

Additional File 3

Eligibility and Screening Criteria Form

Scoping Review Eligibility and Screening Criteria		
RESEARCH QUESTION & SEARCH PARAMETER		
RESEARCH QUESTION: What are the knowledge needs and preferences of parents regarding pediatric rare disease clinical trials (PRDCTs)?		
RESTRICTIONS: English language, no restrictions on date of publication, no restrictions on location of conduct/publication of study		
LIMITS RE: STUDY DESIGN Include: all primary research studies (any study design) Exclude: reviews/knowledge syntheses*, letters, opinion pieces, editorials, conference meeting abstracts, posters, published abstracts, commentaries, study protocols, websites, blogs, pamphlets, magazines, clinical guidelines, scientific reports/statements, association/ organization, reports/statements, books, book chapters, social media posts <i>*Flag potentially relevant reviews/knowledge syntheses for hand-searching of reference lists</i>		
DATA SOURCES - Databases: MEDLINE via Ovid, CINAHL via EBSCOhost, Embase via Ovid, PyschINFO via Ovid, Scopus via Elsevier, Web of Science via Clarivate - Grey literature: Google, Perplexity AI, ProQuest Dissertations & Theses Global database via Clarivate - Websites of relevant rare disease organizations (e.g., Canadian Organization of Rare Diseases and the National Institutes of Health Genetic and Rare Diseases Information Center) - Other: pursuing references in included articles		
SEARCH FILTERS (if applicable): English language		
SCREENING QUESTIONS	INCLUSION CRITERIA	EXCLUSION CRITERIA
Is the study reported in English? *ABSTRACT SCREENING* Yes/No/Unclear	- Reported in English	- Not reported in English
Does this study involve parents of a child with a rare disease (RD)? *ABSTRACT SCREENING* Yes/No/Unclear	Population: - Parents of children/youth (0-21 years) with a RD** - Study population has multiple diagnoses which are reported in the study, and at least one is a RD	- Parents of adult children (i.e., the parent's child was >22 years at the time of the study) - Study population has multiple diagnoses, but specific diagnoses not reported
Does this study investigate parent experience with their child's RD (treatment, management, care, research, etc.)? *ABSTRACT SCREENING* Yes/No/Unclear	Concept: - Parent experiences, views, perceptions, attitudes, beliefs re: their child's RD	- Investigation is not concerned with parent perspective - No investigation of parent experiences, views, perceptions, attitudes, beliefs re: their child's RD

Is the type of evidence source one of the following: *ABSTRACT SCREENING* Yes/No/Unclear	- Primary research, any design (i.e., qualitative, quantitative, multi-method, and mixed methods studies) - Secondary analysis of primary data - Theses and dissertations	- Reviews/knowledge syntheses - Letters - Opinion pieces - Editorials - Conference meeting abstracts/posters - Published abstracts - Commentaries - Study protocols - Websites - Blogs - Pamphlets - Magazines - Clinical guidelines - Scientific reports/statements - Association/organization reports/statements - Books - Book chapters - Social media posts
Does the study include investigation of/findings about parent knowledge needs and preferences re: PRDCTs? *FULL TEXT REVIEW* Yes/No/Unclear	Phenomenon of Interest: - Parent knowledge needs re: PRDCTs	- No reference to/inclusion of findings about parent knowledge needs re: PRDCTs
FINAL DECISION: Include/Exclude/Unclear		
**Rare Disease: disease with prevalence of <1 per 2000 people		