



What do we know about the effectiveness of education support programs for young people managing chronic health conditions?

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Overview

1. Taking an evidence-based approach

2. Systematic review

The effectiveness of education support programs for young people managing chronic health conditions?

3. Results

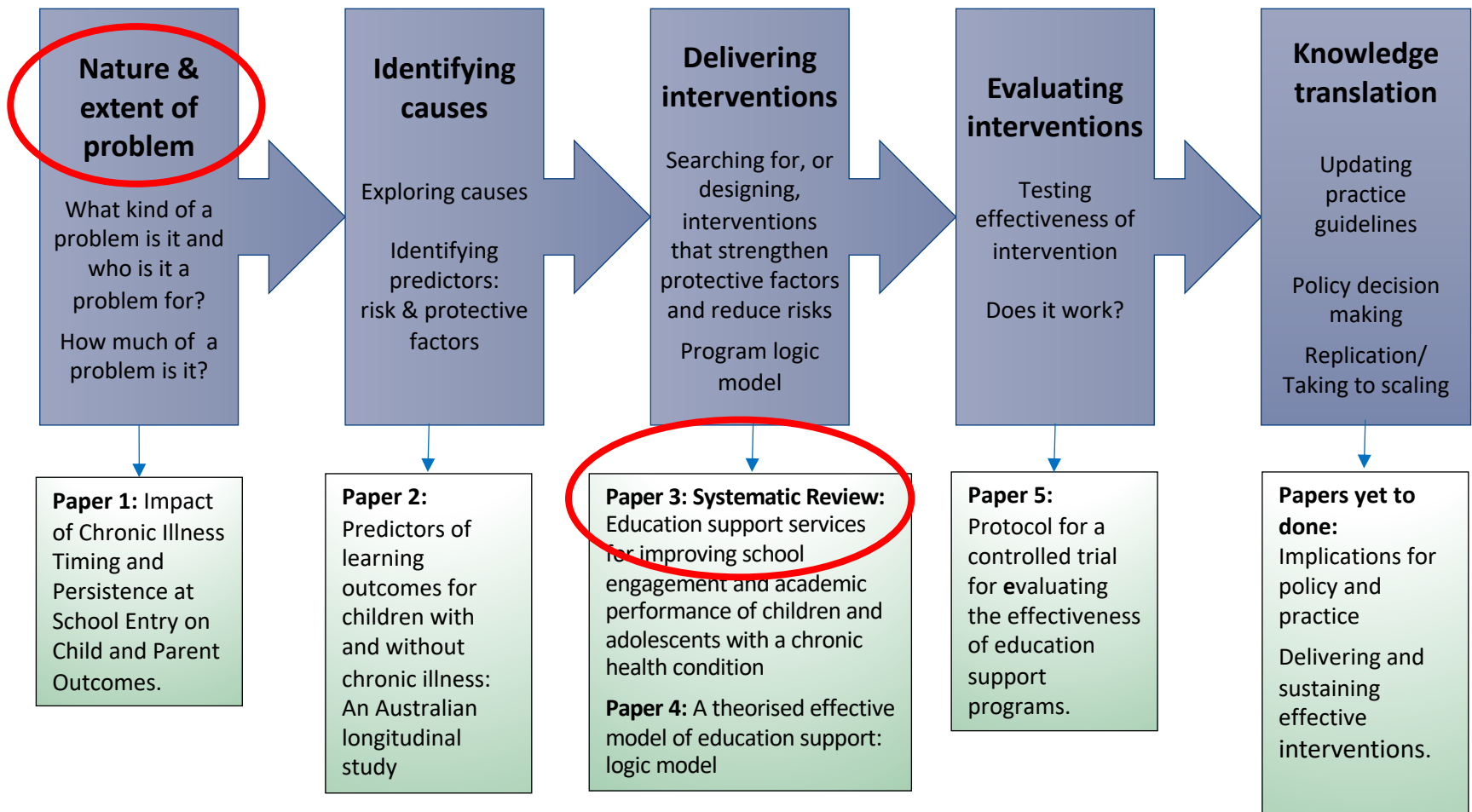
4. Implications for future research and building the evidence-base

➤ Your input, thoughts and questions



The evidence-based schema/approach?

From understanding the problem to delivering effective interventions





Nature and extent of the problem

Definitions of Chronic Health Conditions & prevalence

- “Non communicable illnesses are prolonged in duration, do not resolve spontaneously, and are rarely cured completely” (The Centers for Disease Control and Prevention)
- “Chronic diseases have a duration that has lasted, or is expected to last, at least six months; have a pattern of recurrence or deterioration; have a poor prognosis and produce consequences or sequelae that impact on the individual's quality of life” (O’Halloran, 2004)
- Due to the variety of both different chronic conditions and definitions, it is not easy to gain a clear figure of the prevalence of chronic health conditions in children and adolescents. Estimates range from 22% to 44%.
- Of people with a chronic health condition, an estimated 5% are affected by severe conditions characterised by limitations to daily activities and frequent bother (Newacheck 1992). (In Australia this amounts to approx. 65,000 young people.)



Nature and extent of the problem

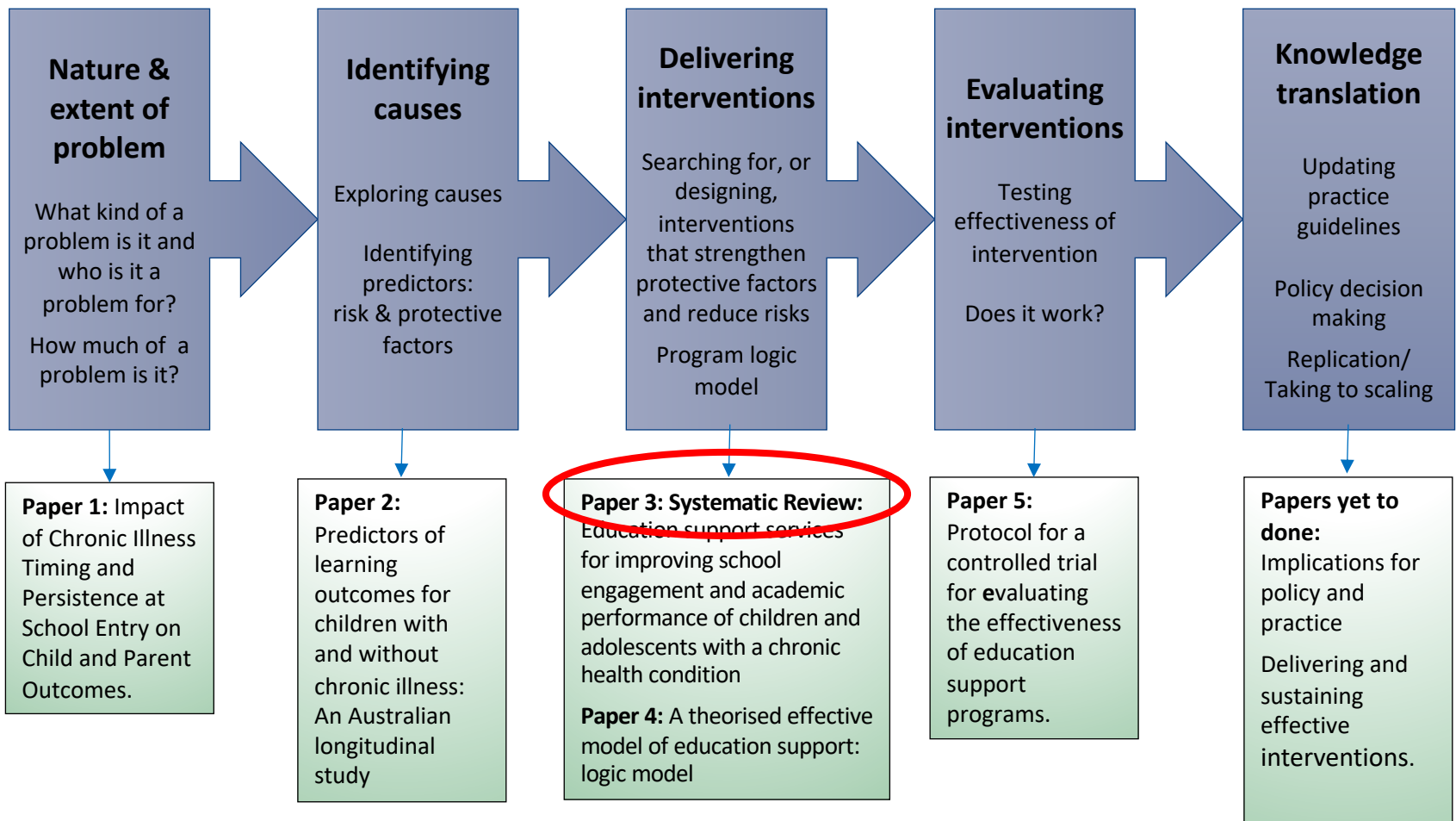
The nature of the problem

- Chronic health conditions for children carry secondary psychological and educational consequences, including effects on school absenteeism, school engagement, school functioning, academic and social-emotional development, and well-being. (Martinez, 2009)
- Disengagement from school is associated with poorer academic achievement, social emotional functioning, career choices and quality of life.
- Education support services for children and adolescents with chronic health conditions therefore aim to prevent them from becoming disengaged from school.



The evidence-based schema/approach?

From understanding the problem to delivering effective interventions





Systematic review: searching for evidence of effective education support interventions



Access provided by: **NHMRC National Cochr...**

Cochrane Database of Systematic Reviews | **Review - Intervention**

Education support services for improving school engagement and academic performance of children and adolescents with a chronic health condition

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The purpose of doing a systematic review

- To describe the nature of educational support interventions for children and adolescents with a chronic health condition, and to examine the effectiveness of these interventions on school engagement and academic achievement.
- But what is a ‘Systematic Review’?

http://www.campbellcollaboration.org/what_is_a_systematic_review/

- A population level approach
- A quantitative research methodology



Systematic reviews: a specific methodology

They must always start with a structured research question

- **P**opulation
- **I**ntervention
- **C**omparison
- **O**utcome
- **T**ime

**Search
Strategy**

**Analysis
and
Synthesis**

**Peer
review**



The key question upfront

Population

- Children and young people aged 4 to 18 years
- Chronic health condition

“Chronic diseases have a duration that has lasted, or is expected to last, at least six months; have a pattern of recurrence or deterioration; have a poor prognosis and produce consequences or sequelae that impact on the individual’s quality of life.”
(O’Halloran, 2004)
- Categorical or non-categorical approach

When the purpose is to determine the need for an intervention or support service, a non-categorical approach is considered more relevant because it takes into account the similarity of the consequences across a range of health conditions.



The key question upfront

Interventions

Education support interventions/programs

Education Support Intervention

Nature of intervention:

- Provider (school, hospital, family, community)
- Staffing (e.g. roles, numbers)
- Pedagogy (e.g. personalised; individual or group; Arts based)
- Technology
- Duration/Intensity
- Cost
- Target of intervention (child, family, school, hospital, community)



The key question upfront

Comparison

Standard/usual care or waiting list

Outcomes

- Primary
 - Engagement
 - Academic performance
- Secondary
 - Quality of life
 - Transition to school/school re-entry,
 - Mental health

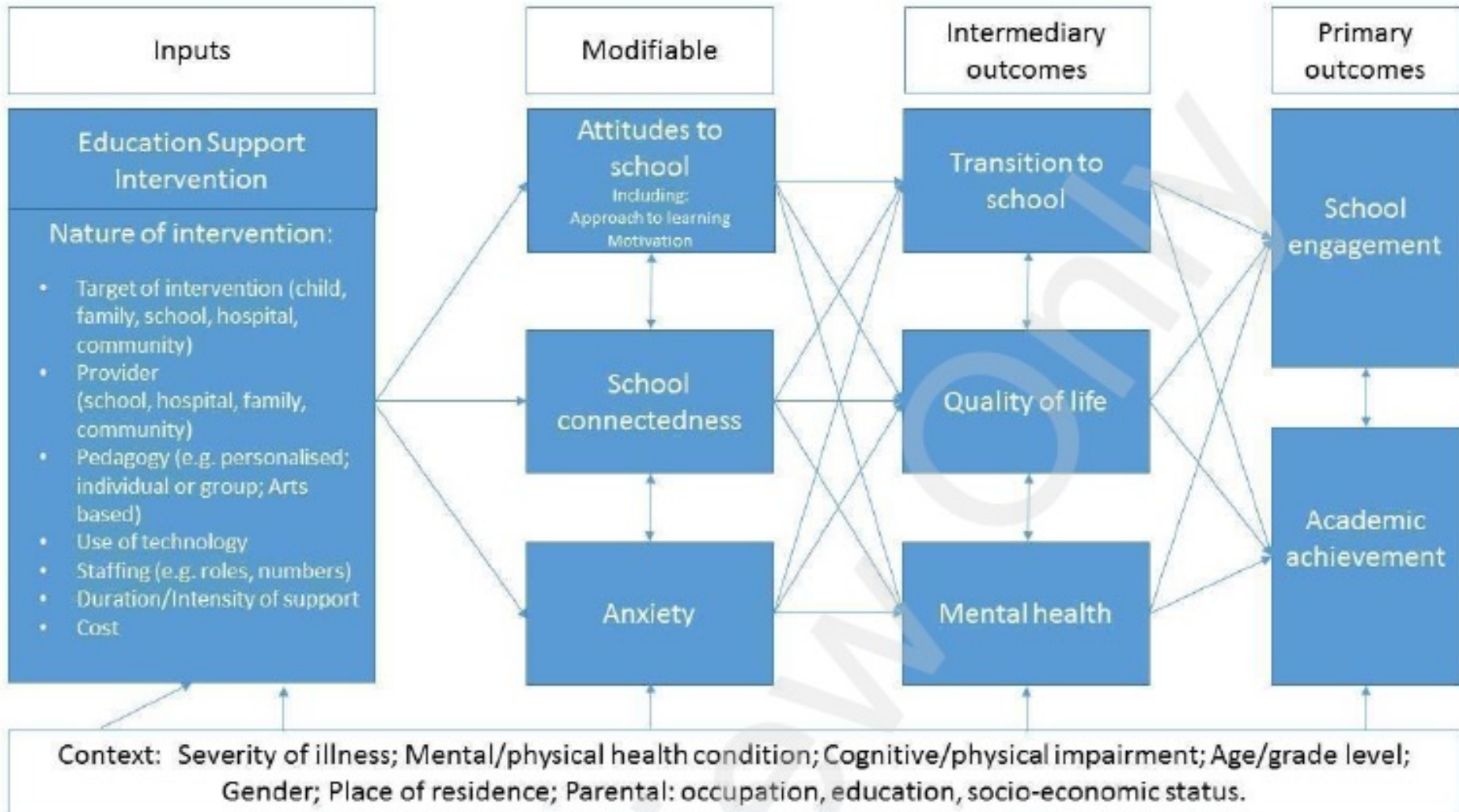
Time

Refers to the length of follow up

E.g. 4 weeks; 6 months; 1 year; at age 25 years?

Our review – no restriction on time of follow up

The links between education support programs and outcomes

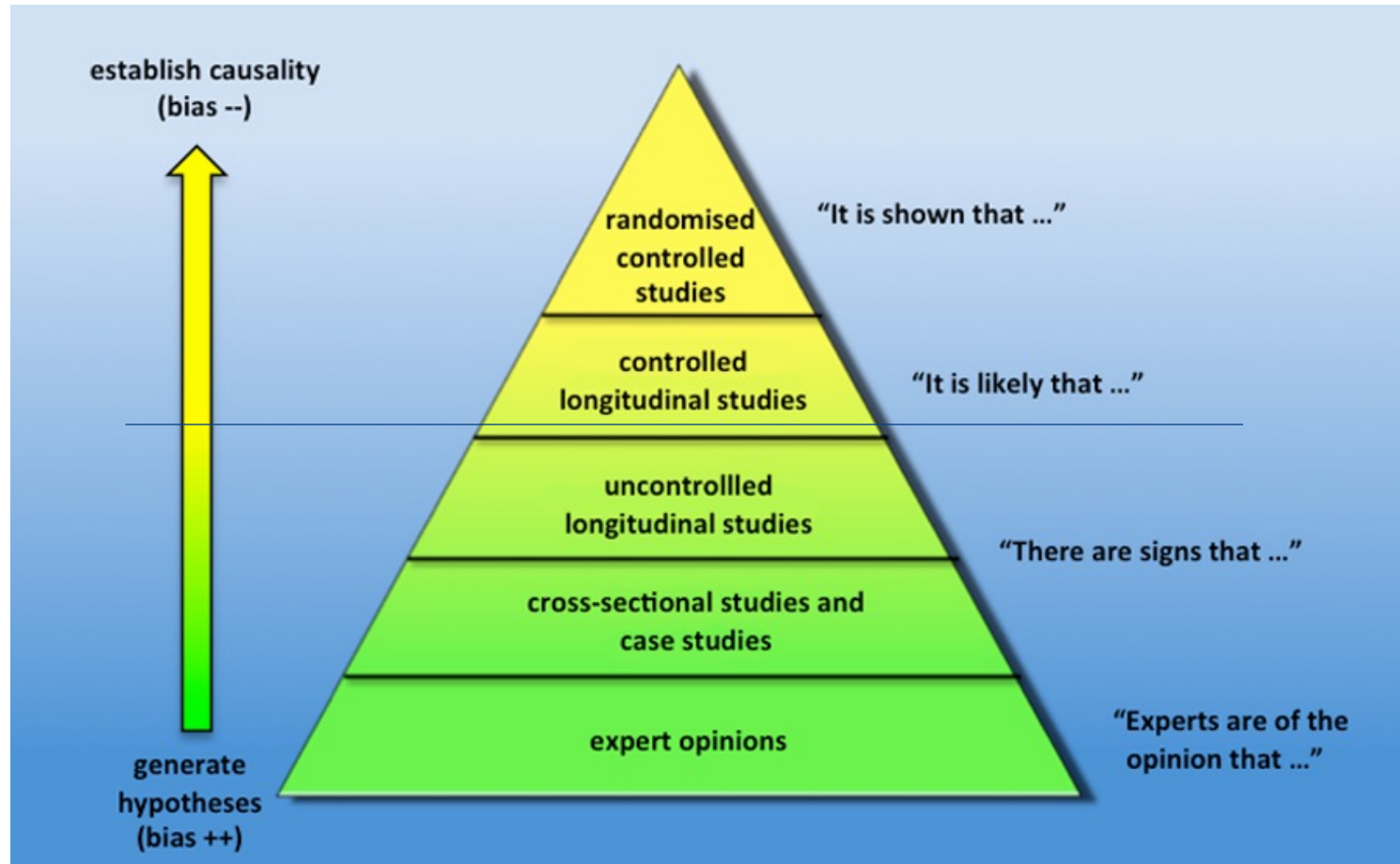




In summary: the systematic review

- To get a clear picture of the current state of the evidence about the effectiveness of education support interventions.
 - To *describe* the nature of educational support interventions for children and adolescents with a chronic health condition
 - To examine the *effectiveness* of these educational support interventions on school engagement and academic achievement.
- Wanted to know possible impact on 5 outcomes
 - 2 primary outcomes: School engagement, Academic performance;
 - 4 secondary outcomes: Quality of life, Transition to school/school re-entry, Mental health.
- Search terms and strategy determined a priori and peer reviewed
- 9 electronic databases searched, plus 5 grey literature databases.
 - MEDLINE; EMBASE; CINAHL; PsycINFO; ERIC (Education Resources Information Centre); Applied Social Sciences Index and Abstracts: ASSIA; PubMed; Cochrane Central Register of Controlled Trials (CENTRAL); Cochrane Public Health Group public health register.

What's in and what's out

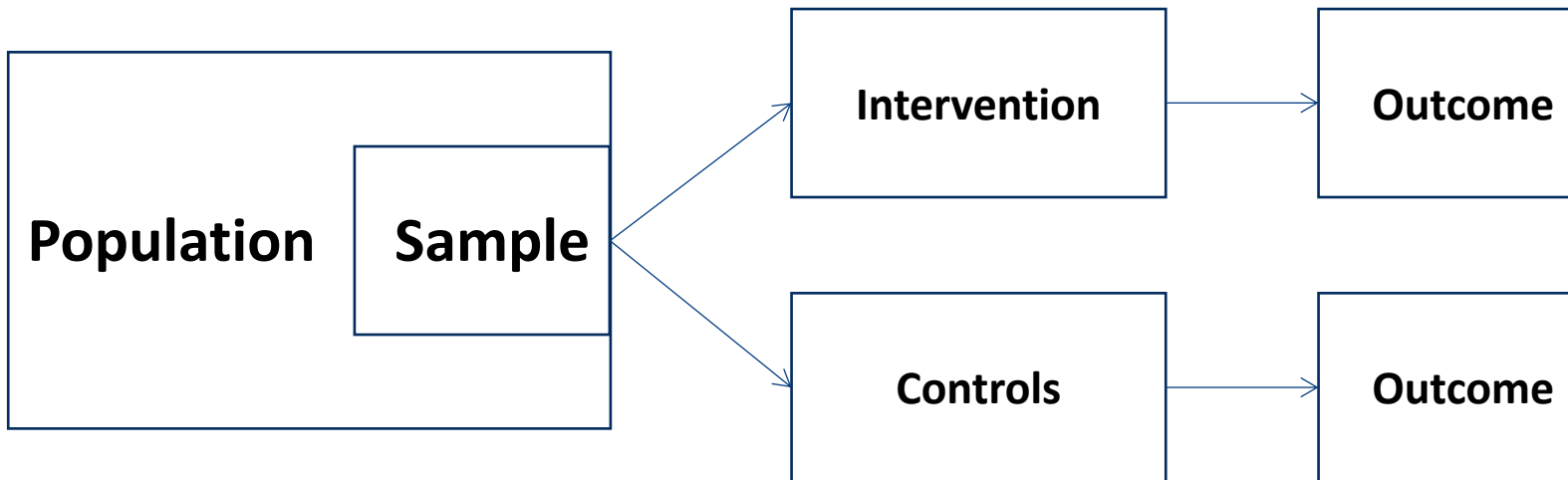




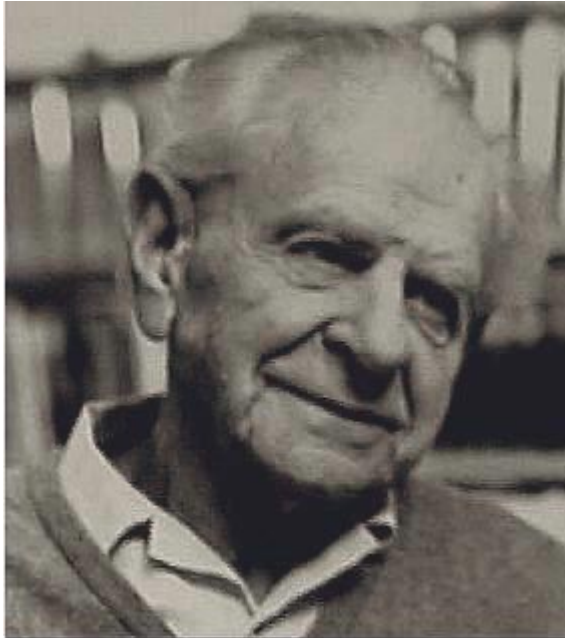
What is a Randomised Controlled Trial (RCT)?

➤ *Not rocket science*

Randomised Controlled Trial (RCT)



Why an RCT: *Causality*



Sir Karl Popper (1902-1994)

Karl Popper is generally regarded as one of the greatest philosophers of science of the twentieth century. He was also a social and political philosopher of considerable stature

Three requirements:

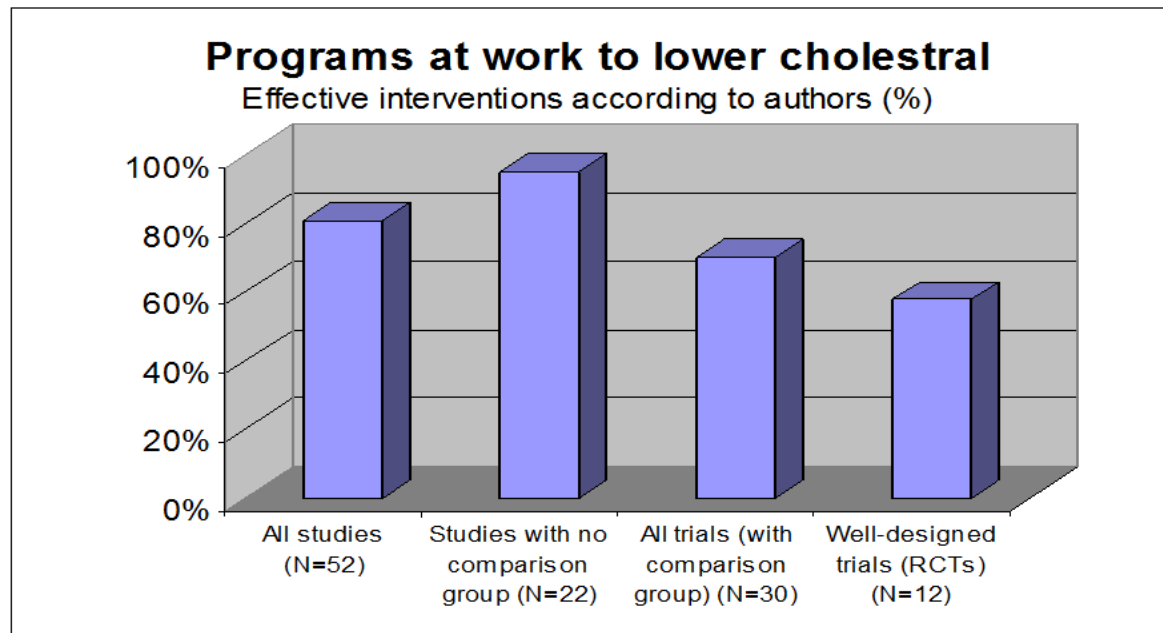
1. Temporal/Time
 - A before B
2. Non-spurious
 - A real relationship must exist between A and B
3. Counterfactual
 - Need to know what happens if you don't get A

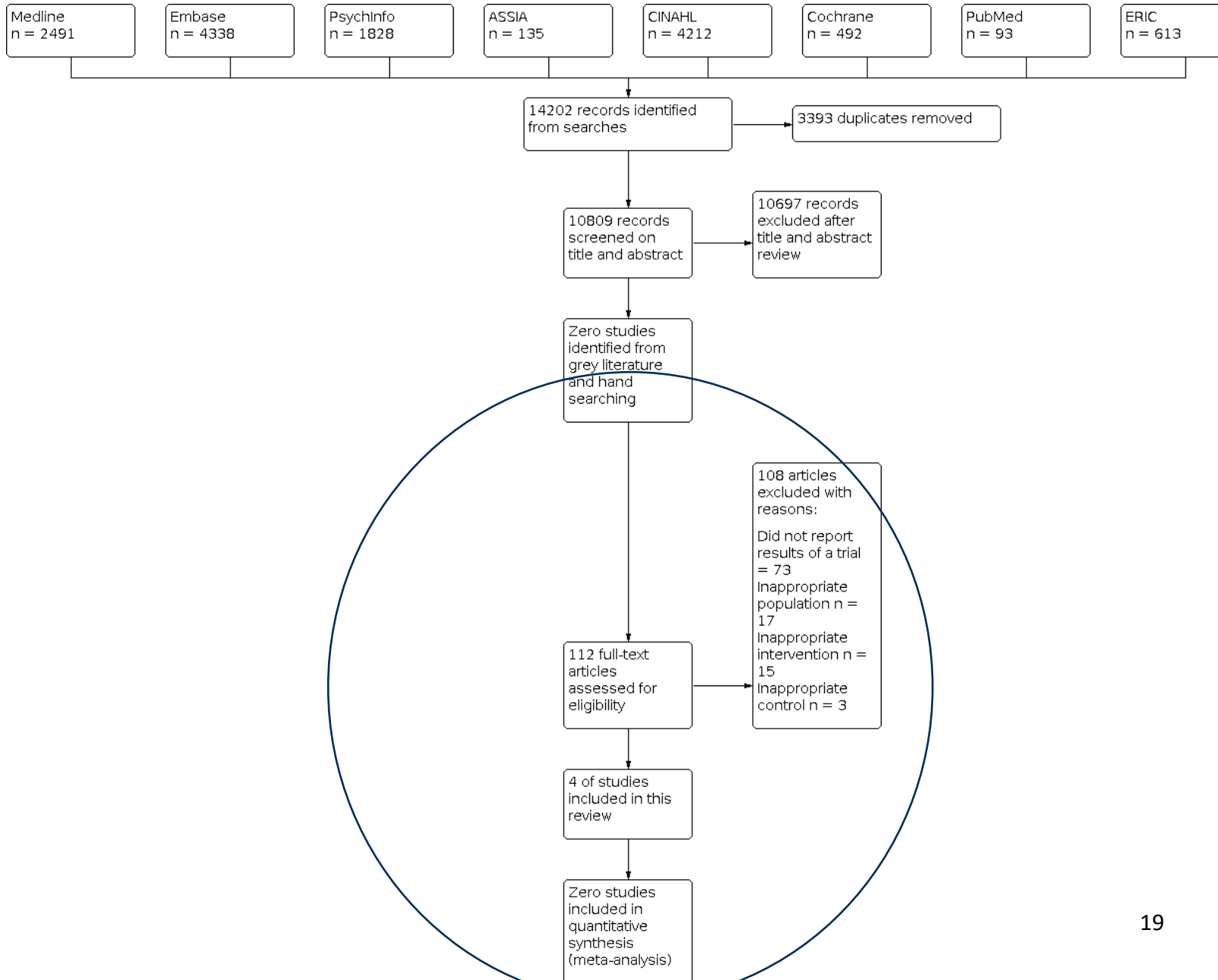
Why an RCT: *Bias*

What is wrong with bias?

[B]ias can mislead people.....into believing that useless or harmful interventions are worthwhile or that interventions are useless when, in truth, they have beneficial effects.”

(Iain Chalmers, 2003:28)





ADDITIONAL TABLES

Table 1. Summary: Characteristics of included studies

Study	Chronic condition	Intervention type	Setting ¹	Sample size	Age (Mean years)	Follow-up (months)	Attrition
Butler 2008	Cancer	Cognitive remediation	Paediatric clinic for children with cancer	163	11	6	27%
Moore 2012	Cancer	Cognitive remediation	Paediatric clinic for children with cancer	57	6.6	12	40%
Varni 1993	Cancer	School reintegration plus social skills training	Paediatric clinic for children with cancer	30	8.2	9	16%
Evans 2007	ADHD	Education consultation and support	School based	79	11.9	30	33%

1. All studies conducted in the United States of America. All studies were randomised controlled studies.



SUMMARY OF FINDINGS

Summary of findings 1. Summary of findings

Education support compared with standard or community care or waitlist, for children and young people with chronic health conditions

Population: children and young people with chronic health conditions

Settings: schools or health centres

Intervention: education support

Comparison: standard or community care or waitlist

Outcomes	Direction of effect/impact (Positive, equivocal or negative)	No of Participants (studies)	Certainty of the evidence (GRADE)	Comments
School engagement (follow-up range 6 months to 30 months)	There was evidence that education support improved school engagement with 3 of 4 studies favouring the intervention (75% (95% CI 19% to 99%), $p = 0.625$).	269 (4)	⊕⊕⊕⊕ very low ^{a,b,c}	We are uncertain whether education support interventions improve school engagement.
Academic achievement (follow-up range 6 months to 30 months)	Three studies measured academic achievement but only two studies provided effect estimates. Based on the vote counting method we found contradictory results from the studies: one study showed a positive direction of effect and the second study showed a negative direction of effect.	227 (3)	⊕⊕⊕⊕ very low ^{a,c,d}	We are uncertain whether education support interventions improve measures of academic achievement.
Transition back to school (follow-up 9 months)	One study measured transition back to school and found a positive impact of education support favouring the intervention (SMD 0.18, 95% CI -0.46 to 0.96, no P-value reported). The result came from a single study with a small sample size ($n = 30$), and produced a confidence interval that indicated the possibility of a very small or no effect.	30 (1)	⊕⊕⊕⊕ very low ^{a,c*}	We are uncertain whether education support improves transitions back to school following hospitalisation for children and young people with chronic health conditions.
Mental health (follow-up range 6 to 9 months)	Two of 4 studies measured mental health (measured as self-esteem). Both studies reported a positive impact of education support interventions on mental health, and was the only outcome for which the overall certainty of evidence was judged to be low rather than very low.	163 (2)	⊕⊕⊕⊕ low ^{a,c}	Some evidence that education support may improve mental health (measured as self-esteem) slightly.
Quality of life		0 (0)		0 studies measured or reported this outcome.
Adverse effects		0 (0)		0 studies measured or reported this outcome.



SR conclusions & implications for research

- School engagement is important for a child or adolescent with a chronic health condition;
- No studies included common and validated outcome measures – in particular for school engagement;
- All studies were disease specific. No studies spanned different chronic illnesses (non categorical)



SR conclusions & implications for research

To improve the evidence base in this field:

- **more** well-designed and conducted **controlled studies** with adequate power and sample sizes,
- evaluate **non-categorical**/illness type education support interventions,
- include **common and validated outcome measures** with comprehensive and adequate reporting of results data (e.g. means and standard deviations),
- include a validated measure of **quality of life (QoL)**.
In our review, no studies used a validated measure of quality of life (QoL).

Five World associations .. one common mission...

Improve the quality of life for youth

with physical & mental health needs through education



- **HEAL (USA):** Hospital Educator And Academic Liaison.



- **HELP** Health - Educators - Learners - Parents Alliance



- **HOPE:** Hospital Organisation of Pedagogues in Europe.



- **REDLACEH:** Latin American and Caribbean Network for the Right of Education for Children and Youngsters.



- **NAHE:** (UK) National Association for Hospital Education



Why did we only find 4 studies?

- The issue of ' **equipoise** '. Is it ethical to randomise? (Trinder, L & Reynolds, S., 2000)
- The issue of ' **humility** ' to test interventions. (Chalmers, I., 2005)
- The issue of ' **knowledge** ' and/or training about what constitutes empirical research on effectiveness of interventions. (Chalmers, I., 2005; Gibbs, L., 2003)
- **Research** in education is **not the same** as in medicine/health. It is more complicated.
- The issue of ' **data** ' and data linkage. (Gemici, S & Nguyen, N., 2013)
- Your thoughts?



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Thank you

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Outcomes of interest

Individual and peers

- Child verbal cognition
- Child non-verbal cognition
- Language and Literacy
- Mathematics
- Approach to Learning
- Behaviour
- Psychosocial functioning

Family

- Mother and Father mental health

School

- Teacher-Child relationship

