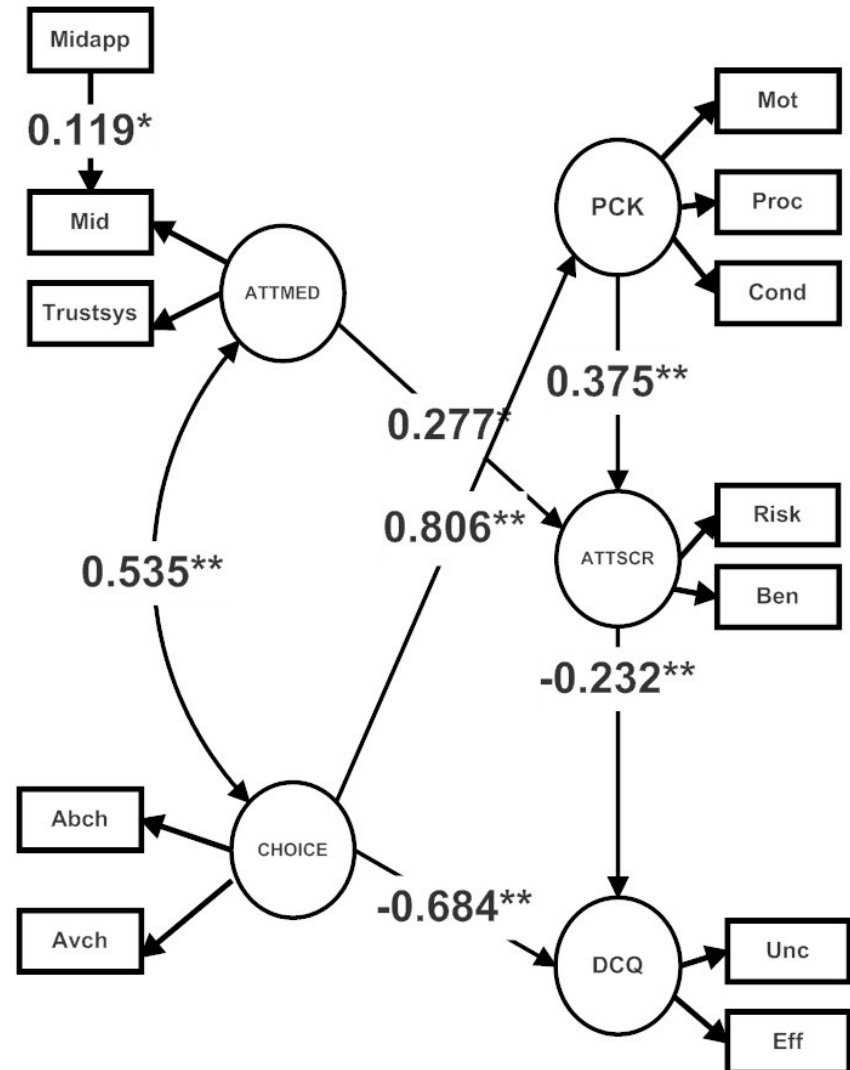
χ^2 (df=48) = 61.396, (p = 0.093)

CFI = 0.979

RMSEA = 0.043

R² (DCQ) = 66%

* = p < 0.05, ** = p < 0.01



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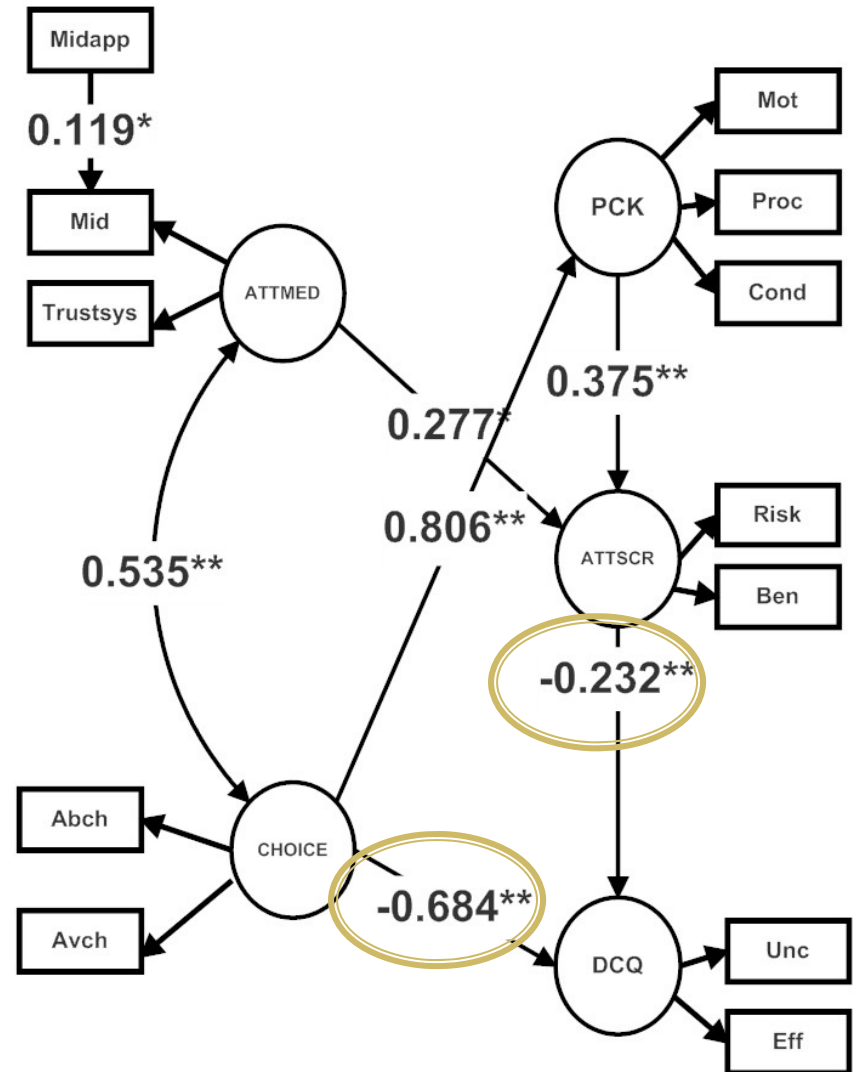
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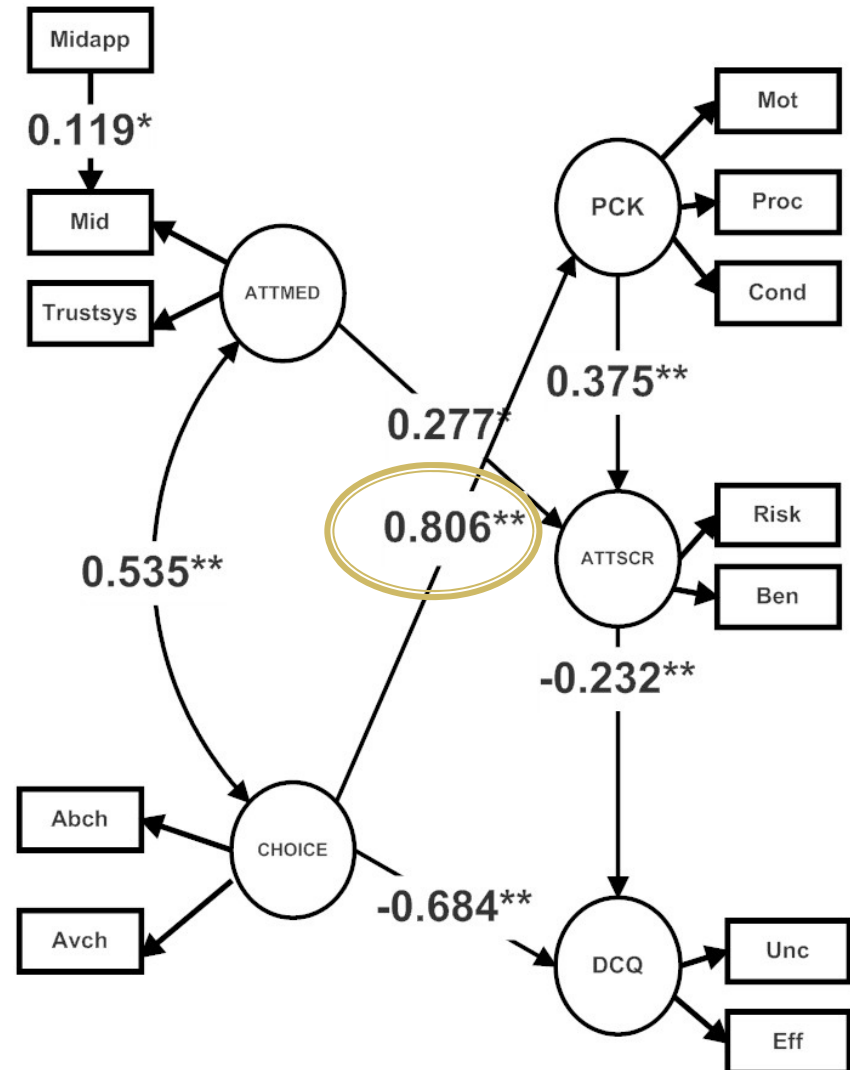
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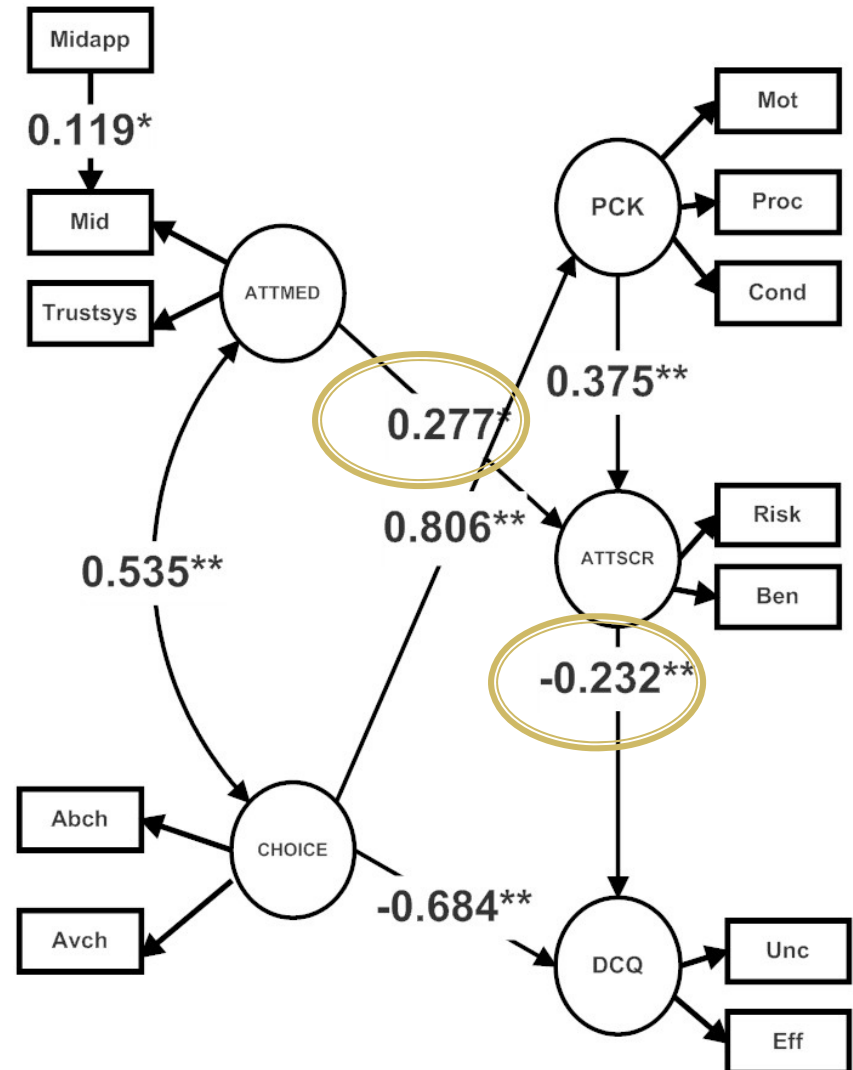
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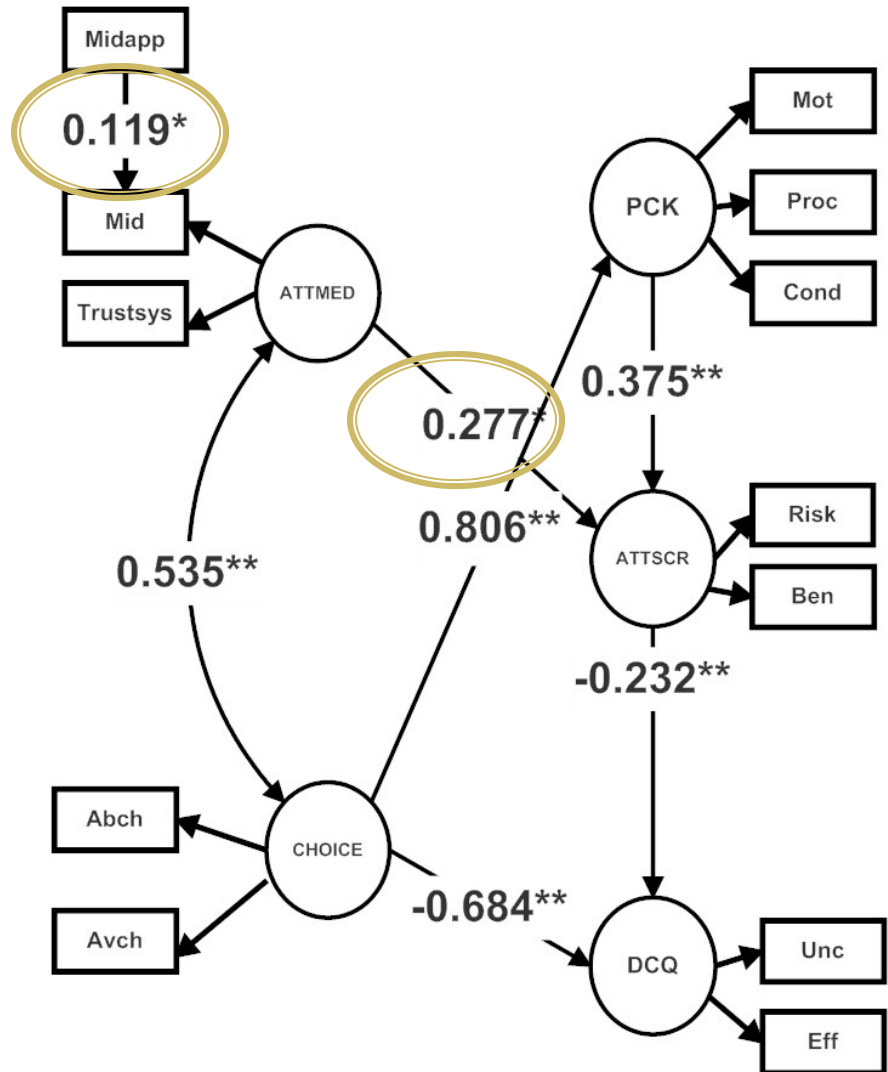
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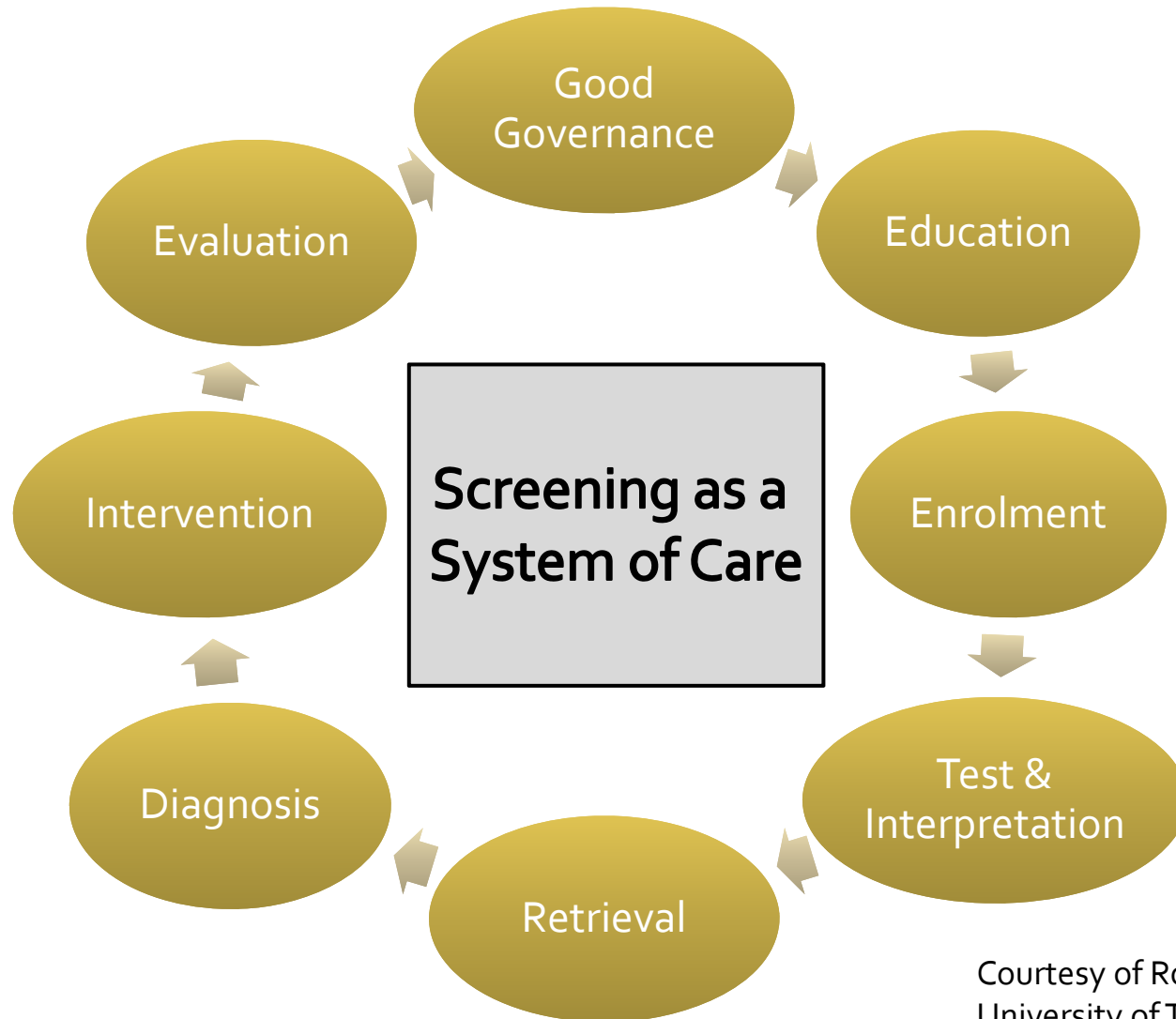
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Conclusions

- Attitudes research tends to focus on the immediate test [5-7]. A failure to differentiate the general and specific may overemphasize the impact of specific attitudes to screening
- Perceived choice positively affects decision quality.
- Role of the health care professional

The NBS system



Courtesy of Robin Hayeems,
University of Toronto

Limitations

- Parents appeared to be older and more educated
- The sample size is also relatively small, and did not allow for group comparisons, such as comparing primiparous and multiparous parents
- The response rate of 32% is also relatively low, but comparable to other survey research in NBS [8, 9, 10]
- All parents had accepted newborn screening

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- Economic and Social Research Council (UK)
- Canadian Institutes of Health Research (Canada)



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