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# Implementing & evaluating models of family centred care for children with long term conditions - where next?

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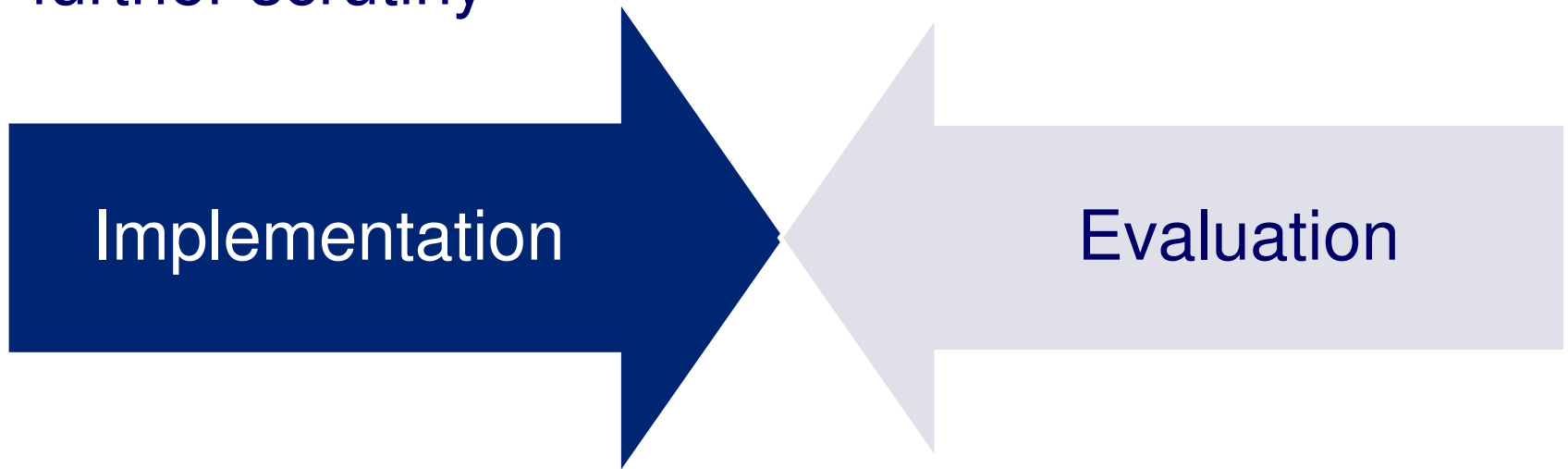
# Background

- Effective collaboration between nurses & families is fundamental to care delivery
  - Family-centred care model is widely espoused as an effective framework
  - Evidence suggests many parents perceive that:
    - They are not supported in their role as manager for their child's condition
    - Their expertise & contribution to care are not valued
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# Rationale & aim

Usefulness of family-centred care model & how implemented & evaluated in practice requires further scrutiny



Complementary critical evaluations of family-centred care research, in the context of childhood long-term conditions, will be presented

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# Embedding family-centred care into practice

- Family is a constant in child's life
  - Parent-professional collaboration facilitated
  - Ethnic, cultural, socio-economic & diversity of families respected
  - Family strengths & individuality respected
  - Complete & unbiased information sharing
- Family-to-family support & networking encouraged & facilitated
  - Healthcare practices respond to child & family developmental needs
  - Policies & practices provide families with emotional & financial support
  - Flexible design of health care services

# Theoretical framework

Value family as constant in the child's life, with strengths & individuality  
Respect individual preferences & values

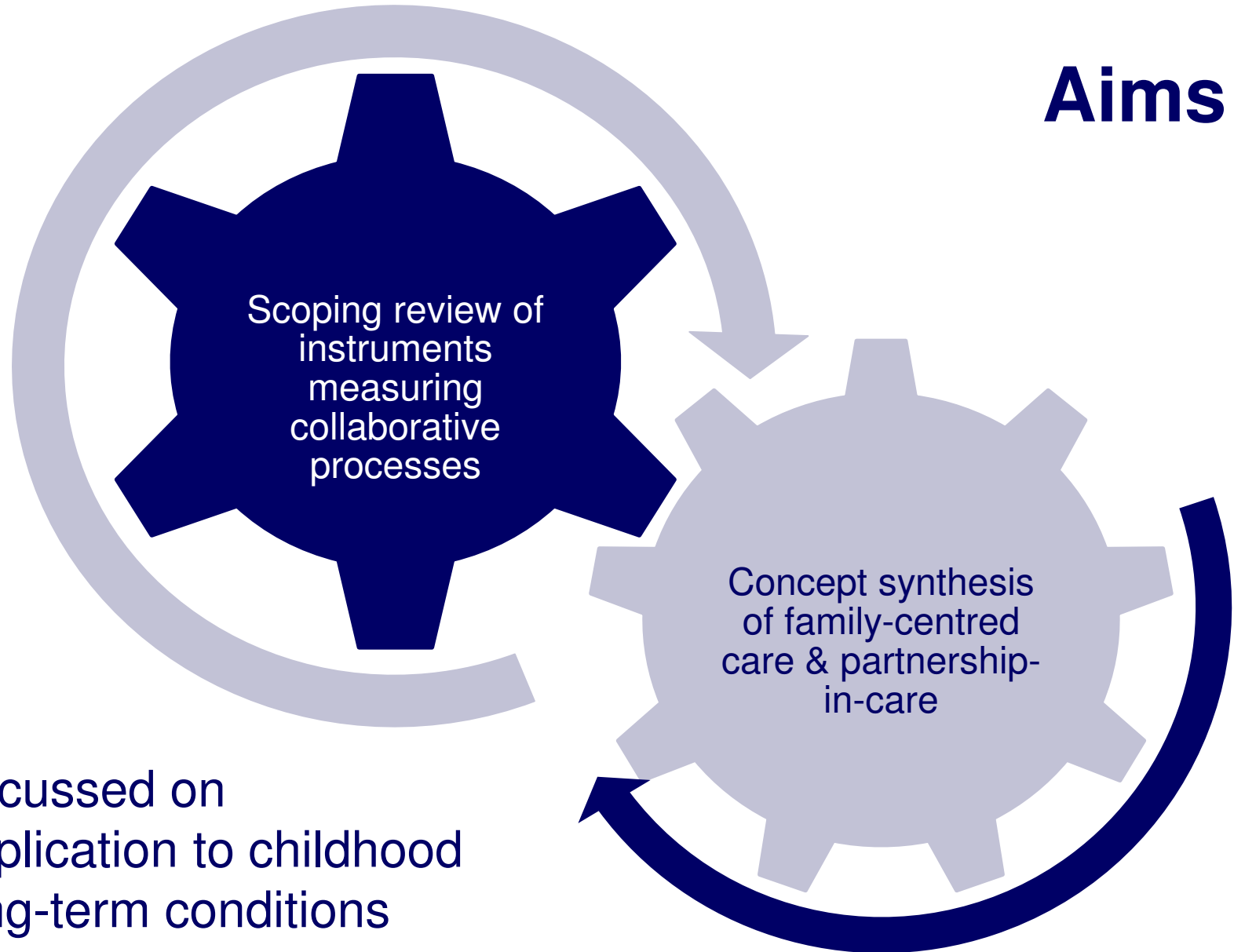
Accurate & comprehensive information provision  
Information sharing facilitates collaboration & partnership working

## Family-centred care

Patient-professional agree treatments/care plans  
Design care in response to family needs  
Negotiation of roles / shared responsibility for care

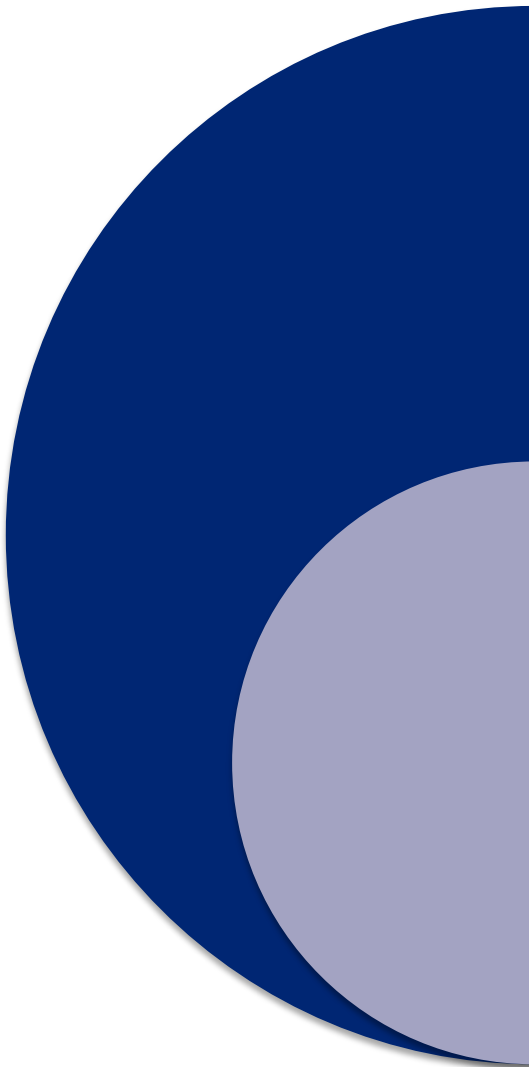
Access to appropriate services  
Encourage family-to family support

# Aims



Focussed on application to childhood long-term conditions

# Methods

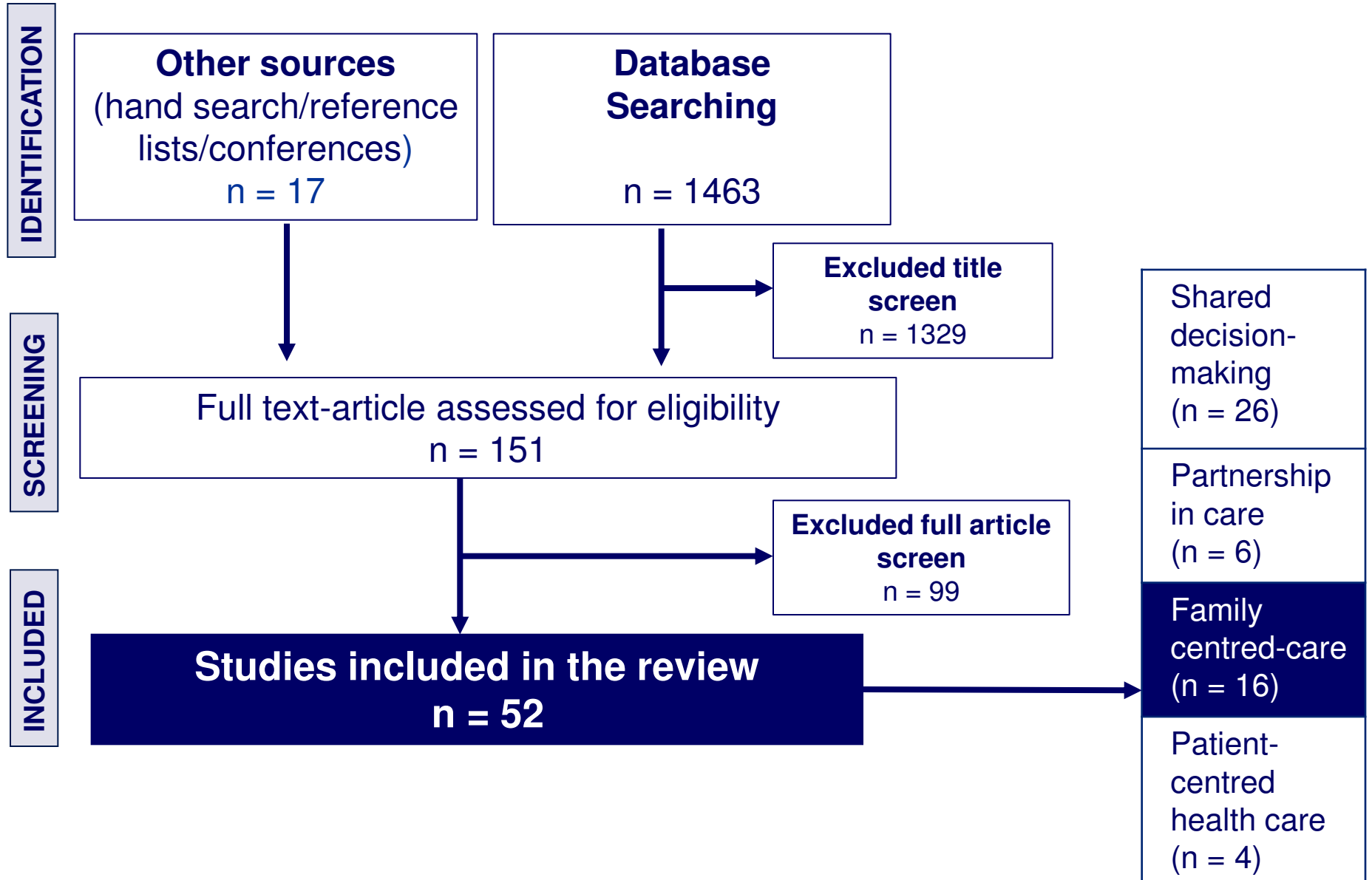


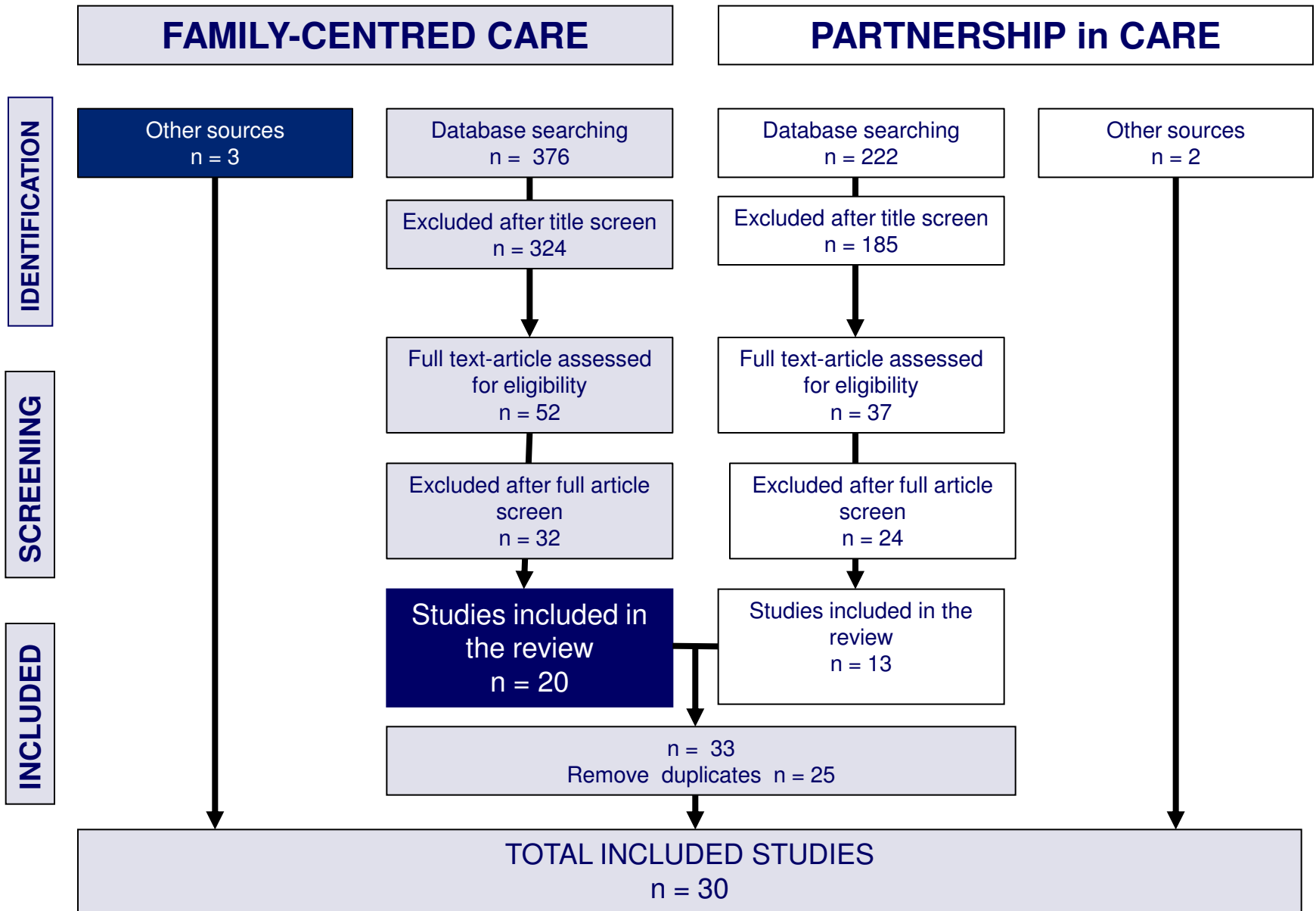
MEDLINE, CINAHL, PSYCINFO  
databases searched from 2000 to 2014 to  
identify instruments that measured family-  
centred care

Scopus, CINAHL, BNI databases  
searched from 1999-2014 to identify  
research on implementing family-centred  
care in practice



# INSTRUMENTS THAT MEASURE FAMILY-CENTRED CARE





# Measures of family-centred care

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- 16 studies related to family-centred care

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- Processes of Care (MPOC) most used measure; self-report of parents' perceptions of care

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- Measures not specifically developed to evaluate family-centred care in the context of long-term conditions in children

# Antecedents & attributes of family-centred care

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- 23 studies included relating to embedding family centred care in practice

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- Antecedents: ‘unclear roles & boundaries’ ‘entrenched professional practices & attitudes’ ‘lack guidelines / policies supporting family-centred care’

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- Attributes: ‘valuing parents knowledge & experiences’ ‘supporting parents role as care giver’ ‘incorporating parents expertise into care delivery’

# Measures of patient-centred care models

Model	Validated Instruments
Shared decision-making (n = 26)	COMRADE (Edwards et al 2003) CONNECT (Haidet et al 2008), OPTION (Elwyn et al 2003) Control Preference Scale (Degner 1997) Decisional Conflict Scale (O'Conner 1995) Perceived Involvement of Care Scale (Lemann et al 1995) Shared Decision-Making Questionnaire Decisional Conflict Scale) (O'Conner 1995)
Family centred-care (n = 16)	Measure of Processes of Care (MPOC -20, MPOC -56 & MPOC-SP)
Partnership in care (n = 6) & Patient-centred health care (n = 4)	
No validated measures identified	

# Framework for involving parents in care of a child with long-term condition

<b>Domain</b>	Valuing parents' knowledge & experiences	Supporting parents in their role as care giver	Incorporating parents' expertise into clinical & psychosocial care
<b>Collaborative processes</b>	Developing effective parent-professional relationships	Negotiating with parents preferred level of support	Ensuring transparency of participatory processes
<b>Actions</b>	<ul style="list-style-type: none"> <li>▪ Elicit &amp; respond to parents' concerns</li> <li>▪ Establishing rapport - develop a trusting relationship through clear communication, learning about family context , active listening &amp; share parents' experiences</li> </ul>	<ul style="list-style-type: none"> <li>▪ Mutual information exchange</li> <li>▪ Establish parents' contribution to child's clinical care &amp; desired level of involvement</li> <li>▪ Share decisions with parents &amp; other professionals; collaborate when planning care</li> </ul>	<ul style="list-style-type: none"> <li>▪ Involving parents in diagnosis &amp; treatment decisions</li> <li>▪ Facilitate parents to express their opinions about care decisions</li> <li>▪ Incorporate parents' knowledge of child &amp; care experiences in assessment, planning, delivery &amp; evaluation of care</li> </ul>

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# Key messages

- Promoting & facilitating involvement requires nurses to work collaboratively with the family
  - Tools measuring the implementation of & evaluation of family centred-care are limited & need to be informed by evidence & appropriate theories
  - Implementation of family-centred care remains problematic
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**Thank you for listening**

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# References

- Smith, J., Swallow, V., Coyne, I. (2015) Involving parents in managing their child's long-term condition: a concept synthesis of family centred-care and partnership-in care. *Journal of Pediatric Nursing*, 30, 1; 143-59;
  - Smith, J., Cheater, F., Bekker, H. (2013) Parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature. *Health Expectations*, online doi: 10.1111/hex.12040;
  - Shelton, T., Jepson, E. & Johnson, B.H. (1987) *Family-centred care for children with special health care needs*. Washington, DC: Association for the Care of Children's Health.
  - Shields L., Zhou H., Pratt J., Taylor M., Hunter J. and Pascoe E. (2012) Family-centred care for hospitalised children aged 0-12 years. *Cochrane Database of Systematic Reviews 2012, Issue 10*. Art. No.: CD004811. DOI: 10.1002/14651858.CD004811.pub3.
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