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## Search Strategy for "The Benefits, Burdens, and Risks of Participation in Pediatric Palliative Care and End of Life Research: a Systematic Review"

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**Authors**

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Title:

"The benefits, burdens, and risks of participation in pediatric palliative care and end of life research: a systematic review"

MEDLINE

S1	TI ((participat* OR subject* OR enrol* OR acru* OR recruit* OR select* OR consent* OR willing* OR agree*) AND (interview* OR survey* OR questionnaire* OR 'focus group*' OR study)) OR (MM "Selection Bias") OR (MM "Health Services Research+") OR (MM "Research Design+") OR (MM "Research+") OR (MM "Research Subjects+")
S2	TI (research OR researcher*)
S3	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*)
S4	S2 OR (S1 AND S3)
S5	TI (("be heard" OR "help others" OR "tell their story" OR altru* OR attitude OR barrier* OR benef* OR block* OR burden* OR challeng* OR complexit* OR comfort* OR concerns OR cost* OR disrupt* OR distress* OR empower* OR enlighten* OR experienc* OR gain* OR gatekeep* OR harm* OR helpful* OR hurdle* OR impact* OR incentiv* OR logistic* OR motivat* OR negative OR obstacle* OR painful OR perceiv* OR perception* OR positive OR reaction* OR readiness OR ready OR reflection OR regret* OR reward* OR risk* OR "self awareness" OR stress* OR unwilling* OR useful OR valu* OR voice OR willing* OR imped* OR deter* OR cathar*) N10 (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR "non responder*" OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*))
S6	AB (("be heard" OR "help others" OR "tell their story" OR altru* OR attitude OR barrier* OR benef* OR block* OR burden* OR challeng* OR complexit* OR comfort* OR concerns OR cost* OR disrupt* OR distress* OR empower* OR enlighten* OR experienc* OR gain* OR gatekeep* OR harm* OR helpful* OR hurdle* OR impact* OR incentiv* OR logistic* OR motivat* OR negative OR obstacle* OR painful OR perceiv* OR perception* OR positive OR reaction* OR readiness OR ready OR reflection OR regret* OR reward* OR risk* OR "self awareness" OR stress* OR unwilling* OR useful OR valu* OR voice OR willing* OR imped* OR deter* OR cathar*) N10 (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR "non responder*" OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*))

S7	S5 OR S6
S8	(MH "Parents+") OR (MH "Research Subjects+")
S9	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric* ) OR AB (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric* )
S10	S8 OR S9
S11	(MH "Stress, Psychological+") OR (MH "Bias (Epidemiology)+") OR "nonresponse bias" OR "non-response bias" OR (MH "Attitude of Health Personnel+") OR (MH "Risk+") OR (MH "Risk Assessment+") OR (MH "Attitude+") OR (MH "Motivation+") OR (MH "Patient Selection")
S12	S10 AND S11
S13	(MH "Health Personnel+/PX") OR (MH "Patients+/PX") OR (MH "Family+/PX") OR (MH "Siblings/PX")
S14	TI ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR AB ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR SO ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* )
S15	(MH "Advance Care Planning+") OR (MH "Bereavement+") OR (MH "Hospice Care") OR (MH "Palliative Care") OR (MH "Terminal Care+") OR (MH "Terminally Ill")
S16	S14 OR S15
S17	TI (infant* OR baby OR babies OR nicu OR neonat* OR perinatal OR preemi* OR prematurity OR premi OR premie OR premies OR preterm OR newborn* OR child OR child* OR children OR children* OR stepchild OR stepchildren OR "step child" OR "step children" OR kid OR kids OR girl OR girls OR boy OR boys OR teenage* OR youth* OR youngster* OR adolescent* OR adolescence OR preschool* OR "pre school*" OR kindergarten* OR "high schooler*" OR "elementary school" OR "junior high" OR "middle school" OR "high school" OR juvenile* OR minors OR childhood OR pediatric* OR paediatrician* OR paediatric* OR paediatrician* OR picu) OR AB (infant* OR baby OR babies OR nicu OR neonat* OR perinatal OR preemi* OR prematurity OR premi OR premie OR premies OR preterm OR newborn* OR child OR child* OR children OR children* OR stepchild OR stepchildren OR "step child" OR "step children" OR kid OR kids OR girl OR girls OR boy OR boys OR teenage* OR youth* OR youngster* OR adolescent* OR adolescence OR preschool* OR "pre school*" OR kindergarten* OR "high schooler*" OR "elementary school" OR "junior high" OR "middle school" OR "high school" OR juvenile* OR minors OR childhood OR pediatric* OR paediatrician* OR paediatric* OR paediatrician* OR picu)
S18	(MH "Infant+") OR (MH "Child+") OR (MH "Adolescent")
S19	S17 OR S18

S20	S4 AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19
S21	S4 AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19
S22	S4 AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19
S23	S4 AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19
S24	S4 AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19
S25	(S2 OR (S3 AND S25)) AND (S5 OR S6 OR S12 OR S13) AND S16 AND S19 Limits: Limiters - English Language; Date of Publication: 20020101-20171231 Editorials and Case Reports removed.

## CINAHL

S1	TI research OR researcher*
S2	TI (("be heard" OR "help others" OR "tell their story" OR altru* OR attitude OR barrier* OR benef* OR block* OR burden* OR challeng* OR complexit* OR comfort* OR concerns OR cost* OR disrupt* OR distress* OR empower* OR enlighten* OR experienc* OR gain* OR gatekeep* OR harm* OR helpful* OR hurdle* OR impact* OR incentiv* OR logistic* OR motivat* OR negative OR obstacle* OR painful OR perceiv* OR perception* OR positive OR reaction* OR readiness OR ready OR reflection OR regret* OR reward* OR risk* OR "self awareness" OR stress* OR unwilling* OR useful OR valu* OR voice OR willing* OR imped* OR deter* OR cathar*) N10 (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR "non responder*" OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*))
S3	AB (("be heard" OR "help others" OR "tell their story" OR altru* OR attitude OR barrier* OR benef* OR block* OR burden* OR challeng* OR complexit* OR comfort* OR concerns OR cost* OR disrupt* OR distress* OR empower* OR enlighten* OR experienc* OR gain* OR gatekeep* OR harm* OR helpful* OR hurdle* OR impact* OR incentiv* OR logistic* OR motivat* OR negative OR obstacle* OR painful OR perceiv* OR perception* OR positive OR reaction* OR readiness OR ready OR reflection OR regret* OR reward* OR risk* OR "self awareness" OR stress* OR unwilling* OR useful OR valu* OR voice OR willing* OR imped* OR deter* OR cathar*) N10 (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR "non responder*" OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*))
S4	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR

	pediatrician* OR paediatrician* ) OR AB (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder** OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric* )
S5	TI ("advance care planning" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR AB ("advance care planning" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* )
S6	TI (infant* OR baby OR babies OR nicu OR neonat* OR perinatal OR preemi* OR prematurity OR premi OR premie OR premies OR preterm OR newborn* OR child OR child* OR children OR children* OR stepchild OR stepchildren OR "step child" OR "step children" OR kid OR kids OR girl OR girls OR boy OR boys OR teenage* OR youth* OR youngster* OR adolescent* OR adolescence OR preschool* OR "pre school*" OR kindergarten* OR "high schooler*" OR "elementary school" OR "junior high" OR "middle school" OR "high school" OR juvenile* OR minors OR childhood OR pediatric* OR pediatrician* OR paediatric* OR paediatrician* OR picu) OR AB (infant* OR baby OR babies OR nicu OR neonat* OR perinatal OR preemi* OR prematurity OR premi OR premie OR premies OR preterm OR newborn* OR child OR child* OR children OR children* OR stepchild OR stepchildren OR "step child" OR "step children" OR kid OR kids OR girl OR girls OR boy OR boys OR teenage* OR youth* OR youngster* OR adolescent* OR adolescence OR preschool* OR "pre school*" OR kindergarten* OR "high schooler*" OR "elementary school" OR "junior high" OR "middle school" OR "high school" OR juvenile* OR minors OR childhood OR pediatric* OR paediatric* OR picu)
S7	TI ((participat* OR subject* OR enrol* OR acru* OR recruit* OR select* OR consent* OR willing* OR agree*) AND (interview* OR survey* OR questionnaire* OR 'focus group*' OR study)) OR (MM "Selection Bias+") OR (MM "Research+") OR (MM "Research Methodology+") OR (MM "Research Subject Recruitment") OR (MM "Research Subject Retention") OR (MM "Researcher-Subject Relations") OR (MM "Research Subjects+")
S8	(MH "Parental Attitudes+") OR (MH "Parents+") OR (MH "Research Subjects+")
S9	(MH "Stress+") OR (MH "Life Experiences+") OR (MH "Perception+") OR (MH "Nonresponse Bias") OR (MH "Cost Benefit Analysis") OR (MH "Risk Assessment") OR (MH "Attitude+") OR (MH "Motivation+") OR (MH "Patient Selection") OR (MH "Psychology+")
S10	(MH "Patient Attitudes") OR (MH "Parental Attitudes+") OR (MH "Attitude of Health Personnel+") OR (MH "Nonresponse Bias")
S11	((S4 OR S8 ) AND S9) OR S10
S12	(MH "Advance Care Planning") OR (MH "Palliative Care") OR (MH "Terminal Care+") OR (MH "Terminal Care (Saba CCC)+") OR (MH "Hospice Care") OR (MH "Hospice and Palliative Nursing") OR (MH "Hospice Patients") OR (MH "Hospices") OR (MH "Terminally Ill Patients+")
S13	S5 OR S12
S14	(MH "Infant+") OR (MH "Infant Death+") OR (MH "Child+") OR (MH "Adolescence+")
S15	S6 OR S14
S16	TI ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR AB ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR SO ("advance care" OR bereave* OR death

	OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* )
S17	S12 OR S16
S18	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*)
S19	S1 OR (S18 AND S7)
S20	S19 AND (S2 OR S3 OR S11) AND S17 AND S15 Limiters - Published Date: 20020101-20171231; English Language Removed Case Reports and Editorials

## PsycINFO

S1	TI (research OR researcher*)
S2	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*)
S3	TI (("be heard" OR "help others" OR "tell their story" OR altru* OR attitude OR barrier* OR benef* OR block* OR burden* OR challeng* OR complexit* OR comfort* OR concerns OR cost* OR disrupt* OR distress* OR empower* OR enlighten* OR experienc* OR gain* OR gatekeep* OR harm* OR helpful* OR hurdle* OR impact* OR incentiv* OR logistic* OR motivat* OR negative OR obstacle* OR painful OR perceiv* OR perception* OR positive OR reaction* OR readiness OR ready OR reflection OR regret* OR reward* OR risk* OR "self awareness" OR stress* OR unwilling* OR useful OR valu* OR voice OR willing* OR imped* OR deter* OR cathar*) N10 (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR "non responder*" OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*))
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	OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric*)
S5	TI (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric* ) OR AB (invit* OR recruit* OR accrual OR enrol* OR retain* OR retention OR 'non responder*' OR responder* OR refus* OR participa* OR subject* OR family OR families OR child* OR adolesc* OR teen* OR toddler* OR youth* OR youngster* OR minors OR kid OR kids OR patient* OR parent* OR father* OR mother* OR guardian* OR caregiver* OR sibling* OR sister* OR brother* OR surrogat* OR personnel OR staff OR investigator* OR coordinator* OR assistant* OR researcher* OR nurse* OR physician* OR doctor* OR oncologist* OR pediatric* OR paediatric* )
S6	TI ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR AB ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* ) OR SO ("advance care" OR bereave* OR death OR dying OR "end of life" OR hospice* OR "life limiting" OR "life threatening" OR palliative OR terminal* )
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S8	TI ((participat* OR subject* OR enrol* OR acru* OR recruit* OR select* OR consent* OR willing* OR agree*) AND (interview* OR survey* OR questionnaire* OR 'focus group*' OR study)) OR MM "Experimenter Bias" OR MM "Experimenter Expectations" OR MM "Experimenters" OR MM "Experimentation" OR MM "Action Research" OR MM "Consumer Research" OR MM "Interdisciplinary Research" OR MM "Online Experiments" OR MM "Qualitative Research" OR MM "Quantitative Methods" OR MM "Research Setting" OR MM "Experimental Design" OR MM "Between Groups Design" OR MM "Clinical Trials" OR MM "Cohort Analysis" OR MM "Followup Studies" OR MM "Hypothesis Testing" OR MM "Longitudinal Studies" OR MM "Repeated Measures" OR MM "Experimental Methods" OR MM "Quasi Experimental Methods" OR MM "Stimulus Presentation Methods" OR MM "Experimentation" OR MM "Action Research" OR MM "Animal Research" OR MM "Consumer Research" OR MM "Interdisciplinary Research" OR MM "Online Experiments" OR MM "Qualitative Research" OR MM "Quantitative Methods" OR MM "Research Setting" OR MM "Methodology" OR MM "Causal Analysis" OR MM "Cohort Analysis" OR MM "Content Analysis" OR MM "Data Collection" OR MM "Empirical Methods" OR MM



	"Grounded Theory" OR MM "Meta Analysis" OR MM "Parent Report" OR MM "Qualitative Research" OR MM "Quantitative Methods" OR MM "Self-Report" OR MM "Experimental Subjects"
S9	DE "Parents" OR DE "Adoptive Parents" OR DE "Fathers" OR DE "Foster Parents" OR DE "Homosexual Parents" OR DE "Mothers" OR DE "Single Parents" OR DE "Stepparents" OR DE "Surrogate Parents (Humans)" OR DE "Experimental Subjects"
S10	DE "Stress" OR DE "Chronic Stress" OR DE "Environmental Stress" OR DE "Post-Traumatic Stress" OR DE "Psychological Stress" OR DE "Social Stress" OR DE "Stress Reactions" OR DE "Experimenter Bias" OR DE "Risk Assessment" OR DE "Attitudes" OR DE "Adolescent Attitudes" OR DE "Adult Attitudes" OR DE "Child Attitudes" OR DE "Client Attitudes" OR DE "Consumer Attitudes" OR DE "Counselor Attitudes" OR DE "Death Attitudes" OR DE "Employee Attitudes" OR DE "Employer Attitudes" OR DE "Explicit Attitudes" OR DE "Female Attitudes" OR DE "Health Personnel Attitudes" OR DE "Implicit Attitudes" OR DE "Male Attitudes" OR DE "Occupational Attitudes" OR DE "Parental Attitudes" OR DE "Paternalism" OR DE "Psychologist Attitudes" OR DE "Public Opinion" OR DE "Racial and Ethnic Attitudes" OR DE "Sex Role Attitudes" OR DE "Sexual Attitudes" OR DE "Socioeconomic Class Attitudes" OR DE "Stereotyped Attitudes" OR DE "Student Attitudes" OR DE "Teacher Attitudes" OR DE "Motivation" OR DE "Affiliation Motivation" OR DE "Educational Incentives" OR DE "Employee Motivation" OR DE "Extrinsic Motivation" OR DE "Fear of Success" OR DE "Incentives" OR DE "Intrinsic Motivation" OR DE "Monetary Incentives" OR DE "Procrastination" OR DE "Self-Expansion" OR DE "Patient Selection"
S11	DE "Client Attitudes" OR DE "Client Satisfaction" OR DE "Parental Attitudes" OR DE "Parental Expectations" OR DE "Health Personnel Attitudes" OR DE "Therapist Attitudes"
S12	DE "Advance Directives" OR DE "Bereavement" OR DE "Grief" OR DE "Hospice" OR DE "Palliative Care" OR DE "Terminally Ill Patients"
S13	S1 OR (S2 AND S8)
S14	( S1 OR (S2 AND S8) ) AND ( ((S5 OR S9) AND S10) OR S11 )
S15	S12 OR S6
S16	S13 AND (S14 OR S3 OR S4 ) AND S15 AND S7
S17	S13 AND (S14 OR S3 OR S4 ) AND S15 Limiters - Age Groups: Childhood (birth-12 yrs)
S18	S13 AND (S14 OR S3 OR S4 ) AND S15 Limiters - Age Groups: Adolescence (13-17 yrs)
S19	S16 OR S17 OR S18 Limiters - Published Date: 20020101-20181231; English; Removed Editorials

#### EMBASE

(research:ti OR researcher\*:ti OR ((invit\*:ti OR recruit\*:ti OR accrual:ti OR enrol\*:ti OR retain\*:ti OR retention:ti OR 'non responder\*':ti OR responder\*:ti OR refus\*:ti OR participa\*:ti OR subject\*:ti OR family:ti OR families:ti OR child\*:ti OR adolesc\*:ti OR teen\*:ti OR toddler\*:ti OR youth\*:ti OR youngster\*:ti OR minors:ti OR kid:ti OR kids:ti OR patient\*:ti OR parent\*:ti OR father\*:ti OR mother\*:ti OR guardian\*:ti OR caregiver\*:ti OR sibling\*:ti OR sister\*:ti OR brother\*:ti OR surrogat\*:ti OR personnel:ti OR staff:ti OR investigator\*:ti OR coordinator\*:ti OR assistant\*:ti OR researcher\*:ti OR nurse\*:ti OR physician\*:ti OR doctor\*:ti OR oncologist\*:ti OR pediatric\*:ti OR paediatric\*:ti) AND ( ((participat\*:ti OR subject\*:ti OR enrol\*:ti OR acru\*:ti OR recruit\*:ti OR select\*:ti OR consent\*:ti OR willing\*:ti OR agree\*:ti) AND (interview\*:ti OR survey\*:ti OR

questionnaire\*:ti OR 'focus group\*':ti OR study:ti)) OR 'selection bias'/exp/mj OR 'health services research'/exp/mj OR 'methodology'/exp/mj OR 'research'/exp/mj OR 'research participation'/exp/mj OR 'research subject'/exp/mj))) AND (((('be heard' OR 'help others' OR 'tell their story' OR altru\* OR attitude OR barrier\* OR benef\* OR block\* OR burden\* OR challeng\* OR complexit\* OR comfort\* OR concerns OR cost\* OR disrupt\* OR distress\* OR empower\* OR enlighten\* OR experienc\* OR gain\* OR gatekeep\* OR harm\* OR helpful\* OR hurdle\* OR impact\* OR incentiv\* OR logistic\* OR motivat\* OR negative OR obstacle\* OR painful OR perceiv\* OR perception\* OR positive OR reaction\* OR readiness OR ready OR reflection OR regret\* OR reward\* OR risk\* OR 'self awareness' OR stress\* OR unwilling\* OR useful OR valu\* OR voice OR willing\* OR imped\* OR deter\* OR cathar\*) NEAR/10 (invit\* OR recruit\* OR accrual OR enrol\* OR retain\* OR retention OR 'non responder\*' OR responder\* OR refus\* OR participa\* OR subject\* OR family OR families OR child\* OR adolesc\* OR teen\* OR toddler\* OR youth\* OR youngster\* OR minors OR kid OR kids OR patient\* OR parent\* OR father\* OR mother\* OR guardian\* OR caregiver\* OR sibling\* OR sister\* OR brother\* OR surrogat\* OR personnel OR staff OR investigator\* OR coordinator\* OR assistant\* OR researcher\* OR nurse\* OR physician\* OR doctor\* OR oncologist\* OR pediatric\* OR paediatric\*)) OR ((invit\*:ti OR recruit\*:ti OR accrual:ti OR enrol\*:ti OR retain\*:ti OR retention:ti OR 'non responder\*':ti OR responder\*:ti OR refus\*:ti OR participa\*:ti OR subject\*:ti OR family:ti OR families:ti OR child\*:ti OR adolesc\*:ti OR teen\*:ti OR toddler\*:ti OR youth\*:ti OR youngster\*:ti OR minors:ti OR kid:ti OR kids:ti OR patient\*:ti OR parent\*:ti OR father\*:ti OR mother\*:ti OR guardian\*:ti OR caregiver\*:ti OR sibling\*:ti OR sister\*:ti OR brother\*:ti OR surrogat\*:ti OR personnel:ti OR staff:ti OR investigator\*:ti OR coordinator\*:ti OR assistant\*:ti OR researcher\*:ti OR nurse\*:ti OR physician\*:ti OR doctor\*:ti OR oncologist\*:ti OR pediatric\*:ti OR paediatric\*:ti OR 'parent'/exp OR 'research participation'/exp) AND ('psychotrauma'/exp OR 'psychotrauma assessment'/exp OR 'stress'/exp OR 'experience'/exp OR 'personal experience'/exp OR 'psychological aspect'/exp OR 'perception'/exp OR 'nonresponse bias'/exp OR 'risk benefit analysis'/exp OR 'attitude'/exp OR 'motivation'/exp OR 'risk'/exp OR 'patient selection'/exp OR 'psychology'/exp OR 'wellbeing'/exp)) OR 'patient attitude'/exp OR 'nonresponse bias'/exp OR 'health personnel attitude'/exp) AND ('advance care':ab,ti,jt OR bereave\*:ab,ti,jt OR death:ab,ti,jt OR dying:ab,ti,jt OR 'end of life':ab,ti,jt OR hospice\*:ab,ti,jt OR 'life limiting':ab,ti,jt OR 'life threatening':ab,ti,jt OR palliative:ab,ti,jt OR terminal\*:ab,ti,jt OR 'palliative therapy'/exp OR 'terminal care'/exp OR 'terminally ill patient'/exp OR 'terminal disease'/exp OR 'dying'/exp) AND ([newborn]/lim OR [infant]/lim OR [child]/lim OR [preschool]/lim OR [school]/lim OR [adolescent]/lim OR infant\*:ab,ti OR baby:ab,ti OR babies:ab,ti OR nicu:ab,ti OR neonat\*:ab,ti OR perinatal:ab,ti OR preemi\*:ab,ti OR prematurity:ab,ti OR premi:ab,ti OR premie:ab,ti OR premies:ab,ti OR preterm:ab,ti OR newborn\*:ab,ti OR child:ab,ti OR child\*:ab,ti OR children:ab,ti OR children\*:ab,ti OR stepchild:ab,ti OR stepchildren:ab,ti OR 'step child':ab,ti OR 'step children':ab,ti OR kid:ab,ti OR kids:ab,ti OR girl:ab,ti OR girls:ab,ti OR boy:ab,ti OR boys:ab,ti OR teenage\*:ab,ti OR youth\*:ab,ti OR youngster\*:ab,ti OR adolescent\*:ab,ti OR adolescence:ab,ti OR preschool\*:ab,ti OR 'pre school\*':ab,ti OR kindergarten\*:ab,ti OR 'high schooler\*':ab,ti OR 'elementary school':ab,ti OR 'junior high':ab,ti OR 'middle school':ab,ti OR 'high school':ab,ti OR juvenile\*:ab,ti OR minors:ab,ti OR childhood:ab,ti OR pediatric\*:ab,ti OR pediatric\*:ab,ti OR paediatric\*:ab,ti OR paediatrician\*:ab,ti OR picu:ab,ti) NOT ('conference abstract'/it OR 'editorial'/it OR 'case report'/de) AND [english]/lim AND [2002-2017]/py

#### Scopus:

( TITLE ( research OR researcher\* ) OR TITLE ( ( invit\* OR recruit\* OR accrual OR enrol\* OR retain\* OR retention OR "non responder\*" OR responder\* OR refus\* OR participa\* OR subject\* OR family OR families OR child\* OR adolesc\* OR teen\* OR toddler\* OR youth\* OR youngster\* OR minors OR kid OR kids OR patient\* OR parent\* OR father\* OR mother\* OR guardian\* OR caregiver\* OR sibling\* OR sister\* OR brother\* OR surrogat\* OR personnel OR staff OR investigator\* OR coordinator\* OR assistant\* OR researcher\* OR nurse\* OR physician\* OR doctor\* OR oncologist\* OR pediatric\* OR paediatric\* ) AND ( participat\* OR subject\* OR enrol\* OR acru\* OR recruit\* OR select\* OR consent\* OR willing\* OR agree\* ) AND ( interview\* OR

survey\* OR questionnaire\* OR 'focus AND group\*' OR study ) ) AND TITLE-ABS-KEY ( ( "be heard" OR "help others" OR "tell their story" OR altru\* OR attitude OR barrier\* OR benef\* OR block\* OR burden\* OR challeng\* OR complexit\* OR comfort\* OR concerns OR cost\* OR disrupt\* OR distress\* OR empower\* OR enlighten\* OR experienc\* OR gain\* OR gatekeep\* OR harm\* OR helpful\* OR hurdle\* OR impact\* OR incentiv\* OR logistic\* OR motivat\* OR negative OR obstacle\* OR painful OR perceiv\* OR perception\* OR positive OR reaction\* OR readiness OR ready OR reflection OR regret\* OR reward\* OR risk\* OR "self awareness" OR stress\* OR unwilling\* OR useful OR valu\* OR voice OR willing\* OR imped\* OR deter\* OR cathar\* ) W/10 ( invit\* OR recruit\* OR accrual OR enrol\* OR retain\* OR retention OR "non responder\*" OR responder\* OR refus\* OR participa\* OR subject\* OR family OR families OR child\* OR adolesc\* OR teen\* OR toddler\* OR youth\* OR youngster\* OR minors OR kid OR kids OR patient\* OR parent\* OR father\* OR mother\* OR guardian\* OR caregiver\* OR sibling\* OR sister\* OR brother\* OR surrogat\* OR personnel OR staff OR investigator\* OR coordinator\* OR assistant\* OR researcher\* OR nurse\* OR physician\* OR doctor\* OR oncologist\* OR pediatric\* OR paediatric\* ) ) AND ( TITLE-ABS-KEY ( "advance care " OR bereave\* OR death OR dying OR "end of life" OR hospice\* OR "life limiting" OR "life threatening" OR palliative OR terminal\* ) OR SRCTITLE ( "advance care " OR bereave\* OR death OR dying OR "end of life" OR hospice\* OR "life limiting" OR "life threatening" OR palliative OR terminal\* ) ) AND TITLE-ABS-KEY ( infant\* OR baby OR babies OR nicu OR neonat\* OR perinatal OR preemi\* OR prematurity OR premi OR premie OR premies OR preterm OR newborn\* OR child OR child\* OR children OR children\* OR stepchild OR stepchildren OR "step child" OR "step children" OR kid OR kids OR girl OR girls OR boy OR boys OR teenage\* OR youth\* OR youngster\* OR adolescent\* OR adolescence OR preschool\* OR "pre school\*" OR kindergarten\* OR "high schooler\*" OR "elementary school" OR "junior high" OR "middle school" OR "high school" OR juvenile\* OR minors OR childhood OR pediatric\* OR paediatrician\* OR paediatric\* OR paediatrician\* OR picu ) AND ( EXCLUDE ( DOCTYPE , "ed " ) ) AND ( LIMIT-TO ( PUBYEAR , 2017 ) OR LIMIT-TO ( PUBYEAR , 2016 ) OR LIMIT-TO ( PUBYEAR , 2015 ) OR LIMIT-TO ( PUBYEAR , 2014 ) OR LIMIT-TO ( PUBYEAR , 2013 ) OR LIMIT-TO ( PUBYEAR , 2012 ) OR LIMIT-TO ( PUBYEAR , 2011 ) OR LIMIT-TO ( PUBYEAR , 2010 ) OR LIMIT-TO ( PUBYEAR , 2009 ) OR LIMIT-TO ( PUBYEAR , 2008 ) OR LIMIT-TO ( PUBYEAR , 2007 ) OR LIMIT-TO ( PUBYEAR , 2006 ) OR LIMIT-TO ( PUBYEAR , 2005 ) OR LIMIT-TO ( PUBYEAR , 2004 ) OR LIMIT-TO ( PUBYEAR , 2003 ) OR LIMIT-TO ( PUBYEAR , 2002 ) ) AND ( LIMIT-TO ( LANGUAGE , "English " ) ) )

## The Cochrane Library

- #1 MeSH descriptor: [Selection Bias] explode all trees
- #2 MeSH descriptor: [Health Services Research] explode all trees
- #3 MeSH descriptor: [Research Design] explode all trees
- #4 MeSH descriptor: [Research] explode all trees
- #5 MeSH descriptor: [Research Subjects] explode all trees
- #6 research or researcher\*:ti
- #7 ((participat\* or subject\* or enrol\* or acru\* or recruit\* or select\* or consent\* or willing\* or agree\*) and (interview\* or survey\* or questionnaire\* or 'focus group\*' or study)):ti
- #8 invit\* or recruit\* or accrual or enrol\* or retain\* or retention or 'non responder\*' or responder\* or refus\* or participa\* or subject\* or family or families or child\* or adolesc\* or teen\* or toddler\* or youth\* or youngster\* or minors or kid or kids or patient\* or parent\* or father\* or mother\* or guardian\* or caregiver\* or sibling\* or sister\* or brother\* or surrogat\* or personnel or staff or investigator\* or coordinator\* or assistant\* or researcher\* or nurse\* or physician\* or doctor\* or oncologist\* or pediatric\* or paediatric\*:ti
- #9 #6 or (#8 and (#7 or #5 or #4 or #3 or #2 or #1))
- #10 (("be heard" or "help others" or "tell their story" or altru\* or attitude or barrier\* or benef\* or block\* or burden\* or challeng\* or complexit\* or comfort\* or concerns or cost\* or disrupt\* or distress\* or empower\* or enlighten\* or experienc\* or gain\* or gatekeep\* or harm\* or

- helpful\* or hurdle\* or impact\* or incentiv\* or logistic\* or motivat\* or negative or obstacle\* or painful or perceiv\* or perception\* or positive or reaction\* or readiness or ready or reflection or regret\* or reward\* or risk\* or "self awareness" or stress\* or unwilling\* or useful or valu\* or voice or willing\* or imped\* or deter\* or cathar\*) near/10 (invit\* or recruit\* or accrual or enrol\* or retain\* or retention or "non responder\*" or responder\* or refus\* or participa\* or subject\* or family or families or child\* or adolesc\* or teen\* or toddler\* or youth\* or youngster\* or minors or kid or kids or patient\* or parent\* or father\* or mother\* or guardian\* or caregiver\* or sibling\* or sister\* or brother\* or surrogat\* or personnel or staff or investigator\* or coordinator\* or assistant\* or researcher\* or nurse\* or physician\* or doctor\* or oncologist\* or pediatric\* or paediatric\*)):ti,ab,kw
- #11 invit\* or recruit\* or accrual or enrol\* or retain\* or retention or 'non responder\*' or responder\* or refus\* or participa\* or subject\* or family or families or child\* or adolesc\* or teen\* or toddler\* or youth\* or youngster\* or minors or kid or kids or patient\* or parent\* or father\* or mother\* or guardian\* or caregiver\* or sibling\* or sister\* or brother\* or surrogat\* or personnel or staff or investigator\* or coordinator\* or assistant\* or researcher\* or nurse\* or physician\* or doctor\* or oncologist\* or pediatric\* or paediatric\*:ti,ab,kw
- #12 MeSH descriptor: [Parents] explode all trees
- #13 MeSH descriptor: [Research Subjects] explode all trees
- #14 MeSH descriptor: [Stress, Psychological] explode all trees
- #15 MeSH descriptor: [Bias (Epidemiology)] explode all trees
- #16 MeSH descriptor: [Attitude of Health Personnel] explode all trees
- #17 MeSH descriptor: [Risk] explode all trees
- #18 MeSH descriptor: [Risk Assessment] explode all trees
- #19 MeSH descriptor: [Attitude] explode all trees
- #20 MeSH descriptor: [Motivation] explode all trees
- #21 MeSH descriptor: [Patient Selection] explode all trees
- #22 MeSH descriptor: [Health Personnel] explode all trees
- #23 MeSH descriptor: [Patients] explode all trees and with qualifier(s): [Psychology - PX]
- #24 MeSH descriptor: [Family] explode all trees and with qualifier(s): [Psychology - PX]
- #25 MeSH descriptor: [Siblings] explode all trees and with qualifier(s): [Psychology - PX]
- #26 ((#11 or #12 or #13) and (#14 or #15 or #16 or #17 or #18 or #19 or #20 or #21)) or #22 or #23 or #24 or #25
- #27 MeSH descriptor: [Advance Care Planning] explode all trees
- #28 MeSH descriptor: [Bereavement] explode all trees
- #29 MeSH descriptor: [Hospice Care] explode all trees
- #30 MeSH descriptor: [Palliative Care] explode all trees
- #31 MeSH descriptor: [Terminal Care] explode all trees
- #32 MeSH descriptor: [Terminally Ill] explode all trees
- #33 "advance care" or bereave\* or death or dying or "end of life" or hospice\* or "life limiting" or "life threatening" or palliative or terminal\*:ti
- #34 "advance care" or bereave\* or death or dying or "end of life" or hospice\* or "life limiting" or "life threatening" or palliative or terminal\*:so
- #36 MeSH descriptor: [Child] explode all trees
- #37 MeSH descriptor: [Infant] explode all trees
- #38 MeSH descriptor: [Adolescent] explode all trees
- #39 infant\* or baby or babies or nicu or neonat\* or perinatal or preemi\* or prematurity or premi or premie or premies or preterm or newborn\* or child or child\* or children or children\* or stepchild or stepchildren or "step child" or "step children" or kid or kids or girl or girls or boy or boys or teenage\* or youth\* or youngster\* or adolescent\* or adolescence or preschool\* or "pre school\*" or kindergarten\* or "high schooler\*" or "elementary school" or "junior high" or "middle school" or "high school" or juvenile\* or minors or childhood or pediatric\* or pediatrician\* or paediatric\* or paediatrician\* or picu:ti,ab,kw
- #40 #36 or #37 or #38 or #39
- #41 "advance care" or bereave\* or death or dying or "end of life" or hospice\* or "life limiting" or "life threatening" or palliative or terminal\*:ab
- #42 #27 or #28 or #29 or #30 or #31 or #32 or #33 or #34 or #41

#43 #9 and (#10 or #26) and #42 and #40 Publication Year from 2002 to 2017