National Institute for Health and Care Excellence

FINAL

Babies, children and young people's experience of healthcare

[C] Consent, privacy and confidentiality

NICE guideline NG204

Evidence reviews underpinning recommendations 1.1.1, 1.1.3 and 1.4.1 to 1.4.14 in the NICE guideline

August 2021

Final

These evidence reviews were developed by the National Guideline Alliance which is a part of the Royal College of Obstetricians and Gynaecologists

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Review question

How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Introduction

Babies, children and young people accessing healthcare have the right to consent to treatment, and rights to privacy and confidentiality. These rights are outlined both in the United Nations Convention on the Rights of the Child (UNCRC) and the NHS Constitution, and this review did not aim to assess the validity of these rights.

The provision of consent is covered by professional frameworks and international human rights laws, and young people over 16 have the right to consent to their own treatment. Those under the age of 16 can consent if they have the competence to do so, otherwise someone with parental responsibility can consent on their behalf.

The right to privacy includes privacy and dignity during discussions, examination, treatment and care, and the right to confidentiality includes the restricted use and sharing of personal and identifiable data and access to health records.

The aim of this review was to determine how children and young people, and the parents or carers of babies and young children prefer discussions about their privacy and confidentiality to be addressed by healthcare services and healthcare providers, as well as their views and preferences on discussions about consent.

Summary of the protocol

See Table 1 for a summary of the population, phenomenon of interest and primary outcomes characteristics of this review.

Table 1: Summary of the protocol

Population	• People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and o The baby or child of the parent or carer is under 5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child.
Phenomenon of interest	Experience of healthcare, in particular situations in which issues of consent, privacy, or confidentiality are discussed
Primary outcome	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Availability of areas that enable privacy or provision of alternative measures to allow this (e.g. headphones on neonatal ward rounds) • Difference between consent and assent • Establishing that child or young person understands legal issues or their rights

	• Knowledge of child's or young person's attitude to confidentiality, privacy, and consent • Knowledge and understanding of what child or young person is legally entitled to or has the right to do • Knowledge and understanding of when information can be shared (e.g. with parents) • Prior promotion of rights to, or respect for, privacy and confidentiality • Provision of or access to age-appropriate information • Reflection by staff on their own attitudes towards confidentiality, privacy and consent

For further details see the review protocol in appendix A.

Methods and process

This evidence review was developed using the methods and process described in developing NICE guidelines: the manual. Methods for this review question are described in the review protocol in appendix A and the methods supplement.

Clinical evidence

Included studies

This was a qualitative review with the aim of:

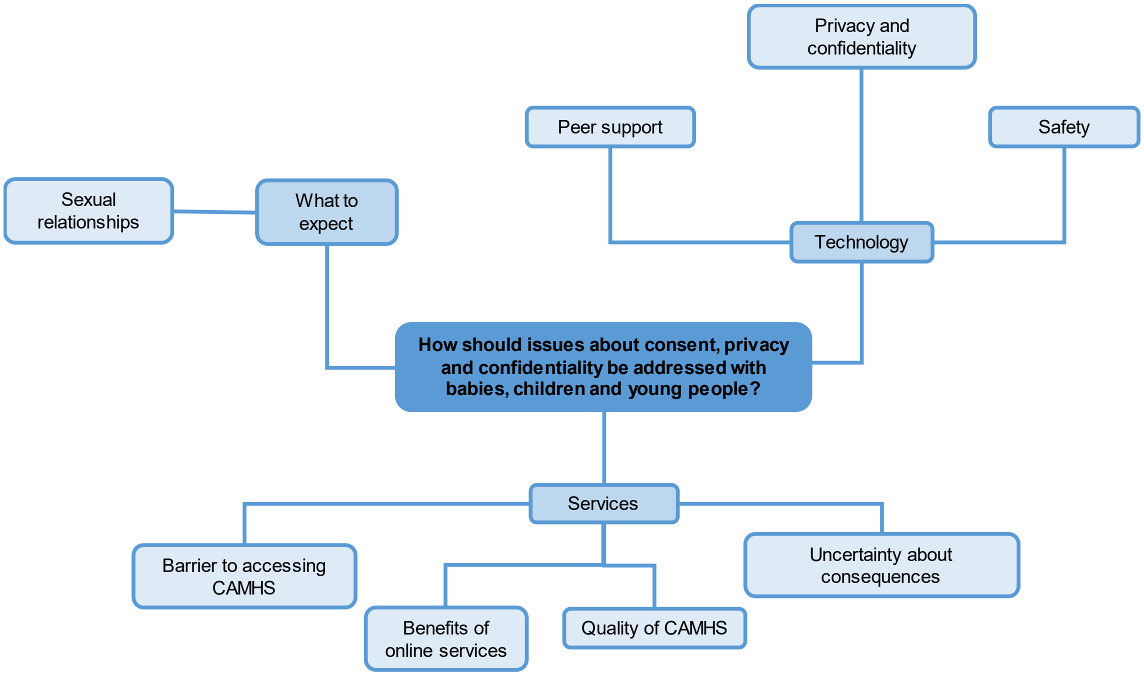
- Understanding how children and young people, or the parents or carers of babies and very young children prefer discussions about privacy and confidentiality to be addressed by healthcare services and healthcare providers
- Understanding the views and preferences of children and young people, or the parents or carers of babies and very young children regarding discussions about consent

A systematic review of the literature was conducted using a combined search. Five studies were included in this review; 4 were qualitative studies (Ali 2017, Babbage 2018, Sullivan 2020, and Svirydzenka 2017) and 1 used a mixed-methods study design (Edbrooke-Childs 2019). Of the 4 qualitative studies, 3 conducted semi-structured interviews and 1 conducted a focus group. All studies were conducted in the UK.

The included studies are summarised in Table 2.

The data from the included studies were synthesised and explored in a number of central themes and sub-themes (as shown in Figure 1). Main themes are shown in dark blue, and sub-themes in pale blue.

Figure 1: Theme map



CAMHS: Child and Adolescent Mental Health Services

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

Summary of studies included in the evidence review

Summaries of the studies that were included in this review are presented in Table 2.

Table 2: Summary of included studies

Study	Population	Methods	Themes
Ali 2017 **Study design** Focus group **Aim of the study** To explore young Pakistani's views of barriers and facilitators to accessing mental health services and to suggest actions to improve access to them.	N=33 children and young people **Characteristics** Age (range): 11-19 • It was not possible to establish how many participants were ≥18 years old. Themes have been downgraded for relevance where applicable. Gender (M/F): 17/16	**Recruitment** Via personal communication from local schools, madrasas (Islamic religious education institutions) or youth groups **Data collection** Single-sex focus groups, facilitated by a discussion guide **Analysis** Framework analysis. Themes developed themes through group consensus	• Services: Barriers to accessing CAMHS

Study	Population	Methods	Themes
Peterborough, UK			
Babbage 2018 **Study design** Semi-structured interview **Aim of the study** To examine what features of a self-management digital tool for well-being are prioritised by young people. Nottinghamshire, UK	N=14 young people **Characteristics** Age (mean; range): 14.6 years; 12-18 years Gender (M/F): 11/3	**Recruitment** Community recruitment using social media, digital forums, leaders of local youth groups, schools and study participation registers **Data collection** Semi-structured interviews with open-ended questions used initially, with follow-up prompts for specific detail if needed **Analysis** Inductive theme analysis. One researcher generated initial codes. Themes and sub-themes defined with two other researchers	• Technology: Peer support • Technology: Privacy and confidentiality • Technology: Safety
Edbrooke-Childs 2019 **Study design** Mixed-methods including semi-structured interview **Aim of the study** To determine the effectiveness, usage and acceptability of a new smartphone/ tablet app, Power Up. England, UK	N=11 children and young people **Characteristics** Age (mean; range): 15.6 years; 11-17 Gender (M/F): not reported	**Recruitment** Initial recruitment for parent RCT from 5 CAMHS and 6 schools**.** Participants from this trial invited for interview **Data collection** Post-RCT short semi-structured interviews covering participant's experiences of using 'Power Up', a new mobile app **Analysis** Thematic analysis using NVivo	• Technology: Peer support • Technology: Privacy and confidentiality • Technology: Safety
Sullivan 2020 **Study design** Semi-structured interview + co-produced workshop	*Semi-structured interviews* N=2 young people (+ N=2 safeguarding experts) *Co-produced workshops* N=7 young people (+ N=9 key stakeholders)	**Recruitment** Representatives from recruited local support organisations recruited appropriate young people **Data collection**	• What to expect: Sexual relationships • Services: Uncertainty about consequences

Study	Population	Methods	Themes
Aim of the study To identify factors that will encourage users of online sexual health services to disclose safeguarding concerns and facilitate appropriate responses. London, UK	**Characteristics** *Semi-structured interviews* Age (range): 16-21 years Gender (M/F): 0/2 *Co-produced workshops* Age (mean; range): 17 years; 16-18 years Gender (M/F): 6/1 • Only the views of young people were included o It was not possible to establish how many participants were ≥18 years old. o Themes have been downgraded for relevance where applicable.	Semi-structured interview using case studies to facilitate discussion; co-produced workshop with young people and key stakeholders **Analysis** Thematic (framework) approach with three researchers involved in 3 rounds of coding	• Technology: Privacy and confidentiality
Svirydzenka 2017 **Study design** Semi-structured interview **Aim of the study** To explore key stakeholder's - children/adolescents, treatment providers, and NHS commissioners - views on CAMHS services and ways of improving their quality. UK	N=3 children/adolescents **Characteristics** Age: not reported Gender (M/F): not reported	**Recruitment** Purposive sampling from CAMHS database of recently discharged patients **Data collection** Semi-structured interviews focusing on quality meaning within CAMHS, and barriers to implementation **Analysis** Thematic analysis. Multiple researchers analysed data, and inter-rater reliability ensured	• Services: Quality of CAMHS

CAMHS: Child and Adolescent Mental Health Service; F: female; M: male; N: number; RCT: randomised controlled trial

See the full evidence tables in appendix D. No meta-analysis was conducted (and so there are no forest plots in appendix E).

Quality assessment of studies included in the evidence review

A summary of the strength of evidence (overall confidence), assessed using GRADE-CERQual is presented according to the main themes. For each of the sub-themes the overall confidence was judged to be:

Main theme 1: What to expect

- Sub-theme 1.1: Sexual relationships. The overall confidence in this theme was judged to be very low.

Main theme 2: Services

- Sub-theme 2.1: Barriers to accessing Child and Adolescent Mental Health Service (CAMHS). The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.2: Benefits of using online services. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.3: Quality of CAMHS. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 2.4: Uncertainty about consequences. The overall confidence in this sub-theme was judged to be very low.

Main theme 3: Technology

- Sub-theme 3.1: Peer support. The overall confidence in this sub-theme was judged to be low.
- Sub-theme 3.2: Privacy and confidentiality. The overall confidence in this sub-theme was judged to be very low.
- Sub-theme 3.3: Safety. The overall confidence in this sub-theme was judged to be low.

Findings from the studies are summarised in GRADE-CERQual tables. See the evidence profiles in appendix F.

Evidence from reference groups and focus groups

The children and young people's reference groups and focus groups provided additional evidence for this review. A summary of the findings is presented in Table 3.

Table 3: Summary of the evidence from reference groups and focus groups

Age groups	• <7 years • 7-11 years • 11-14 years
Areas covered	• Meaning of consent, privacy and confidentiality • With whom to discuss confidentiality and privacy • Who would you like to be present when discussing confidentiality
Illustrative quotes	• Meaning of consent: ○ 'Asking for permission' ○ 'Something personal' • 'I want my parents or someone to be with me' • 'If it was private, I would not want anybody to know because it is a secret' • 'I can make up my own mind' • Who would you like in the room with you?: - [parent/guardian] 'To help you understand and relax a bit so it's a bit more comfortable with your parent in the room'

	- [just myself] 'Definitely I would rather be by myself but I'm not sure if I could as there is a requirement not to be on your own if you are under 16 I think'

See the full evidence summary in appendix M.

Evidence from national surveys

The grey literature review of national surveys of children and young people's experience provided additional evidence for this review. A summary of the findings is presented in Table 4.

Table 4: Summary of the evidence from national surveys

National surveys	• Care Quality Commission. Children and young people's inpatient and day case survey 2018 • National Children's Bureau. Listening to children's views on health provision 2012 • Picker Institute/NHS England/Bliss. Neonatal Survey 2014
Areas covered	• Privacy provision • Privacy and ethnic minority groups
Key findings	• Parents and carers of babies (including those in the neonatal unit), children and young people felt they were given sufficient privacy • People from a range of ethnic backgrounds reported reduced trust in the confidentiality of mental healthcare services, and this might mean they were less likely to access these services

See the full evidence summary in appendix N.

Economic evidence

Included studies

A systematic review of the economic literature was conducted but no studies were identified which were applicable to this review question. A single economic search was undertaken for all topics included in the scope of this guideline. See supplementary material 6 for details

Excluded studies

Economic studies not included in this review are listed, and reasons for their exclusion are provided in appendix K.

Summary of studies included in the economic evidence review

No studies were identified which were applicable to this review question.

Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

The committee’s discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The aim of this review was to identify how to address issues about consent, privacy and confidentiality with children and young people, and with the parents or carers of babies and young children. To address this, the review was qualitative and as a result the committee could not specify in advance the data that would be identified. Instead they identified the following main themes to guide the review, although the list was not intended to be exhaustive:

- Availability of areas that enable privacy or provision of alternative measures to allow this (e.g. headphones on neonatal ward rounds)
- Difference between consent and assent
- Establishing that child or young person understands legal issues or their rights
- Knowledge of child’s or young person’s attitude to confidentiality, privacy, and consent
- Knowledge and understanding of what child or young person is legally entitled to or has the right to do (e.g.
- Knowledge and understanding of when information can be shared (e.g. with parents)
- Prior promotion of rights to, or respect for, privacy and confidentiality
- Provision of or access to age-appropriate information
- Reflection by staff on their own attitudes towards confidentiality, privacy and consent

The themes that were identified from the data were: what to expect regarding (especially about sexual relationships); barriers to accessing, and benefits of using and knowing about, services; and the use of technology (e.g. mobile phone applications) and related issues regarding how their data can be used (e.g. privacy and confidentiality). The committee did not prioritise any of these outcomes and considered all of them when writing their recommendations.

The quality of the evidence

The quality of the evidence for this review was assessed using GRADE-CERQual. The quality of the methodology of the individual studies was assessed using the Critical Appraisal Skills Programme (CASP) checklist.

The quality of included review findings ranged from very low to low and no study was directly relevant to the review question. All sub-themes were downgraded in all areas of quality assessment. Methodological limitations of the included studies lowered the quality assessment mainly due to concerns about how data analysis was conducted. The evidence was also downgraded for coherence as there were few studies for each sub-theme and the evidence supporting them was at best only reasonably compelling. The evidence was also downgraded due to relevance as none of the studies were directly relevant to the review question. Two studies also included young people over 18-years old and neither study reported sufficient information to determine the number of such participants (Ali 2017, Sullivan 2020).

The committee also noted that the evidence came from a limited number of settings (e.g. CAMHS, digital healthcare), but that there was evidence relating to mental health services, physical health services, digital health services, and also from a minority ethnic group.

Finally, the evidence was downgraded for adequacy because the studies taken together for each sub-theme only provided small amounts of data.

In addition to the small amount of evidence from the systematic review, the committee considered some evidence from the focus and reference groups and from the review of national surveys, as well as using their knowledge and experience when drafting the recommendations.

Benefits and harms

Before reviewing the evidence, the committee agreed that discussions about consent, privacy and confidentiality should be held directly with children and young people as soon as they were able to understand these concepts, and not by default with their parents or carers, and so made a recommendation to this effect. The committee discussed the fact that children and young people have the right to consent to (or refuse) treatment, and have rights to privacy and confidentiality. These rights are defined in the NHS Constitution and the United Nations Convention on the Rights of the Child (UNCRC), but the committee agreed that children and young people were not always aware of their rights. They therefore made an over-arching recommendation to ensure that children and young people were informed of their rights. The committee were also aware of guidance from national regulators such as the General Medical Council and the Nursing and Midwifery Council which put a responsibility on healthcare professionals to adhere to certain standards relating to consent, privacy and confidentiality, and so the committee included this in an over-arching recommendation.

None of the systematic review evidence related specifically to consent, but the committee agreed, based on their experience, that all children and young people should be involved as much as possible in decisions about their care, and be supported to make their own consent decisions, where they had the capacity to do so. The committee discussed how different children will have different levels of understanding of their care and treatment, for example the age, and/or developmental stage of the child can influence their level of understanding, and this should be considered by the person discussing consent with them.

The committee discussed that sometimes treatment was required and consent (or assent) could not be obtained (for example emergency treatment, or treatment where children were at risk), but in these situations, it was still necessary to provide as much information and support as possible to the child or young person.

The committee discussed when there is a difference of opinion related to a healthcare situation that requires consent to be given. This difference of opinion could be between a child or young person and their parents or carers, or between the child and young person (or the parents or carers on behalf of a baby or young child), and healthcare professionals. The committee found it difficult to make specific recommendations about this situation, as there are often many factors to take into consideration (such as the severity of the condition, the age of the child, the balance of risks and benefits of the treatment options), but agreed that the key requirement was that families had access to independent advice and support to help resolve the situation, and so this is what they included in their recommendation.

The committee agreed it was important to have a separate recommendation on checking understanding and revisiting consent decisions. The committee discussed that as treatment progresses, and as the child's opinion or ability to consent may change over time, it was important that consent is revisited, especially after any changes in care.

For the topics of privacy and confidentiality, the committee discussed how the themes that had been identified could inform their recommendations, but also agreed that as the right to privacy was in the NHS Constitution it would be useful to reiterate this in a recommendation. The committee adapted the wording from the NHS constitution to include privacy during discussions, examination and care. The committee made an additional recommendation about methods to ensure confidentiality, which included the use of private spaces for conversations.

The systematic review evidence presented included three main themes relating to privacy and confidentiality: what to expect (sub-themes: sexual relationships), services (sub-themes: quality, barriers to access) and technology (sub-themes: peer support, safety, privacy and confidentiality).

The evidence on technology showed that children are very aware of the risks to their privacy when technology is used, but also showed that children and young people think technology can be an important tool, for example, to allow peer support and sharing of experiences. There were some instances where children and young people thought that information on electronic applications should be private, but also recognised that in some instances for their own safety it may be necessary for information to be shared with their parents. The committee discussed how it is important that the same level of privacy and confidentiality is considered when information is collected or provided digitally as well as face to face, and made a recommendation to highlight that when using digital or virtual methods for consultations or discussions, children and young people should confirm that they are able to talk freely and are in a private space if needed.

The evidence theme on services identified that some children see that a service that keeps information anonymous or confidential is a measure of a good quality service. Children also expressed the view that involvement of their family in discussions about their health and wellbeing may vary depending on what aspect of healthcare was being discussed.

Based on the evidence and their own experience and expertise, the committee recommended that healthcare information should be kept private and confidential, but that confidentiality could not be maintained in certain circumstances (such as safeguarding concerns), and that ensuring the child or young person is fully informed is crucial. The committee also used the evidence on the involvement of family members to make a recommendation that children and young people should be offered the opportunity to see a healthcare professional without their parents or carers, or with another adult or peer, if they wish to. The committee noted that for some children and young people with communication difficulties, and who usually relied on their parents or carers for support with communication, it would be necessary to make special arrangements to ensure these children and young people could have private conversations without their parents or carers present, and so the committee specified this in a recommendation.

The committee also reviewed the evidence from the focus and reference groups relating to issues of consent, privacy and confidentiality. There was very limited evidence from the 4-7 year olds that they wanted to be asked before things were ‘done to them’. Across the older groups, there was limited understanding on the meaning of consent, privacy and in particular of confidentiality, and the committee agreed that this reinforced their recommendations that these issues should be explained to children in language they could understand. There were mixed views on whether it was better to discuss private issues with the doctor alone, or with parents or carers present, although most children and young people seemed to think that parents or carers could be useful and supportive when discussing sensitive matters, or could help explain things. The committee agreed that these comments were covered under their recommendations as these allowed for the option for children or young people to be seen with or without their parents or carers.

The national surveys had identified that young people were positive about having the opportunity to talk to a doctor or nurse without their parent or carer being present if they wanted to, which was one of the recommendations that had been made by the committee, and that most agreed that they had enough privacy when receiving care and treatment. The committee noted that young people from a range of ethnic backgrounds had reported reduced trust in the confidentiality of mental healthcare services, and this might mean they were less likely to access these services. However, this was only one of the factors mentioned by the young people (others were trust in the person, a good relationship and feeling at ease, safe and understood). The committee noted that the recommendations on privacy and confidentiality already included the fact that cultural sensitivities should be taken into account, and the recommendations on communication by healthcare staff covered building trust, putting people at ease and communicating with cultural sensitivity. The committee therefore decided not to make an additional recommendation based on the results of this survey.

Finally, the surveys reported that parents of babies on neonatal units reported that they valued privacy when discussing their baby's care with staff and when breastfeeding or expressing milk. The committee noted that recommendations about privacy for breastfeeding and expressing milk were already covered by the NICE guideline on postnatal care.

The committee discussed the potential harms relating to consent, and noted that it was sometimes unclear who was responsible for obtaining consent, and that sometimes determining who undertakes this (providing the necessary information to the child or young person and discussing consent) may lead to delays. The committee also discussed that healthcare professionals require adequate training to ensure discussions around consent were carried out to a high standard. The committee discussed that fully informing children and young people of risks and benefits as part of obtaining consent may increase their anxiety, and agreed that children, young people or their parents should not be overburdened with information, but given information at an appropriate time and pace, and their understanding of key points checked.

The committee identified some potential harms relating to issues around privacy or confidentiality: children and young people may feel that being offered the opportunity to see a healthcare professional on their own means that this is what is expected of them, and that they may therefore feel pressured to be seen alone, even though they may prefer to have a parent or carer with them. The committee discussed that another possible harm from these recommendations was that a child or young person may request another adult to be present who may not be considered appropriate, and that safeguarding concerns should be considered in this instance

Cost effectiveness and resource use

There was no existing economic evidence for this review. The committee agreed that the recommendations could be adopted into routine practice, but there were potential costs to the health service as more time might be needed to allow discussions to take place concerning consent, privacy and confidentiality. The committee agreed that there may also be a need to consider the environment in which healthcare is delivered to provide privacy and ensure confidentiality. The committee expressed the view that any expense, which is likely to be modest, around consent and privacy is justifiable as this is central to the development of trust between doctors and children and young people, and such practices are a fundamental part of the UK's healthcare system.

Other factors the committee took into account

In addition to the rights of the child described above, the committee were aware that there is also legislation enacted by the General Data Protection Regulations (GDPR) which governs the collection and use of personal data.

Based on stakeholder feedback the committee clarified the rights of children and young people to make decisions about their healthcare and to consent to treatment. This information was contained with the professional guidance documents that the committee had cross-referred to in the section on the guideline on consent, but the stakeholders requested that the key principles be included in the guideline itself. The committee therefore added an additional over-arching recommendation at the beginning of the guideline to state that children and young people aged 16 or 17 years are entitled to make decisions about their own healthcare and to consent to or refuse treatment, and that those under 16 can do this if they are deemed by the healthcare professional to be Gillick competent. |The committee agreed that making judgements on the competence of children or young people in this way was part of the professional role of all healthcare professionals who worked with children and young people.

Recommendations supported by this evidence review

This evidence review supports recommendations 1.1.1, 1.1.3 and 1.4.1 to 1.4.14 in the NICE guideline.

References

Ali 2017

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Appendices

Appendix A – Review protocol

Review protocol for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Table 5: Review protocol

Field	**Content**
PROSPERO registration number	CRD42019152551
Review title	Talking about consent, privacy and confidentiality
Review question	How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?
Objective	To establish how healthcare issues about consent, privacy and confidentiality should be addressed with babies, children and young people.
Searches	The following databases will be searched: • CENTRAL • CDSR • Embase • MEDLINE • MEDLINE IN-Process • PsycINFO One broad, guideline-wide, search will be conducted for qualitative questions, capturing the population and the settings. A UK filter will be applied to identify relevant UK studies and a systematic review filter will be applied to the remainder of the results to identify relevant reviews that include evidence from non-UK high-income countries. If no systematic reviews of this type are identified, then a more focused search may be conducted to identify studies conducted in the following high-income countries: Australia, Austria, Belgium, Canada Denmark, Finland, France, Germany, Greece, Iceland, Ireland, Italy, Liechtenstein, Luxembourg, Malta, Monaco, Netherlands, New Zealand, Norway, Portugal, Spain, Sweden, Switzerland, and USA. Searches will be restricted by: • Date: 2009 • Language of publication: English language only

Field	Content
	• Publication status: Conference abstracts will be excluded because these do not typically provide sufficient information to fully assess risk of bias • Standard exclusions filter (animal studies/low level publication types) will be applied • For each search (including economic searches), the principal database search strategy is quality assured by a second information specialist using an adaption of the PRESS 2015 Guideline Evidence-Based Checklist
Condition or domain being studied	• Babies, children and young people's experience of healthcare
Population	• People <18 years-old who have experience of healthcare • Studies that use the views of parents or carers as proxies will be included only if they are responding on behalf of their child or charge, and o The baby or child of the parent or carer is under-5 years-old, or o There is a clear rationale provided as to why the study is using parents' or carers' views on and experiences of healthcare as proxies for their child. Note: Studies where part of the population is <18 years-old and part of the population is ≥18 years-old will only be included if it is clear that the themes are supported by evidence from the former group only.
Phenomenon of interest	Experience of healthcare, in particular of situations in which issues of consent, privacy, or confidentiality were appropriate
Comparator/Reference standard/Confounding factors	Not applicable
Types of study to be included	• Systematic reviews of qualitative studies • Studies using qualitative methods: focus groups, semi-structured and structured interviews, observations • Surveys conducted using open ended questions and a qualitative analysis of responses Note: Mixed methods studies will be included but only qualitative data will be extracted and risk of bias assessed. Systematic reviews that include evidence from both high- and non-high income countries, as defined by the World Bank, will only be included if the source of themes and evidence from high-income countries can be clearly established. Evidence from individual qualitative studies conducted in the high-income countries listed in the search strategy will be included only if no relevant systematic review evidence is identified.
Other exclusion criteria	STUDY DESIGN • Studies using quantitative methods only (including surveys that report only quantitative data) • Surveys using mainly closed questions or which quantify open ended answers for analysis TOPIC OF STUDY

Field	Content
	Studies on the following topics will also be excluded: • Discussions about consent, confidentiality and privacy with respect to non-NHS commissioned health promotion interventions • Non-NHS commission health promotion interventions • UK Law and legal protections relating to consent, privacy and confidentiality for babies, children and young people. This will include (but will not be limited to) Fraser competence, Mental Capacity Act 2005, and Child Abuse and Prevention Act 1974 • Views and experiences of healthcare professionals and service managers • Views and experiences of people reporting on shared decision making in the context of social care planning Studies that focus explicitly on the following topics rather than focussing on the views on and experiences of babies, children and young people in healthcare will be excluded as they are covered by the following NICE guidelines: • Child abuse and maltreatment: o Child abuse and neglect (NG76) o Child maltreatment: when to suspect maltreatment in under 18s (CG89) • Community engagement o Community engagement (NG44) • Drug misuse in children and young people: o Alcohol: school-based interventions (PH7) o Alcohol-use disorders: diagnosis, assessment and management of harmful drinking and alcohol dependence (CG115) o Alcohol-use disorders: prevention (PH24) o Drug misuse prevention: targeted interventions (NG64) • End of life care for infants, children and young people with life-limiting conditions: planning and management (NG61) • Immunisations: reducing differences in uptake in under 19s (PH21) • Oral health promotion: general dental practice (NG30) • Physical activity and weight management: o Maternal and child nutrition (PH11) o Obesity prevention (CG43) o Physical activity for children and young people (PH17) o Weight management: lifestyle services for overweight or obese children and young people (PH47) • Pregnancy, including routine antenatal, intrapartum or postnatal care:

Field	Content
	○ Antenatal and postnatal mental health: clinical management and service guidance (CG192) ○ Antenatal care for uncomplicated pregnancies (CG62) ○ Intrapartum care for healthy women and babies (CG190) ○ Intrapartum care for women with existing medical conditions or obstetric complications and their babies (NG121) ○ Multiple pregnancy: antenatal care for twin and triplet pregnancies (CG129) ○ Postnatal care up to 8 weeks after birth (CG37) ○ Pregnancy and complex social factors: a model for service provision for pregnant women with complex social factors (CG110) • Self-harm: ○ Self-harm in over 8s: long-term management (CG133) ○ Self-harm in over 8s: short-term management and prevention of recurrence (CG16) • Sexual health and contraception ○ Contraceptive services for under 25s (PH51) ○ Sexually transmitted infections and under-18 conceptions: prevention (PH3) ○ Harmful sexual behaviour among children and young people (NG55) • Smoking prevention: ○ Smoking: preventing uptake in children and young people (PH14) ○ Smoking prevention in schools (PH23) ○ Stop smoking interventions and services (NG92) • Transition from children's to adult's services for young people using health or social care services (NG43)
Context	UK studies from 2009 onwards will be prioritised for decision making by the committee as those conducted in other countries may not be representative of current expectations about either services or current attitudes and behaviours of healthcare professionals. The committee presumes that due to their development, particular circumstances and/or condition, there are some topics that babies, children and young people may not be in a position to pronounce on, and that in these circumstances, it may be necessary to treat the 'indirect' views of their parents or carers as proxies for their own views on and experiences of healthcare in order to make recommendations. The guideline committee will be consulted on whether a study should be included if it is unclear why parents' or carer's views are being reported instead of their child or charge, and reasons for exclusion if appropriate will be documented. The topic about which the babies, children and young people are talking about should be generalizable to the wider healthcare context (e.g. a study on the views on and experience of communication with healthcare professionals whilst receiving chemotherapy would be included, whilst a study on experience of chemotherapy would be too narrow and not generalizable to wider healthcare context and therefore excluded). Recommendations will apply to those receiving care in all settings where NHS- or local authority- commissioned healthcare is provided (including home, school,

Field	Content
	community, hospital, specialist and transport settings). Specific recommendations for groups listed in the Equality Considerations section of the scope may be also be made as appropriate.
Primary outcomes (critical outcomes)	Themes will be identified from the literature. The committee identified the following potential themes (however, not all of these themes may be found in the literature, and additional themes may be identified): • Availability of areas that enable privacy or provision of alternative measures to allow this (e.g. headphones on neonatal ward rounds) • Difference between consent and assent • Establishing that child or young person understands legal issues or their rights • Knowledge of child's or young person's attitude to confidentiality, privacy, and consent • Knowledge and understanding of what child or young person is legally entitled to or has the right to do (e.g. • Knowledge and understanding of when information can be shared (e.g. with parents) • Prior promotion of rights to, or respect for, privacy and confidentiality • Provision of or access to age-appropriate information • Reflection by staff on their own attitudes towards confidentiality, privacy and consent The following themes will not be covered by this review, despite relating to communication in healthcare: • Availability of information in different formats (reviewed in RQ 2.1) • Barriers to, and facilitators of, access to healthcare (reviewed in RQ 8.1) • Barriers to, and facilitators of, continuity of healthcare (reviewed in RQ 8.2) • Communication with healthcare staff (reviewed in RQ 1.2) • Involvement in health care and informed, shared decision making (reviewed in RQ 1.1) • Physical healthcare environment (reviewed in RQ 6.1)
Secondary outcomes (important outcomes)	Not applicable
Data extraction (selection and coding)	• All references identified by the searches and from other sources will be uploaded into STAR and de-duplicated. Titles and abstracts of the retrieved citations will be screened to identify studies that potentially meet the inclusion criteria outlined in the review protocol. • Duplicate screening will not be undertaken for this question. • Full versions of the selected studies will be obtained for assessment. Studies that fail to meet the inclusion criteria once the full version has been checked will be excluded at this stage. Each study excluded after checking the full version will be listed, along with the reason for its exclusion. A standardised form will be used to extract data from studies, including study reference, research question, theoretical approach, data collection and analysis methods used, participant characteristics, second-order themes, and relevant first-order themes (i.e. supporting quotes). One reviewer will extract relevant data into a standardised form, and this will be quality assessed by a senior reviewer.

Field	Content
Risk of bias (quality) assessment	Risk of bias of individual qualitative studies will be assessed using the CASP (Critical Skills Appraisal Programme) Qualitative checklist. Risk of bias of systematic reviews of Qualitative studies will be assessed using the CASP Systematic Review checklist. See Appendix H in Developing NICE guidelines: the manual for further details. The quality assessment will be performed by one reviewer and this will be quality assessed by a senior reviewer.
Strategy for data synthesis	• Extracted second-order study themes and related first-order quotes will be synthesised by the reviewer into third-order themes and related sub-themes. • The GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research; Lewin 2015) approach will be used to summarise the confidence in the third-order themes or sub-themes synthesised from the qualitative evidence. The overall confidence in evidence about each theme or sub-theme will be rated on four dimensions: methodological limitations, coherence, adequacy, and relevance. • Methodological limitations refer to the extent to which there were problems in the design or conduct of the studies and will be assessed with the CASP checklist for qualitative studies or systematic reviews as appropriate. Coherence of findings will be assessed by examining the clarity of the data. Adequacy of data will be assessed by looking at the degree of richness and quantity of findings. Relevance of evidence will be assessed by determining the extent to which the body of evidence from the primary studies are applicable to the context of the review question with respect to the characteristics of the study population, setting, place and time, healthcare system, intervention, and broader social, policy, or political issues.
Analysis of sub-groups	If there is sufficient data, views and experiences will be analysed separately by the following age ranges: • <1 year-old (i.e. 364 days-old or less) • ≥1 to <12 years-old (i.e. 365 days-old to 11 years and 364 days-old • ≥12 to <18 years-old (i.e. 12 years and 0 days-old to 17 years and 364 days-old) The committee are aware that children can experience substantial cognitive and developmental change during the ages of 1 and 12, and that there may be (though not necessarily) substantive differences between children in this group depending on the topic about which they are being asked. The committee will therefore be consulted regarding whether data regarding further subgroups within this age range (e.g. 1-5, 6-11) should be used. Subgroup analysis according to any of the groups listed in the Equality Considerations section of the scope will be conducted if there is sufficient data.
Type and method of review	☐ Intervention
	☐ Diagnostic
	☐ Prognostic
	☒ Qualitative
	☐ Epidemiologic
	☐ Service Delivery

Field	Content		
	☐	Other (please specify)	
Language	English		
Country	England		
Anticipated or actual start date	23 September 2019		
Anticipated completion date	07 April 2021		
Stage of review at time of this submission	Review stage	Started	Completed
	Preliminary searches	☐	☐
	Piloting of the study selection process	☐	☐
	Formal screening of search results against eligibility criteria	☐	☐
	Data extraction	☐	☐
	Risk of bias (quality) assessment	☐	☐
	Data analysis	☐	☐
Named contact	**5a. Named contact** National Guideline Alliance **5b. Named contact e-mail** Infant&younghealth@nice.org.uk **5e Organisational affiliation of the review** National Institute for Health and Care Excellence (NICE) and National Guideline Alliance		
Review team members	NGA Technical Team		
Funding sources/sponsor	This systematic review is being completed by the National Guideline Alliance, which receives funding from NICE.		
Conflicts of interest	All guideline committee members and anyone who has direct input into NICE guidelines (including the evidence review team and expert witnesses) must declare any potential conflicts of interest in line with NICE's code of practice for declaring and dealing with conflicts of interest. Any relevant interests, or changes to interests, will also be declared publicly at the start of each guideline committee meeting. Before each meeting, any potential conflicts of interest will be considered by the guideline committee Chair and a senior member of the development team. Any decisions to exclude a person from all or part of a meeting will be documented. Any changes to a member's declaration of interests will be recorded in the minutes of the meeting. Declarations of interests will be published with the final guideline.		

Field	**Content**
Collaborators	Development of this systematic review will be overseen by an advisory committee who will use the review to inform the development of evidence-based recommendations in line with section 3 of Developing NICE guidelines: the manual. Members of the guideline committee are available on the NICE website: https://www.nice.org.uk/guidance/indevelopment/gid-ng10119/documents
Other registration details	-
Reference/URL for published protocol	https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=152551
Dissemination plans	NICE may use a range of different methods to raise awareness of the guideline. These include standard approaches such as: • notifying registered stakeholders of publication • publicising the guideline through NICE's newsletter and alerts • issuing a press release or briefing as appropriate, posting news articles on the NICE website, using social media channels, and publicising the guideline within NICE.
Keywords	Babies; Children; Experience; Healthcare; Infants; Consent: Privacy: Confidentiality
Details of existing review of same topic by same authors	Not applicable
Current review status	☒ Ongoing ☐ Completed but not published ☐ Completed and published ☐ Completed, published and being updated ☐ Discontinued
Additional information	
Details of final publication	www.nice.org.uk

CASP: critical appraisal skills programme; CDSR: Cochrane database of systematic reviews; CENTRAL/CCTR: Cochrane central register of controlled trials; GRADE-CERQual: grading of recommendations assessment, development and evaluation – confidence in the evidence from reviews of qualitative research; NGA: National Guideline Alliance; NHS: National health service; NICE: National Institute for Health and Care Excellence; PRESS: peer review of electronic search strategies

Appendix B – Literature search strategies

Literature search strategies for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Databases: Embase/Medline/PsycINFO

Date searched: 29/07/2020

#	Searches
1	(ADOLESCENT/ or MINORS/) use ppez
2	exp ADOLESCENT/ use emez
3	(adolescen$ or teen$ or youth$ or young or juvenile? or minors or highschool$).ti,ab,jw,nw.
4	exp CHILD/
5	(child$ or schoolchild$ or "school age" or "school aged" or preschool$ or toddler$ or kid? or kindergar$ or boy? or girl?).ti,ab,jw,nw.
6	exp INFANT/
7	(infan$ or neonat$ or newborn$ or baby or babies).ti,ab,jw,nw.
8	exp PEDIATRICS/ or exp PUBERTY/
9	(p?ediatric$ or pubert$ or prepubert$ or pubescen$ or prepubescen$).ti,ab,jx,ec.
10	or/1-9
11	(Ambulance/ or Ambulance Transportation/ or Child Health Care/ or Community Care/ or Day Care/ or Dentist/ or Dental Facility/ or Pediatric Dentist/ or Dietitian/ or Emergency Care/ or Emergency Health Service/ or Emergency Ward/ or General Practice/ or Health Care/ or Health Care Delivery/ or Health Care Facility/ or Health Service/ or exp Home Care/ or Home Mental Health Care/ or Hospice/ or Hospice Care/ or exp Hospital/ or Hospital Care/ or Intensive Care Unit/ or Mental Health Care/ or Mental Health Service/ or Nursing Care/ or Newborn Care/ or Newborn Intensive Care/ or Neonatal Intensive Care Unit/ or Occupational Therapy/ or Ophthalmology/ or Orthodontics/ or Pediatric Intensive Care Unit/ or Pharmacy/ or exp Primary Health Care/ or Physiotherapy/ or Respite Care/ or School Health Nursing/ or exp School Health Service/ or Secondary Care Center/ or Secondary Health Care/ or "Speech and Language Rehabilitation"/ or Telemedicine/ or Tertiary Care Center/ or Tertiary Health Care/) use emez
12	(Ambulances/ or Adolescent Health Services/ or exp Child Health Services/ or Community Health Services/ or Community Pharmacy Services/ or Community Health Centers/ or Community Mental Health Centers/ or "Delivery of Health Care"/ or Dental Care for Children/ or exp Dental Health Services/ or Dentists/ or Dental Facilities/ or Emergency Medical Services/ or Emergency Service, Hospital/ or General Practice/ or Health Facilities/ or Health Services/ or Home Care Services/ or Home Care Services, Hospital-Based/ or Home Nursing/ or Hospice Care/ or Hospices/ or exp Hospitals/ or Intensive Care Units/ or Intensive Care Units, Pediatric/ or Intensive Care Units, Neonatal/ or exp Mental Health Services/ or Nutritionists/ or Occupational Therapy/ or Orthodontists/ or Pediatric Nursing/ or Pharmacies/ or Primary Health Care/ or Respite Care/ or exp School Health Services/ or School Nursing/ or Secondary Care/ or Telemedicine/ or Tertiary Healthcare/ or "Transportation of Patients"/) use ppez
13	(Adolescent Psychiatry/ or Community Health/ or Community Services/ or Dentists/ or Dental Health/ or Educational Psychology/ or Health Care Delivery/ or Health Care Services/ or Home Care/ or Home Visiting Programes/ or Hospice/ or exp Hospitals/ or Intensive Care/ or Language Therapy/ or exp Mental Health Services/ or Neonatal Intensive Care/ or Occupational Therapy/ or Outreach Programs/ or Pharmacy/ or Physical Therapy/ or Primary Health Care/ or Psychiatric Clinics/ or Psychiatric Units/ or Respite Care/ or Speech Therapy/ or Telemedicine/ or Telepsychiatry/ or Telepsychology/ or Walk In Clinics/) use psyh
14	(hospital patient/ or hospitalized adolescent/ or hospitalized child/ or hospitalized infant/ or hospitalization/ or hospital patient/ or outpatient/) use emez
15	(adolescent, hospitalized/ or child, hospitalized/ or Hospitalization/ or inpatients/ or outpatients/) use ppez
16	(hospitalized patients/ or exp hospitalization/ or outpatients/) use psyh
17	(hospital* or inpatient* or outpatient*).tw.
18	(health* adj3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)).tw.
19	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) adj3 (care or health*)).tw.
20	(emergency adj2 room*).tw.
21	(ambulance* or CAMHS or dentist* or dietics or dieti?ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach adj2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*).tw.
22	((virtual* or online) adj2 (physician* or clinician* or doctor*)).tw.
23	(communit* adj3 (p?ediatric* or nurs*)).tw.
24	(home adj3 visit*).tw.
25	((walk-in or "urgent care") adj2 (centre* or center* or clinic* or service*)).tw.

#	Searches
26	"speech and language therap*".tw.
27	general practice*.tw.
28	(health* and (nursery or nurseries or school*)).tw.
29	(respite adj2 care).tw.
30	(foster care or "looked after children" or "children in care").tw.
31	or/11-30
32	(Experience/ or personal experience/ or attitude to health/ or patient attitude/ or patient preference/ or patient satisfaction/) use emez
33	(attitude to death/ or patient advocacy/ or consumer advocacy/ or professional-patient relationship/) use emez
34	(adverse childhood experience/ or exp attitude to health/ or exp Patient satisfaction/) use ppez
35	(exp Consumer Participation/ or "Patient Acceptance of Health Care"/ or *exp consumer satisfaction/ or patient preference/ or Attitude to Death/ or health knowledge, attitudes, practice/ or Patient Advocacy/ or consumer advocacy/ or narration/ or focus groups/ or Patient-Centered Care/ or exp Professional-Patient Relations/) use ppez
36	(exp Client Attitudes/ or exp Client Satisfaction/ or exp Attitudes/ or exp Health Attitudes/ or exp Preferences/ or exp Client Satisfaction/ or exp Death Attitudes/ or exp Advocacy/ or exp Preferences/ or client centered therapy/) use psyh
37	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*).tw.
38	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) adj4 (decisi* or decid* or involv* or participat*)).tw.
39	("informed choice" or "shared decision making").tw.
40	empowerment.tw.
41	(patient-focused or patient-cent?red).tw.
42	(advocate or advocacy).tw.
43	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) adj2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)).ti,ab.
44	or/32-43
45	10 and 31 and 44
46	Qualitative Research/
47	exp interview/ use emez
48	interview/ use ppez
49	interviews/ use psyh
50	interview*.tw.
51	thematic analysis/ use emez
52	(theme$ or thematic).mp.
53	qualitative.af.
54	questionnaire$.mp.
55	ethnological research.mp.
56	ethnograph$.mp.
57	ethnonursing.af.
58	phenomenol$.af.
59	(life stor$ or women* stor$).mp.
60	(grounded adj (theor$ or study or studies or research or analys?s)).af.
61	((data adj1 saturat$) or participant observ$).tw.
62	(field adj (study or studies or research)).tw.
63	biographical method.tw.
64	theoretical sampl$.af.
65	((purpos$ adj4 sampl$) or (focus adj group$)).af.
66	open ended questionnaire/ use emez
67	(account or accounts or unstructured or openended or open ended or text$ or narrative$).mp.
68	(life world or life-world or conversation analys?s or personal experience$ or theoretical saturation).mp.
69	((lived or life) adj experience$).mp.
70	narrative analys?s.af.
71	or/46-70
72	45 and 71
73	limit 72 to (yr="2009 - current" and english language)
74	exp United Kingdom/

#	Searches
75	(national health service* or nhs*).ti,ab,in,ad,cq.
76	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) adj5 english)).ti,ab.
77	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*).ti,ab,jx,in,ad,cq.
78	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))).ti,ab,in,ad,cq.
79	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's").ti,ab,in,ad,cq.
80	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's").ti,ab,in,ad,cq.
81	(armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's").ti,ab,in,ad,cq.
82	or/74-81
83	((exp africa/ or exp americas/ or exp antarctic regions/ or exp arctic regions/ or exp asia/ or exp oceania/) not (exp united kingdom/ or europe/)) use ppez
84	((exp "arctic and antarctic"/ or exp oceanic regions/ or exp western hemisphere/ or exp africa/ or exp asia/ or exp "australia and new zealand"/) not (exp united kingdom/ or europe/)) use emez
85	83 or 84
86	82 not 85
87	73 and 86
88	Letter/ use ppez
89	letter.pt. or letter/ use emez
90	note.pt.
91	editorial.pt.
92	Editorial/ use ppez
93	News/ use ppez
94	news media/ use psyh
95	exp Historical Article/ use ppez
96	Anecdotes as Topic/ use ppez
97	Comment/ use ppez
98	Case Report/ use ppez
99	case report/ or case study/ use emez
100	Case report/ use psyh
101	(letter or comment*).ti.
102	or/88-101
103	randomized controlled trial/ use ppez
104	randomized controlled trial/ use emez
105	random*.ti,ab.
106	cohort studies/ use ppez
107	cohort analysis/ use emez
108	cohort analysis/ use psyh
109	case-control studies/ use ppez
110	case control study/ use emez
111	or/103-110

#	Searches
112	102 not 111
113	animals/ not humans/ use ppez
114	animal/ not human/ use emez
115	nonhuman/ use emez
116	"primates (nonhuman)"/
117	exp Animals, Laboratory/ use ppez
118	exp Animal Experimentation/ use ppez
119	exp Animal Experiment/ use emez
120	exp Experimental Animal/ use emez
121	animal research/ use psyh
122	exp Models, Animal/ use ppez
123	animal model/ use emez
124	animal models/ use psyh
125	exp Rodentia/ use ppez
126	exp Rodent/ use emez
127	rodents/ use psyh
128	(rat or rats or mouse or mice).ti.
129	or/112-128
130	87 not 129
131	meta-analysis/
132	meta-analysis as topic/
133	systematic review/
134	meta-analysis/
135	(meta analy* or metanaly* or metaanaly*).ti,ab.
136	((systematic or evidence) adj2 (review* or overview*)).ti,ab.
137	((systematic* or evidence*) adj2 (review* or overview*)).ti,ab.
138	(reference list* or bibliograph* or hand search* or manual search* or relevant journals).ab.
139	(search strategy or search criteria or systematic search or study selection or data extraction).ab.
140	(search* adj4 literature).ab.
141	(medline or pubmed or cochrane or embase or psychlit or psyclit or psychinfo or psycinfo or cinahl or science citation index or bids or cancerlit).ab.
142	cochrane.jw.
143	((pool* or combined) adj2 (data or trials or studies or results)).ab.
144	((comprehensive* or integrative or systematic*) adj3 (bibliographic* or review* or literature)).ti,ab,id.
145	(meta-analy* or metaanaly* or "research synthesis").ti,ab,id.
146	(((information or data) adj3 synthesis) or (data adj2 extract*)).ti,ab,id.
147	(review adj5 (rationale or evidence)).ti,ab,id. and "Literature Review".md.
148	(cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or pubmed or scopus or "sociological abstracts" or "web of science").ab.
149	("systematic review" or "meta analysis").md.
150	(or/131-132,135,137-142) use ppez
151	(or/133-136,138-143) use emez
152	(or/144-149) use psyh
153	150 or 151 or 152
154	73 and 153
155	154 not 130
156	155 not 129

Database: Cochrane Library

Date searched: 29/07/2020

#	Search
1	MeSH descriptor: [Adolescent] this term only
2	MeSH descriptor: [Minors] this term only

#	Search
3	(adolescen* or teen* or youth* or young or juvenile* or minors or highschool*):ti,ab,kw
4	MeSH descriptor: [Child] explode all trees
5	(child* or schoolchild* or "school age" or "school aged" or preschool* or toddler* or kid* or kindergar* or boy* or girl*):ti,ab,kw
6	MeSH descriptor: [Infant] explode all trees
7	(infan* or neonat* or newborn* or baby or babies):ti,ab,kw
8	MeSH descriptor: [Pediatrics] explode all trees
9	MeSH descriptor: [Puberty] explode all trees
10	(p*ediatric* or pubert* or prepubert* or pubescen* or prepubescen*):ti,ab,kw
11	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10
12	MeSH descriptor: [Ambulances] this term only
13	MeSH descriptor: [Adolescent Health Services] this term only
14	MeSH descriptor: [Child Health Services] explode all trees
15	MeSH descriptor: [Community Health Services] this term only
16	MeSH descriptor: [Community Pharmacy Services] this term only
17	MeSH descriptor: [Community Health Centers] this term only
18	MeSH descriptor: [Community Mental Health Centers] this term only
19	MeSH descriptor: [Delivery of Health Care] this term only
20	MeSH descriptor: [Dental Care for Children] this term only
21	MeSH descriptor: [Dental Health Services] explode all trees
22	MeSH descriptor: [Dentists] this term only
23	MeSH descriptor: [Dental Facilities] this term only
24	MeSH descriptor: [Emergency Medical Services] this term only
25	MeSH descriptor: [Emergency Service, Hospital] this term only
26	MeSH descriptor: [General Practice] this term only
27	MeSH descriptor: [Health Facilities] this term only
28	MeSH descriptor: [Health Services] this term only
29	MeSH descriptor: [Home Care Services] this term only
30	MeSH descriptor: [Home Care Services, Hospital-Based] this term only
31	MeSH descriptor: [Home Nursing] this term only
32	MeSH descriptor: [Hospice Care] this term only
33	MeSH descriptor: [Hospices] this term only
34	MeSH descriptor: [Hospitals] explode all trees
35	MeSH descriptor: [Intensive Care Units] this term only
36	MeSH descriptor: [Intensive Care Units, Pediatric] this term only
37	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
38	MeSH descriptor: [Mental Health Services] explode all trees
39	MeSH descriptor: [Nutritionists] this term only
40	MeSH descriptor: [Occupational Therapy] this term only
41	MeSH descriptor: [Orthodontists] this term only
42	MeSH descriptor: [Pediatric Nursing] this term only
43	MeSH descriptor: [Pharmacies] this term only
44	MeSH descriptor: [Primary Health Care] this term only
45	MeSH descriptor: [Respite Care] this term only
46	MeSH descriptor: [School Health Services] explode all trees
47	MeSH descriptor: [School Nursing] this term only
48	MeSH descriptor: [Secondary Care] this term only
49	MeSH descriptor: [Telemedicine] this term only
50	MeSH descriptor: [Tertiary Healthcare] this term only
51	MeSH descriptor: [Transportation of Patients] this term only
52	MeSH descriptor: [Adolescent, Hospitalized] this term only
53	MeSH descriptor: [Child, Hospitalized] this term only
54	MeSH descriptor: [Hospitalization] this term only
55	MeSH descriptor: [Inpatients] this term only
56	MeSH descriptor: [Outpatients] this term only

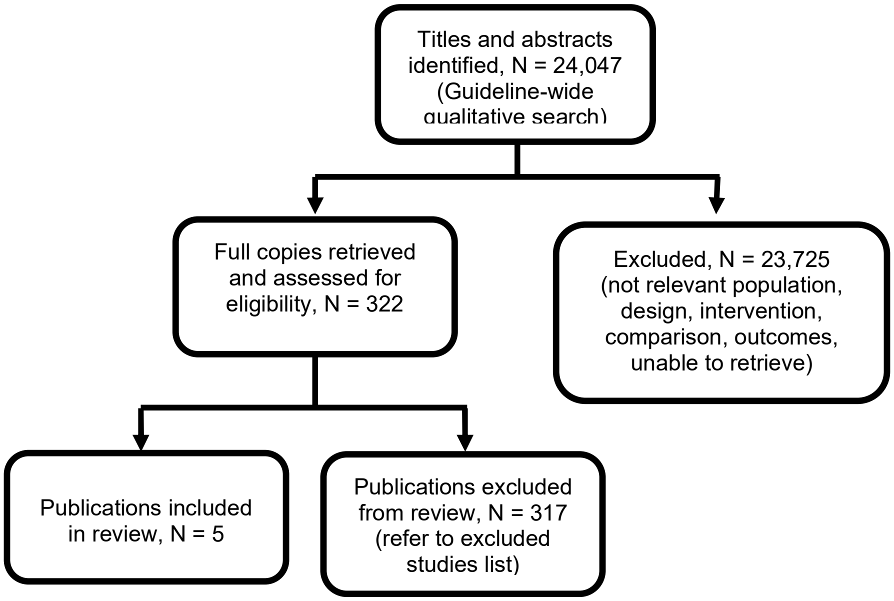
#	Search
57	(hospital* or inpatient* or outpatient*):ti,ab,kw
58	(health* near/3 (care or center* or centre* or clinic* or facility or facilities or service* or setting* or specialist*)):ti,ab,kw
59	((dental or communit* or emergency or hospital* or home or intensive or high-dependen* or mental* or primary or secondary or tertiary) near/3 (care or health*)):ti,ab,kw
60	(emergency near/2 room*):ti,ab,kw
61	(ambulance* or CAMHS or dentist* or dietics or dieti*ian or hospice* or NICU or nutritionist* or orthodont* or ophthalmolog* or (outreach near/2 team*) or pharmacy or pharmacies or physio* or SCBU or SENCO or telemedicine*):ti,ab,kw
62	((virtual* or online) near/2 (physician* or clinician* or doctor*)):ti,ab,kw
63	(communit* near/3 (p*ediatric* or nurs*)):ti,ab,kw
64	(home near/3 visit*):ti,ab,kw
65	((walk-in or "urgent care") near/2 (centre* or center* or clinic* or service*)):ti,ab,kw
66	("speech and language therap*"):ti,ab,kw
67	(general practice*):ti,ab,kw
68	(health* and (nursery or nurseries or school*)):ti,ab,kw
69	(respite near/2 care):ti,ab,kw
70	(foster care or "looked after children" or "children in care"):ti,ab,kw
71	#12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54 OR #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66 OR #67 OR #68 OR #69 OR #70
72	MeSH descriptor: [Adverse Childhood Experiences] this term only
73	MeSH descriptor: [Attitude to Health] explode all trees
74	MeSH descriptor: [Patient Satisfaction] explode all trees
75	MeSH descriptor: [Community Participation] explode all trees
76	MeSH descriptor: [Patient Acceptance of Health Care] this term only
77	MeSH descriptor: [Patient Preference] this term only
78	MeSH descriptor: [Attitude to Death] this term only
79	MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
80	MeSH descriptor: [Patient Advocacy] this term only
81	MeSH descriptor: [Consumer Advocacy] this term only
82	MeSH descriptor: [Narration] this term only
83	MeSH descriptor: [Focus Groups] this term only
84	MeSH descriptor: [Professional-Patient Relations] explode all trees
85	(attitude* or choice* or dissatisf* or expectation* or experienc* or inform* or opinion* or perceive* or perception* or perspective* or preferen* or priorit* or satisf* or thought* or view*):ti,ab,kw
86	((adolescen* or baby or babies or child* or infant* or patient* or teen* or young person*) near/4 (decisi* or decid* or involv* or participat*)):ti,ab,kw
87	("informed choice" or "shared decision making"):ti,ab,kw
88	(empowerment):ti,ab,kw
89	(patient-focused or patient-cent*red):ti,ab,kw
90	(advocate or advocacy):ti,ab,kw
91	((aversion or barrier* or facilitat* or hinder* or obstacle* or obstruct*) near/2 (care or health* or intervention* or pathway* or program* or service* or therap* or treat*)):ti,ab,kw
92	#72 OR #73 OR #74 OR #75 OR #76 OR #77 OR #78 OR #79 OR #80 OR #81 OR #82 OR #83 OR #84 OR #85 OR #86 OR #87 OR #88 OR #89 OR #90 OR #91
93	MeSH descriptor: [Qualitative Research] this term only
94	MeSH descriptor: [Interview] this term only
95	(interview*):ti,ab,kw
96	(theme* or thematic):ti,ab,kw
97	(qualitative):ti,ab,kw
98	(questionnaire*):ti,ab,kw
99	(ethnological research):ti,ab,kw
100	(ethnograph*):ti,ab,kw
101	(ethnonursing):ti,ab,kw
102	(phenomenol*):ti,ab,kw
103	(life stor* or women* stor*):ti,ab,kw

#	Search
104	(grounded near (theor* or study or studies or research or analys*s)):ti,ab,kw
105	((data near/1 saturat*) or participant observ*):ti,ab,kw
106	(field near (study or studies or research)):ti,ab,kw
107	(biographical method):ti,ab,kw
108	(theoretical sampl*):ti,ab,kw
109	((purpos* near/4 samp**) or (focus near group*)):ti,ab,kw
110	(account or accounts or unstructured or openended or open ended or text* or narrative*):ti,ab,kw
111	(life world or life-world or conversation analys*s or personal experience* or theoretical saturation):ti,ab,kw
112	((lived or life) near experience*):ti,ab,kw
113	(narrative analys*s):ti,ab,kw
114	#93 OR #94 OR #95 OR #96 OR #97 OR #98 OR #99 OR #100 OR #101 OR #102 OR #103 OR #104 OR #105 OR #106 OR #107 OR #108 OR #109 OR #110 OR #111 OR #112 OR #113
115	#11 AND #71 AND #92 AND #114 with Cochrane Library publication date Between Jan 2009 and Aug 2020
116	MeSH descriptor: [United Kingdom] explode all trees
117	(national health service* or nhs*):ti,ab,kw
118	(english not ((published or publication* or translat* or written or language* or speak* or literature or citation*) near/5 english)):ti,ab,kw
119	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):ti,ab,kw
120	(gb or "g.b." or britain* or (british* not "british columbia") or uk or "u.k." or united kingdom* or (england* not "new england") or northern ireland* or northern irish* or scotland* or scottish* or ((wales or "south wales") not "new south wales") or welsh*):so
121	(bath or "bath's" or ((birmingham not alabama*) or ("birmingham's" not alabama*) or bradford or "bradford's" or brighton or "brighton's" or bristol or "bristol's" or carlisle* or "carlisle's" or (cambridge not (massachusetts* or boston* or harvard*)) or ("cambridge's" not (massachusetts* or boston* or harvard*)) or (canterbury not zealand*) or ("canterbury's" not zealand*) or chelmsford or "chelmsford's" or chester or "chester's" or chichester or "chichester's" or coventry or "coventry's" or derby or "derby's" or (durham not (carolina* or nc)) or ("durham's" not (carolina* or nc)) or ely or "ely's" or exeter or "exeter's" or gloucester or "gloucester's" or hereford or "hereford's" or hull or "hull's" or lancaster or "lancaster's" or leeds* or leicester or "leicester's" or (lincoln not nebraska*) or ("lincoln's" not nebraska*) or (liverpool not (new south wales* or nsw)) or ("liverpool's" not (new south wales* or nsw)) or ((london not (ontario* or ont or toronto*)) or ("london's" not (ontario* or ont or toronto*)) or manchester or "manchester's" or (newcastle not (new south wales* or nsw)) or ("newcastle's" not (new south wales* or nsw)) or norwich or "norwich's" or nottingham or "nottingham's" or oxford or "oxford's" or peterborough or "peterborough's" or plymouth or "plymouth's" or portsmouth or "portsmouth's" or preston or "preston's" or ripon or "ripon's" or salford or "salford's" or salisbury or "salisbury's" or sheffield or "sheffield's" or southampton or "southampton's" or st albans or stoke or "stoke's" or sunderland or "sunderland's" or truro or "truro's" or wakefield or "wakefield's" or wells or westminster or "westminster's" or winchester or "winchester's" or wolverhampton or "wolverhampton's" or (worcester not (massachusetts* or boston* or harvard*)) or ("worcester's" not (massachusetts* or boston* or harvard*)) or (york not ("new york*" or ny or ontario* or ont or toronto*)) or ("york's" not ("new york*" or ny or ontario* or ont or toronto*))))):ti,ab,kw
122	(bangor or "bangor's" or cardiff or "cardiff's" or newport or "newport's" or st asaph or "st asaph's" or st davids or swansea or "swansea's"):ti,ab,kw
123	(aberdeen or "aberdeen's" or dundee or "dundee's" or edinburgh or "edinburgh's" or glasgow or "glasgow's" or inverness or (perth not australia*) or ("perth's" not australia*) or stirling or "stirling's"):ti,ab,kw
124	armagh or "armagh's" or belfast or "belfast's" or lisburn or "lisburn's" or londonderry or "londonderry's" or derry or "derry's" or newry or "newry's":ti,ab,kw
125	#116 OR #117 OR #118 OR #119 OR #120 OR #121 OR #122 OR #123 OR #124
126	MeSH descriptor: [Africa] explode all trees
127	MeSH descriptor: [Americas] explode all trees
128	MeSH descriptor: [Antarctic Regions] explode all trees
129	MeSH descriptor: [Arctic Regions] explode all trees
130	MeSH descriptor: [Asia] explode all trees
131	MeSH descriptor: [Oceania] explode all trees
132	#126 OR #127 OR #128 OR #129 OR #130 OR #131
133	MeSH descriptor: [United Kingdom] explode all trees
134	MeSH descriptor: [Europe] this term only
135	#133 OR #134
136	#132 not #135
137	#125 not #136
138	#115 AND #137 with Cochrane Library publication date Between Jan 2009 and Aug 2020

Appendix C – Clinical evidence study selection

Study selection for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Figure 2: Study selection flow chart



Appendix D – Clinical evidence tables

Evidence tables for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Table 6: Evidence tables

Study details	Participants	Methods	Themes and findings	Limitations
Full citation Ali, Nasreen, McLachlan, Niel, Kanwar, Shama, Randhawa, Gurch, Pakistani young people's views on barriers to accessing mental health services, International Journal of Culture and Mental Health, 10, 33-43, 2017 **Ref Id** 1052663 **Country/ies where the study was carried out** Peterborough, UK **Study type** Focus group; qualitative **Aim of the study** To explore young Pakistani's views of barriers and facilitators to accessing	**Sample size** N=33 children and young people **Characteristics** Age (range): 11-19 years • It was not possible to establish how many participants were ≥18 years old. • Themes have been downgraded for relevance where applicable. Gender (M/F): 17/16 2 participants were born in Pakistan, rest born in UK.	**Setting** Community **Recruitment** Participants recruited from local schools, madrasas (Islamic religious education institutions) or youth groups. Done by personal communication with one of the researchers. **Data collection** 4 single-sex focus groups (lasting 60-90 mins) were held, facilitated by a discussion guide. This was developed from a variety of literature and included semi-structured questions on religion, knowledge about mental health, awareness of local mental health services and suggestions for changes **Analysis** Framework analysis. Discussions were audio-recorded and transcribed. Researchers met	**Author's themes:** • Awareness of mental health services and treatment options Young people were aware of counselling and medication treatment for mental health issues, although only a few older female children had heard of family-based CBT. General feeling that family-based CBT would be appropriate for their age group. Reasons revolved around the need for privacy from parents, mainly age-related and culture-related. However, some of the older girls (FG4, aged 16-18) felt that family-based CBT might be useful in certain circumstances e.g. eating disorders.	**Limitations** **<u>(assessed using the CASP checklist for qualitative studies)</u>**. *Q1: Was there a clear statement of the aims of the research?* Yes Q2: Was a qualitative methodology appropriate? Yes *Q3: Was the research design appropriate to address the aims of the research?* Yes. Qualitative design and focus groups both justified. *Q4: Was the recruitment strategy appropriate to the aims of the research?* No. Personal communication used for recruitment. This was justified by the researcher having good links to Peterborough Pakistani community but introduces potential for bias which cannot be overlooked. *Q5: Were the data collected in a way that addressed the research*

Study details	Participants	Methods	Themes and findings	Limitations
mental health services in Peterborough, and to design actions to improve access to them. **Study dates** 2012-2013 **Source of funding** This study received support from Cambridgeshire and Peterborough NHS Foundation Trust.	**Inclusion criteria** • Aged 11-19 • Pakistani origin (held or were descended from those who held Pakistani passport) • Resident in Peterborough **Exclusion criteria** None reported. **Interventions** Not applicable.	regularly to discuss and develop themes via group consensus.		*issue?* Probably. Focus groups conducted in community settings for ease and privacy. Single sex focus groups used in order to be more culturally sensitive. Discussion guide used during focus groups, which was informed by existing policy, current literature and study aim as well as designed via consensus with 4 researchers. *Q6: Has the relationship between researcher and participants been adequately considered?* No. No description of potential bias/influence between researcher and participants (particularly an issue with Q4). An incentive (£20 voucher and light refreshments were given to the participants at the end of the focus group. No discussion regarding how that may impact findings. *Q7: Have ethical issues been taken into consideration?* Yes. Consent (parental for under 16s and individual for over 16s) process described and obtained. Study was approved by University of Bedfordshire ethics board. *Q8: Was the data analysis sufficiently rigorous?* Unsure. Reports that a framework approach was used, and that the

Study details	Participants	Methods	Themes and findings	Limitations
				research team met regularly to discuss emerging patterns and themes. Themes were finalised via consensus. Multiple quotes to support and contradictory data is presented and taken into account. However, no mention of how many researchers were involved in analysis (at any of the time points), or how raw data quotes were chosen for reporting. No examination of bias in the study. *Q9: Is there a clear statement of findings?* Probably. Findings are well described, with discussion of multiple views and experiences that were captured in the focus groups. Related to both original research question and current literature. Credibility not discussed. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Probably. 1. Yes. Details how the study findings fit in with current literature and the UK population, and how they can be used to inform best practice. 2. Unsure. Authors mention the small sample size as possible reason for lack of transferability to the rest of UK Pakistani young people.

Study details	Participants	Methods	Themes and findings	Limitations
				Overall judgement of quality: Moderate concerns **Other information** At the end of each focus group, participants were given some light refreshments and each participants received a £20 voucher for WHSmith as a goodwill gesture.
Full citation Babbage, C., Jackson, G. M., Nixon, E., Desired Features of a Digital Technology Tool for Self-Management of Well-Being in a Nonclinical Sample of Young People: Qualitative Study, JMIR Mental Health, 5, e10067, 2018 **Ref Id** 1052975 **Country/ies where the study was carried out** Nottinghamshire, UK **Study type** Semi-structured interview; qualitative **Aim of the study**	**Sample size** N=14 young people **Characteristics** Age (range; mean): 12-18 years; 14.6 years Gender (M/F): 11/3 All from Nottinghamshire, and in Years 10-13 of secondary school. **Inclusion criteria** • Aged 12-18. • Previous history of using digital technology. **Exclusion criteria** None applied.	**Setting** Online, community **Recruitment** Community recruitment in Nottinghamshire using social media and digital forums. Also used leaders of local youth groups, schools and study participation registers. **Data collection** 20 minute, semi-structured interview (voice or video-call). Open ended questions used initially, with follow up prompts for specific detail if needed. Interview guide and prompts designed from Mobile Phone Use Survey and previous research in the field. **Analysis** Inductive theme analysis. Recordings transcribed verbatim	**Author's themes:** • The Ideal Tool Should Be Sensitive to Privacy - Provides Safeguards as Needed to Limit Disclosure of Personal Data • The Ideal Tool Should Enable Engagement With Others - Anonymous Communication for Support While parental involvement was generally not a preferred feature, young people acknowledged that it was acceptable in some situations e.g. elevated risk of self-harm. It was suggested that the application should have a feature, either prompting a user to have a conversation with their parents/carers or communicating with them directly.	**Limitations** **(assessed using the CASP checklist for qualitative studies)**. *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Unsure. Community sampling used. However, breadth of technology usage by participants was much smaller than anticipated. Additionally, while participants were asked about history of mental health, answers were not confirmed. *Q5: Were the data collected in a way that addressed the research*

Study details	Participants	Methods	Themes and findings	Limitations
To examine what features of a self-management digital tool for well-being are prioritised by young people. **Study dates** Not reported. **Source of funding** This study received support from the Economic and Social Research Council and Tourettes Action.	**Interventions** Not applicable.	and double-checked. One researcher familiarised themselves with the data and generated initial codes. Express Scribe Transcription software (version 6.0) used to organise codes into themes. These were reviewed by two other researchers before defining final sub-themes and themes.	Participants wished to use the application to contact others for peer-support, but for this to be outside of social media. Blogs or forums enabling anonymous contact with other young people might offer a different facet of support from friends or relatives.	*issue?* Yes . Participants chose whether to be interviewed via video call or telephone call. Open ended questions to produce initial in-depth information, followed by specific follow-up questions if more information needed. Interview guide and prompts used to minimise differences between interviews. *Q6: Has the relationship between researcher and participants been adequately considered?* Unsure. Self-reflexive approach used throughout, including a reflexive journal which was shared with researchers carrying out interpretation of codes and themes. However, no information given about how it might have been taken into account. *Q7: Have ethical issues been taken into consideration?* Yes. Consent (parental for under 16s and individual for over 16s) process described and obtained at multiple time points. Study was approved by University of Nottingham ethics board. *Q8: Was the data analysis sufficiently rigorous?* Unsure. Detailed account of analysis and methods used. Only 1 researcher organised the theme categories

Study details	Participants	Methods	Themes and findings	Limitations
				and final themes, which was checked by 2 co-authors. Reflexive diary kept alongside the analysis but no information presented on what impact it may have had. No discussion of contradictory opinions or views. *Q9: Is there a clear statement of findings?* Probably. Findings are well described, related to the original research question and current literature. However, there is no discussion about conflicting views/experiences within the sample. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Probably. 1. Details how the study findings fit in with current literature and how they can be used to inform future healthcare app design. 2. Unsure. No demographics of the sample reported and small sample size needs to be taken into account. Overall judgement of quality: Moderate concerns **Other information** History of experience or clinical diagnosis of mental health

Study details	Participants	Methods	Themes and findings	Limitations
				problems was not an exclusion criterion, but participants were asked by the researcher to report on current or previous experience of mental health issues.
Full citation Edbrooke-Childs, J., Edridge, C., Averill, P., Delane, L., Hollis, C., Craven, M. P., Martin, K., Feltham, A., Jeremy, G., Deighton, J., Wolpert, M., A Feasibility Trial of Power Up: Smartphone App to Support Patient Activation and Shared Decision Making for Mental Health in Young People, JMIR MHealth and UHealth, 7, e11677, 2019 **Ref Id** 1055310 **Country/ies where the study was carried out** England, UK **Study type** Mixed-methods including semi-structured interview; qualitative **Aim of the study**	**Sample size** N=11 children and young people **Characteristics** Age (range; mean): 11-17 years; 15.55 years Gender (M/F): not reported **Inclusion criteria** Not reported. **Exclusion criteria** Not reported. **Interventions** Used PowerUp smartphone app	**Setting** Participating in another study, specialist CAMHS centre, school **Recruitment** Recruited from the parent RCT in which participants were recruited from specialist CAMHS centres and 2 schools. Clinicians in the CAMHS centres identified individuals patients aged 11-19 for possible inclusion. 2 schools were randomised into 12 clusters. Participants in both intervention arms were then invited to complete interviews on the acceptability of the application. **Data collection** Interviews covered young people's experiences of using Power Up and it's impact on their self-management of their mental health, acceptability, and possible improvements. Interviews audio recorded and transcribed verbatim. **Analysis** Thematic analysis using NVivo.	**Author's themes:** • Motivation for use • Impact of use. Young people wanted an application that they could trust to be private and secure, allowing them to feeling comfortable in making sensitive and personal entries. Other people should not have access unless young people chose to divulge information. The application allowed young people to communicate personal and sensitive information with peer-supporters, which they might not feel comfortable doing otherwise.	**Limitations** <u>**(assessed using the CASP checklist for qualitative studies)**</u>. *Q1: Was there a clear statement of the aims of the research?* Yes *Q2: Was a qualitative methodology appropriate?* Yes *Q3 Was the research design appropriate to address the aims of the research?* Yes. Mixed methods feasibility study. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Unsure. No description of how participants were chosen from initial RCT, beyond the fact they were asked to participate. No information on how/if there was a criteria beyond that. *Q5: Were the data collected in a way that addressed the research issue?* Probably not. Data collected through interviews and content well described. No justification given, setting described or mention of interview guide. Recruitment expanded

Study details	Participants	Methods	Themes and findings	Limitations
To determine the effectiveness, usage and acceptability of a new smartphone/tablet app, Power Up. **Study dates** 01/2017 to 02/2018 **Source of funding** This study received support from National Institute for Health Research, Invention for Innovation Programme.				from specialist centres to include secondary schools as well due to an expansion of target audience for application. However, no mention at what time in the trial that this happened. *Q6: Has the relationship between researcher and participants been adequately considered? No.* No description of potential bias/influence between researcher and participants. *Q7: Have ethical issues been taken into consideration?* Yes. Consent process described and obtained. Study was approved by Health Research Authority Research ethics committee (RCT) and University College London Research Ethics Committee (cluster RCT). *Q8: Was the data analysis sufficiently rigorous?* Unsure. Very descriptive findings presented with multiple quotes for each finding. No information given regarding analysis method, amount of researchers involved or consideration of bias. *Q9: Is there a clear statement of findings?* Probably not. Findings very detailed in results. There is a very discussion relating the results back to the whole

Study details	**Participants**	**Methods**	**Themes and findings**	**Limitations**
				feasibility trial, rather than simply the qualitative aspect of trial. No discussion on evidence surroundings findings or credibility of findings. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Probably. 1. Yes. Results of the feasibility trial will go on to inform a full-scale RCT on mobile applications in self-management. 2. Unsure. No data reported on who elected to participate in the interviews from the effectiveness study. *Overall judgement of quality:* Moderate concerns **Other information** Many of the concerns come from the fact that qualitative aspect part of a larger mixed-methods feasibility trial i.e. views/experiences not a primary outcome but a way to increase acceptability by further developing the application.
Full citation Sullivan, V., de Sa, J., Hamlyn, E., Baraitser, P., How can we facilitate online	**Sample size** **Semi-structured interview**	**Setting** Online **Recruitment**	**Author's themes:** • What is 'normal' in sexual relationships? • What will happen to my data?	**Limitations <u>(assessed using the CASP checklist for qualitative studies)</u>.**

Study details	Participants	Methods	Themes and findings	Limitations

disclosure of safeguarding concerns in under 18s to support transition from online to face-to-face care?, International Journal of STD and AIDS, 31, 553-559, 2020
Ref Id
1280143
Country/ies where the study was carried out
London, UK
Study type
Semi-structured interview and co-produced workshops; qualitative
Aim of the study
To identify factors that will encourage users of online sexual health services (SHSs) to disclose safeguarding concerns and facilitate appropriate responses
Study dates
Not reported
Source of funding
	N=2 young people (+ N=2 safeguarding experts)
	Co-produced workshops
	N=7 young people (+ N=9 key stakeholders)
	- Only the views of young people were included
	  - It was not possible to establish how many participants were ≥18 years old.
	  - Themes have been downgraded for relevance where applicable.
	Characteristics
	Semi-structured interviews
	Age (range): 16-21 years
	Gender of young person (M/F): 0/2
	Co-produced workshops
	Age of young person (mean; range): 17 years; 16-18 years
		Convenience sampling used with study information provided to several local young person holistic support organisations, of which three - two specialist youth work organisations and one community work organisation - agreed to participate. Representative ('gatekeeper') from organisation given discretion to select appropriate young person (e.g. amenable to participate in research; would not likely be distressed) to request participation in research. Participants offered £10 travel expenses. Sample limited by recruitment difficulties and no-shows. Purposive, maximum variation sample of professionals recruited by direct approach from researchers.
		Data collection
		All participants (young people and professionals) informed of SH:24, an online sexual health service and its existing safeguarding screening tool to identify people under 18 at risk of child sexual exploitation. Semi-structured interview was recorded and transcribed, lasted 60-90 min, conducted at gatekeeper organisation premises or professionals workplace as appropriate, and based around
			- How do I keep control of the process?
			- What can you offer me?
			Young people are concerned about how their data is used and worry about who can access it. They want to have a clear idea as to the processes and outcomes associated with online disclosure (e.g. use of website with examples) and the opportunity to express themselves beyond tick box exercises. Young people may benefit from education/information about what 'normal' relationships consist in.
				Q1: Was there a clear statement of the aims of the research? Yes.
				Q2: Was a qualitative methodology appropriate? Yes.
				Q3: Was the research design appropriate to address the aims of the research? Yes but small sample (n=2) for interviews.
				Q4: Was the recruitment strategy appropriate to the aims of the research? Yes.
				Q5: Were the data collected in a way that addressed the research issue? Yes.
				Q6: Has the relationship between researcher and participants been adequately considered? Can't tell. Insufficient details reported to determine.
				Q7: Have ethical issues been taken into consideration? Yes. Ethical approval from King's College London Ethics Committee.
				Q8: Was the data analysis sufficiently rigorous? Yes.
				Q9: Is there a clear statement of findings? Yes.

Study details	Participants	Methods	Themes and findings	Limitations
Reports no financial support received	Gender of young person (M/F): 6/1 **Inclusion criteria** • Young person aged 16 to 21 years • Safeguarding experts required experience of working with safeguarding young people in senior capacity (service delivery or policy) • Clinicians required experience of sexual health services and safeguarding young people • Other professionals required experience of working with online SHSs, DBS clearance and appropriate safeguarding training. **Exclusion criteria** For young people • Outside specified age range (under 16 or over 21 years-old) • Thought to be too vulnerable by young	two example safeguarding 'cases'. Young people asked to read cases and were asked about barriers and facilitators to disclosure of a safeguarding concern and transition from online to face-to-face services. Professionals asked more general questions about challenges to support online disclosure and transition to clinic care. Two-hour co-produced workshop conducted at community centre with young people and key stakeholders (safeguarding experts, clinicians, website developers, designers) and run by expert facilitators. Structured around initial 'icebreaker' and series of questions around online sharing of personal data, barriers to disclosure of safeguarding concern, and factors to encourage disclosure. Online tool SH:24, and how it could be improved, also discussed. Interviews and workshops recorded, and transcribed, then anonymised with all participants assigned identity code. **Analysis** Thematic (Framework) approach used with interview texts read by one researcher several times to generate numerical coding categories. Categories then		*Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* Yes. 1. Yes, discusses in context of literature. 2. Small sample and use of convenience sampling limit generalisability. Also gender imbalance in interviews (2 female) compared to workshops (6 male, 1 female). *Overall judgement of quality:* Serious concerns **Other information**

Study details	Participants	Methods	Themes and findings	Limitations
	person's gatekeeper representative - Researcher felt that young person had insufficient command of English language **Interventions** Online sexual health services	refined via three coding/modification rounds by three researchers, with differences resolved through discussion.		
Full citation Svirydzenka, N., Ronzoni, P., Dogra, N., Meaning and barriers to quality care service provision in Child and Adolescent Mental Health Services: Qualitative study of stakeholder perspectives, BMC health services research, 17, 151, 2017 **Ref Id** 961054 **Country/ies where the study was carried out** England, UK **Study type** Semi-structured interview; qualitative	**Sample size** N=3 children/adolescents **Characteristics** No details reported. **Inclusion criteria** Not reported. **Exclusion criteria** Not reported. **Interventions** Not applicable.	**Setting** CAMHS **Recruitment** Purposive sampling from CAMHS database of recently discharged patients. **Data collection** Semi-structured, individual (i.e. without parents) interviews in the children's home. Interviews focused on quality meaning within CAMHS, and barriers to implementation. Children (different from the stakeholders) not asked about methods of quality assessment. Interviews audio recorded and transcribed verbatim. **Analysis**	**Author's themes:** - Conflicts in quality definition Quality care included reputable and trustworthy services, communication between healthcare providers and young people, and continued support.	**Limitations** **(assessed using the CASP checklist for qualitative studies).** *Q1: Was there a clear statement of the aims of the research?* Yes. *Q2: Was a qualitative methodology appropriate?* Yes. *Q3: Was the research design appropriate to address the aims of the research?* Yes. *Q4: Was the recruitment strategy appropriate to the aims of the research?* Probably not. Very low number of child/adolescent participants, minimal information given regarding how participants were recruited and no discussion about why some people decided not to take part.

Study details	Participants	Methods	Themes and findings	Limitations
Aim of the study To explore key stakeholder's - children/adolescents, treatment providers, and NHS commissioners - views on CAMHS services and ways of improving quality. **Study dates** 03/2013 to 07/2013 **Source of funding** This study received support from NHS FSF and LNR CLRN Flexibility and Sustainability Funding.		Thematic analysis. Multiple researchers analysed data, and inter-rater reliability ensured. Results coded into a 3 layer process - coding framework coalesced into 12 primary themes, which were then sorted into 3 overarching themes.		*Q5: Were the data collected in a way that addressed the research issue?* Unsure. Detailed information presented on interviews including settings and process. However, lack of information regarding the content of interviews or if a guide was used. *Q6: Has the relationship between researcher and participants been adequately considered?* Unsure. Mentions reflexivity - team identified their own perspectives and bias about how they thought stakeholders would identify quality. Themes identified independently by multiple researches and discussed to mitigate bias. *Q7: Have ethical issues been taken into consideration?* Yes. Consent process described and obtained. Study was approved by NHS National Research Ethics Service *Q8: Was the data analysis sufficiently rigorous?* Probably not. Detailed description of analysis and reflexivity discussed. However, there is a lack of BCYP raw data presented in the themes and no information regarding how

Study details	Participants	Methods	Themes and findings	Limitations
				data that was presented was chosen. *Q9: Is there a clear statement of findings?* No. Overall findings are well described, related to the original research question and current literature with discussion about conflicting views/experiences within the sample. However, cannot be ignored that there are only 3 BCYP participants which corresponds to a lack of raw data and coherence within the sub-groups. *Q10: Is the research valuable for the UK? (1. Contribution to literature and 2. Transferability)* No. 1. BCYP findings do not contribute strongly to the conclusions. 2. Probably not. Only 3 BCYP participants. *Overall judgement of quality:* Serious concerns **Other information** Also includes views of parents but as no information given on age of BCYP, no data extracted for these.

CAMHS: Child and Adolescent Mental Health Service; CBT: cognitive behavioural therapy; FG: focus group; N: number; NHS: National Health Service; RCT: randomised controlled trial

Appendix E – Forest plots

Forest plots for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No meta-analysis was conducted for this review question and so there are no forest plots.

Appendix F – GRADE-CERQual tables

GRADE-CERQual tables for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Table 7: Evidence summary (GRADE-CERQual) for theme 1: What to expect

No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
Sub-theme 1.1: Sexual relationships							
1 (Sullivan 2020)	Semi-structured interview/ co-produced workshop	Data from 1 study showed that some children and young people are not clear about what constitutes 'normal sexual relationships' and wanted educational materials (e.g. website) to explain process and outcomes of online disclosure. Using closed questions was also felt to limit their opportunities to express themselves. *'Young person: 'I think some people aren't clear about what would constitute people being 'really worried' about them and having to tell their parents.'* *Interviewer: 'In case one, do you think other YP would understand that this is rape?'* *Young person: 'My guy friends - I wouldn't think so - they wouldn't know about consent. The girl might think it's love and affection and that's how a relationship is. But it's not.'' (Sullivan 2020, page 556)*	Moderate concerns[1]	Minor concerns[2]	Serious concerns[3]	Moderate concerns[4]	VERY LOW

1 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for coherence because only one study contributed to the review finding

3 Evidence was downgraded for relevance because study topic was online disclosure of safeguarding concerns and so not directly relevant to review question; sample also included some participants over the age of 18
4 Evidence was downgraded for adequacy because study offered some rich data

Table 8: Evidence summary (GRADE-CERQual) for theme 2: Services

Study information		Description of theme or finding	CERQUAL Quality assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 2.1: Barriers to accessing CAMHS							
1 (Ali 2017)	Focus group	Data from 1 study suggested that family based treatment options may only be suitable for adolescents in certain situations. *‘it depends because like you were saying eating disorders, like that is the type of thing that family can help but if it was like relationship issues you wouldn't want your parents to know and you wouldn't be comfortable in sharing it with your parents... sometimes people go out with people because it is against our culture and stuff... and you, you don't want your parents to find out about it sometimes so...’ (Ali 2017, page 4)*	Serious concerns[1]	Moderate concerns[2]	Moderate concerns[3]	Serious concerns[4]	VERY LOW
Sub-theme 2.2: Benefits of using online services							
1 (Sullivan 2020)	Semi-structured interview/ co-produced workshop	Data from 1 study showed that children and young people may be willing to engage in online disclosure of safeguarding concerns but wanted a measure of control over the process, the freedom to express themselves, and clarity about the benefits of online disclosure and the support available. *‘Some get turned off. Is it going to benefit me or benefit you? If I can see why it might benefit me to tell you then*	Moderate concerns[5]	Moderate concerns[2]	Serious concerns[6]	Moderate concerns[7]	VERY LOW

Study information		**Description of theme or finding**	**CERQUAL Quality assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
		I'm more likely to answer the question.' (Sullivan 2020, page 557)					
Sub-theme 2.3: Quality of CAMHS							
1 (Svirydzenka 2017)	Semi-structured interview	Data from 1 study suggested that anonymity is identified by children and young people as a measure of the quality of a healthcare service. *'They are very kind to you and treat you separately to others [anonymously] and making sure that you're looked after properly.' (Svirydzenka 2017, page 4)*	Serious concerns[1]	Moderate concerns[2]	Serious concerns[8]	Serious concerns[4]	VERY LOW
Sub-theme 2.4: Uncertainty about consequences							
1 (Sullivan 2020)	Semi-structured interview/ co-produced workshop	Data from 1 study showed that children and young people were concerned about the unintended or unforeseen consequences of revealing 'private' information to people or services, which, for example, might be used against them in some way or result in an unwanted healthcare or other outcome. *'There are a lot of thresholds. Don't put required fields in and stop them going to the next bit. Let them see the whole process, then they can add what they want. Otherwise it's like floodgates. A portion of people won't go past a particular thing because they don't know what's beyond it.' (Sullivan 2020, page 557)*	Serious concerns[1]	Moderate concerns[9]	Moderate concerns[10]	Serious concerns[4]	VERY LOW

1 Evidence was downgraded due to serious concerns about methodological limitations as per CASP qualitative checklist
2 Evidence was downgraded for coherence because only one study contributed to the review finding
3 Evidence was downgraded for relevance because focus group included participants up to 19 years-old
4 Evidence was downgraded for adequacy because study did not offer rich data

5 Evidence was downgraded due to moderate concerns about methodological limitations as per CASP qualitative checklist
6 Evidence was downgraded for relevance because study topic was online disclosure of safeguarding concerns and so not directly relevant to review question; sample also included some participants over the age of 18
7 Evidence was downgraded for adequacy because studies together offered some rich data
8 Evidence was downgraded for relevance because study was examination of what children and young people consider to be quality CAMHS care and so not directly relevant to review question
9 Evidence was downgraded for coherence because evidence for review finding is only reasonably compelling given age difference in participants of the study
10 Evidence was downgraded for relevance because study topic was online disclosure of safeguarding concerns and so not directly relevant to review question; sample also included some participants over the age of 18

Table 9: Evidence summary (GRADE-CERQual) for theme 3: Technology

Study information		**Description of theme or finding**	**CERQUAL Quality Assessment**				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 3.1: Peer support							
2 (Babbage 2018, Edbrooke-Childs 2019)	Mixed method, semi-structured interview	Data from 2 studies suggested that, while privacy is a preferred feature for healthcare technology, there were some situations where this could be broken if personal safety was threatened. These included an imminent risk of self-harm. Children and young people also mentioned that having a designated person that can access their information as both a safety measure and a way of communicating that isn't face-to-face. *'I like that I can write everything, um, for myself and my mum can log into my account and check as well… (Young Person's parent: 'It's fine, I mean, there's things that he hasn't told me and then I've seen them, but he's writing them in there...') ...but I was happy that my mum can see all my diary entries and she can only see it.' (Edbrooke-Childs 2019, page 9)*	Serious concerns[1]	Minor concerns[2]	Minor concerns[3]	Minor concerns[4]	LOW

Study information		Description of theme or finding	CERQUAL Quality Assessment				
No of studies	**Design**		**Methodological limitations**	**Coherence of findings**	**Relevance of evidence**	**Adequacy of data**	**Overall confidence**
Sub-theme 3.2: Privacy and confidentiality							
3 (Babbage 2018, Edbrooke-Childs 2019, Sullivan 2020)	Mixed method, semi-structured interview/ co-produced workshop	Data from 3 studies showed that digital privacy and how their data was used were important concerns for children and young people. Children and young people expect a measure of control over their data in how it is used and who can access it, as well as some protection when using services such as a self-management app or online safeguarding site. *‘Maybe like blog like a forum, or something, where other people can anonymously put things and ask for advice of other people’ (Babbage 2018, page 5)*	Serious concerns[1]	Moderate concerns[5]	Moderate concerns[6]	Moderate concerns[7]	VERY LOW
Sub-theme 3.3: Safety							
2 (Babbage 2018, Edbrooke-Childs 2019)	Interview	Data from 2 studies suggested that children and young people were concerned about the level of privacy a digital healthcare application could afford them, especially with data location and site monitoring. They wanted a service that meant they could communicate personal and sensitive entries privately, and for them to have the power of choosing who can access that information. *‘I guess the best word to describe it would be, I think, safe, because you can say honestly, you can say honestly anything you want, things you wouldn’t share with other people,*	Serious concerns[1]	Minor concerns[2]	Minor concerns[3]	Minor concerns[4]	LOW

Study information		Description of theme or finding	CERQUAL Quality Assessment				
No of studies	Design		Methodological limitations	Coherence of findings	Relevance of evidence	Adequacy of data	Overall confidence
		plans that you want to make for the better that you don't feel like telling everyone or your parents and it's a bit of, like, some alone time because some people work best when they're by themselves' (Edbrooke Childs 2019, page 8)					

1 Evidence was downgraded for methodological limitations as per CASP Qualitative checklist
2 Evidence was downgraded for coherence because evidence supporting review finding is reasonably compelling
3 Evidence was downgraded for relevance because studies do not directly address review question
4 Evidence was downgraded for adequacy because studies together offered moderately rich data
5 Evidence was downgraded for coherence because evidence supporting review finding is only moderately compelling
6 Evidence was downgraded for relevance because studies do not directly address review question and one study includes participants over the age of 18 years
7 Evidence was downgraded for adequacy because studies together offer some rich data

Appendix G – Economic evidence study selection

Economic evidence study selection for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No economic evidence was identified which was applicable to this review question.

Appendix H – Economic evidence tables

Economic evidence tables for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No evidence was identified which was applicable to this review question.

Appendix I – Economic evidence profiles

Economic evidence profiles for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No economic evidence was identified which was applicable to this review question.

Appendix J – Economic analysis

Economic evidence analysis for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No economic analysis was conducted for this review question.

Appendix K – Excluded studies

Excluded studies for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Clinical studies

Table 10: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Palatability of hypoallergenic formulas for cow's milk allergy and healthcare professional recommendation, Pediatric allergy and immunology, 29, 857-862, 2018	Healthcare providers views only
Can text messages increase safer sex behaviours in young people? Intervention development and pilot randomized controlled trial, Health technology assessment. 20 (57) (pp 1-81), 2016. Date of publication: august 2016., 2016	No relevant qualitative data
Diagnosis, assessment, and treatment of childhood eczema in primary care: crosssectional study, BJGP open, 1, 2017	No qualitative data
Aagaard, L., Christensen, A., Hansen, E. H., Information about adverse drug reactions reported in children: A qualitative review of empirical studies, British Journal of Clinical Pharmacology, 70, 481-491, 2010	Systematic review - included studies checked for inclusion, no relevant studies
Aantaa,R., Sedation in PICU, Acta Anaesthesiologica Scandinavica, Supplement, 53, 3-5, 2009	Conference Abstract
Aarthun, A., Akerjordet, K., Parent participation in decision-making in health-care services for children: an integrative review, Journal of nursing management, 22, 177-191, 2014	Systematic review. Included studies checked for inclusion - 2 were identified
Aazh, H., Moore, B. C., Lammaing, K., Cropley, M., Tinnitus and hyperacusis therapy in a UK National Health Service audiology department: Patients' evaluations of the effectiveness of treatments, International journal of audiology, 55, 514-522, 2016	No qualitative data
Abbas, F., Luhar, A., Terry, D., Swallowing medicines: A study of paediatric patients, Archives of disease in childhood, 99 (8), e3, 2014	Conference Abstract
Abbott, David, Carpenter, John, "The things that are inside of you are horrible": Children and young men with Duchenne muscular dystrophy talk about the impact of living with a long-term condition, Child Care in Practice, 21, 67-77, 2015	Information too specific to be generalisable
Abbott, M., Bernard, P., Forge, J., Communicating a diagnosis of Autism Spectrum Disorder - a qualitative study of parents' experiences, Clinical Child Psychology and Psychiatry, 18, 370-382, 2013	Population not in protocol - parental views with age of children 8-15.
Abdelrahim, Z., Dooley, A., Khan, A., Development of a paediatric specialist multidisciplinary down syndrome clinic, Archives of disease in childhood, 103 (Supplement 1), A162-A163, 2018	Conference Abstract
Abela, K. M., Wardell, D., Rozmus, C., LoBiondo-Wood, G., Impact of Pediatric Critical Illness and Injury on Families: An Updated Systematic Review, Journal of pediatric nursing, 51, 21-31, 2020	Systematic review - included studies checked for inclusion, no relevant studies
Abelman, D. D., Mitigating risks of students use of study drugs through understanding motivations for use and applying harm reduction theory: a literature review, Harm reduction journal, 14, 68, 2017	Narrative review
Aberdeen, J. N., Burnett, R. K. F., Stewart, H. F., Greenberg, E., The use of patient reported outcome measures by primary medical providers in the pediatric sports population, Orthopaedic Journal of Sports Medicine. Conference: 6th Annual Meeting of	Conference Abstract

Study	Reason for Exclusion
the Pediatric Research in Sports Medicine Society, PRiSM, 7, 2019	
Abhyankar, P., Summers, B. A., Velikova, G., Bekker, H. L., Framing Options as Choice or Opportunity: Does the Frame Influence Decisions?, Medical decision making : an international journal of the Society for Medical Decision Making, 34, 567-582, 2014	Population not in protocol - adult women
Abrines Jaume, N., Hoffman, J., Wolpert, M., Law, D., Wright, E., Shared decision making in child and adolescent mental health services, Neuropsychiatrie de l'Enfance et de l'Adolescence, 1), S294, 2012	Conference Abstract
Abu-Rajab, K., Scoular, A., Church, S., Connell, J., Winter, A., Hart, G., Identifying opportunities for sexually transmitted infection prevention: Analysis of critical points in the care pathways of patients with gonorrhoea, International Journal of STD and AIDS, 20, 170-175, 2009	Population not in protocol - age 15-66 with no way of discerning age of individual qualitative data.
Achten, J., Parsons, N. R., Edlin, R. P., Griffin, D. R., Costa, M. L., A randomised controlled trial of total hip arthroplasty versus resurfacing arthroplasty in the treatment of young patients with arthritis of the hip joint, BMC musculoskeletal disorders, 11, 8, 2010	Published protocol
Ackner, S., Skeate, A., Patterson, P., Neal, A., Emotional abuse and psychosis: A recent review of the literature, Journal of Aggression, Maltreatment and Trauma, 22, 1032-1049, 2013	Too specific - child abuse and psychosis
Actrn,, Mitii ABI: "Move it to improve it": a randomised trial of novel web-based intervention for children with acquired brain injury, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12613000403730, 2013	Ongoing trial - still recruiting
Actrn,, Patient navigators in children with chronic kidney disease, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001152213, 2018	Ongoing trial - still recruiting
Actrn,, A randomized controlled trial comparing knowledge transfer regarding preoperative information to children and parents: interactive web-based format (Anesthesia Web) vs. conventional brochure information, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000528459, 2016	Ongoing trial - still recruiting
Actrn,, A randomised controlled trial of a group intervention for family and friends of youth with borderline personality disorder, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12616000304437, 2016	Ongoing trial - still recruiting
Actrn,, HARTI HAUORA TAMARIKI A Randomised Controlled Trial of an Opportunistic, Holistic and Family Centred Approach to Improving Outcomes for Hospitalised Children and their Families, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12618001079235, 2018	Ongoing trial - still recruiting
Actrn,, A study of the impact of treating seizures that can be seen and those that can be seen only on a brain monitor in newborn babies, who are having seizures or at high risk of seizures, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12611000327987, 2011	Ongoing trial - still recruiting
Actrn,, Action: pACT. Be Active. Online. A trial to promote physical activity in young people with cystic fibrosis, Http://www.who.int/trialsearch/trial2.aspx?Trialid=actrn12617001009303, 2017	Ongoing trial - still recruiting
Adams, C., Lockton, E., Freed, J., Gaile, J., Earl, G., McBean, K., Nash, M., Green, J., Vail, A., Law, J., The Social Communication Intervention Project: a randomized controlled trial of the effectiveness of speech and language therapy for school-age children who have pragmatic and social	No qualitative data

Study	Reason for Exclusion
communication problems with or without autism spectrum disorder, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 233-244, 2012	
Adams, C., Lockton, E., Gaile, J., Earl, G., Freed, J., Implementation of a manualized communication intervention for school-aged children with pragmatic and social communication needs in a randomized controlled trial: the Social Communication Intervention Project, International journal of language & communication disorders / Royal College of Speech & Language Therapists, 47, 245-256, 2012	No qualitative data
Adams, N., Churchill, R., Eve, E., Chronic widespread pain in adolescents: A primary care based study, European Journal of Pain Supplements, 5 (1), 146, 2011	Conference Abstract
Adewumi, A. D., Hollingworth, S. A., Maravilla, J. C., Connor, J. P., Alati, R., Prescribed Dose of Opioids and Overdose: A Systematic Review and Meta-Analysis of Unintentional Prescription Opioid Overdose, CNS Drugs, 32, 101-116, 2018	Systematic review - included studies checked for inclusion, no relevant studies
Aebi, M., Kuhn, C., Banaschewski, T., Grimmer, Y., Poustka, L., Steinhausen, H. C., Goodman, R., The contribution of parent and youth information to identify mental health disorders or problems in adolescents, Child and adolescent psychiatry and mental health, 11 (1) (no pagination), 2017	No qualitative data.
Aebi, Marcel, Kuhn, Christine, Metzke, Christa Winkler, Stringaris, Argyris, Goodman, Robert, Steinhausen, Hans-Christoph, The use of the development and well-being assessment (DAWBA) in clinical practice: A randomized trial, European child & adolescent psychiatry, 21, 559-567, 2012	No qualitative data
Ager, A., Zimmerman, C., Unlu, K., Rinehart, R., Nyberg, B., Zeanah, C., Hunleth, J., Bastiaens, I., Weldy, A., Bachman, G., Blum, A. B., Strottman, K., What strategies are appropriate for monitoring children outside of family care and evaluating the impact of the programs intended to serve them?, Child Abuse & Neglect, 36, 732-42, 2012	Systematic review - included studies checked for inclusion, no relevant studies
Agnew, T., Shared experience, Nursing Standard, 26, 22-4, 2012	Narrative article, not study
Agrawal, S., Morris, K., Whitehouse, W. P., Parent's views about drug trials in children with refractory convulsive status epilepticus, Developmental Medicine and Child Neurology, 1), 16, 2009	Conference Abstract
Agwu, C. J., Scanlon, J., McCrea, K., Raffeeq, P., Kershaw, M., Broomhead, S., Eminson, J., Peer review: A tool to improve paediatric diabetes services, Hormone Research in Paediatrics, 1), 213, 2013	Conference Abstract
Ahmed, M., Boyd, C., Vavilikolanu, R., Rafique, B., Visual symptoms and childhood migraine: Qualitative analysis of duration, location, spread, mobility, colour and pattern, Cephalalgia, 38, 2017-2025, 2018	No qualitative data
Ahmed, S. A., Arasu, A., Ethical dilemma in neonatology, Archives of Disease in Childhood, 97, A300, 2012	Conference Abstract
Ahmed, S. A., Arasu, A., Another ethical dilemma in neonatology, Archives of Disease in Childhood, 96, A72, 2011	Conference Abstract
Ahmed, S., Ihe, C., Findings from a pre-clinic questionnaire given prior consultation at an NHS paediatric diabetes outpatient service in England-the patient's perspective: A survey of patient/carer experience of a paediatric diabetes outpatient service, Pediatric Diabetes, 17 (Supplement 24), 127-128, 2016	Conference Abstract
Ainsworth, S., Raiising awareness of invisible illnesses in schools and education, Annals of the rheumatic diseases, 77 (Supplement 2), 10, 2018	Conference Abstract

Study	Reason for Exclusion
Ainsworth, S., Ainsworth, J., Preston, J., Stones, S., Challinor, R., Rowe, M., Introducing RAiISE-raising awareness of invisible illnesses in schools and education, Pediatric Rheumatology, 15 (Supplement 2), 67-68, 2017	Conference Abstract
Akhtar, M. A., Honeyman, C., Aziz, F., Greenough, C., Kalyan, R., Hekal, W., The sky's the limit: Raising the quality and scope of communication for children with scoliosis and their families using digital and social media, British journal of neurosurgery, 30 (2), 177, 2016	Conference Abstract
Al Maghaireh, Dua'a Fayiz, Abdullah, Khatijah Lim, Chan, Chong Mei, Piaw, Chua Yan, Al Kawafha, Mariam Mofleh, Systematic review of qualitative studies exploring parental experiences in the Neonatal Intensive Care Unit, Journal of Clinical Nursing, 25, 2745-2756, 2016	Systematic review - included studies checked for inclusion - 4 were identified
Aladangady, N., Shaw, C., Gallagher, K., Stokoe, E., Marlow, N., Short-Term outcome of treatment limitation discussions for newborn infants, a multicentre prospective observational cohort study, Archives of Disease in Childhood: Fetal and Neonatal Edition, 102, F104-F109, 2017	No qualitative data
Alan, D., Woolner, A. F., Skinner, R., King, D., Evaluation of infection control advice for patients at risk of chemotherapy-induced neutropaenia in two paediatric oncology centres in south africa and the United Kingdom, Pediatric Blood and Cancer, 57 (5), 846-847, 2011	Conference Abstract
Alderson, H., Brown, R., Copello, A., Kaner, E., Tober, G., Lingam, R., McGovern, R., The key therapeutic factors needed to deliver behavioural change interventions to decrease risky substance use (drug and alcohol) for looked after children and care leavers: a qualitative exploration with young people, carers and front line workers, BMC medical research methodology, 19, 38â , 2019	Population not in protocol - age 15-19 with no way of determining source of quote.
Alderson, H., Brown, R., Smart, D., Lingam, R., Dovey-Pearce, G., 'You've come to children that are in care and given us the opportunity to get our voices heard': The journey of looked after children and researchers in developing a Patient and Public Involvement group, Health expectations : an international journal of public participation in health care and health policy., 21, 2019	No information on communication
Alexakis, C., Davies, G., Stephens, J., Clark, S., Rogers, S., Poullis, A., Perspectives and attitudes of young patients with inflammatory bowel disease: Symptoms, burden of disease and communication with their healthcare professionals, Frontline Gastroenterology, 5, 197-202, 2014	No qualitative data
Alexakis, C., Nash, A., Lloyd, M., Brooks, F., Lindsay, J. O., Poullis, A., Inflammatory bowel disease in young patients: challenges faced by black and minority ethnic communities in the UK, Health & Social Care in the Community, 23, 665-672, 2015	No qualitative data for RQ1s in under 18s
Alexander, R., Walter, L. K., Progressive techniques to effectively prepare children for radiotherapy: A supportive framework combining informative films with a miniature working model LINAC, Pediatric Blood and Cancer, 62 (Supplement 4), S209, 2015	Conference Abstract
Alexander, S., Bath, L., McDonald, M., Adolescent diabetic outpatient clinics-more than just an HbA1c, Archives of disease in childhood, 101 (Supplement 1), A275-A277, 2016	Conference Abstract
Al-Gamal, Ekhlas, Long, Tony, The MM-CGI Cerebral Palsy: Modification and pretesting of an instrument to measure anticipatory grief in parents whose child has cerebral palsy, Journal of clinical nursing, 23, 1810-1819, 2014	No qualitative data

Study	Reason for Exclusion
Al-Harthy, Z. S., Cowling, J. P., Mann, G. K., Salama, M., Medical intervention for children with medical complexity (MICMAC), Archives of disease in childhood, 3), A127-A128, 2015	Conference Abstract
Alifrangis, C., Koizia, L., Rozario, A., Rodney, S., Harrington, M., Somerville, C., Peplow, T., Waxman, J., The experiences of cancer patients, Qjm, 104, 1075-81, 2011	Population not in protocol - aged 21 years and over
Aljafari, A. K., Scambler, S., Gallagher, J. E., Hosey, M. T., Parental views on delivering preventive advice to children referred for treatment of dental caries under general anaesthesia: A qualitative investigation, Community dental health, 31, 75-79, 2014	Views of parents with no way of discerning age of children.
Allcock, D., Smith, K., Exploring parent views of community matrons, Nursing Times, 110, 21-23, 2014	Questionnaires sent to parents - no way of discerning child age.
Allen, D., Gillen, E., Rixson, L., The Effectiveness of Integrated Care Pathways for Adults and Children in Health Care Settings: A Systematic Review, JBI Library of Systematic Reviewis, 7, 80-129, 2009	No qualitative data
Allen, D., Scarinci, N., Hickson, L., The Nature of Patient- and Family-Centred Care for Young Adults Living with Chronic Disease and their Family Members: A Systematic Review, International Journal of Integrated Care [Electronic Resource]Int J Integr Care, 18, 14, 2018	Systematic review - included studies checked for inclusion - studies 5 were identified.
Allen, Kimberly A., Parental decision-making for medically complex infants and children: An integrated literature review, International Journal of Nursing Studies, 51, 1289-1304, 2014	Systematic review - included studies checked for inclusion - 1 was identified
Almunef, M., Mason, J., Curtis, C., Jalal, Z., The role of primary care pharmacist in the management of chronic illnesses in young people aged 10-24 years: A systematic review, International Journal of Pharmacy Practice, 27, 48-49, 2019	Poster abstract
Almunef, M., Mason, J., Curtis, C., Jalal, Z., Management of chronic illness in young people aged 10-24 years: A systematic review to explore the role of primary care pharmacists, Archives of Disease in Childhood, 104, 2019	Conference abstract
Alvi, S., Priestley, J., Whitehead, A., Walker, J., Mushtaq, T., The impact on families of receiving a diagnosis of congenital hypothyroidism, Hormone Research in Paediatrics, 1), 549, 2015	Conference Abstract
Al-Zawaadi, M., Kayyali, R., Kelly, P., Evaluation of a pharmacist-led health intervention in a primary school, International journal of pharmacy practice, 27 (Supplement 1), 8-9, 2019	Conference Abstract
Ambrogi, V., Tezenas Du Montcel, S., Collin, E., Coutaux, A., Bourgeois, P., Bourdillon, F., Care-related pain in hospitalized patients: Severity and patient perception of management, European journal of pain (united kingdom), 19, 313-321, 2015	No qualitative data.
Ames, C. S., Richardson, J., Payne, S., Smith, P., Leigh, E., Mindfulness-based cognitive therapy for depression in adolescents, Child and Adolescent Mental Health, 19, 74-78, 2014	Population not in protocol - received psychological treatment for depression/anxiety and symptoms of depression
Ames, K., Rennick, J., & Baillargeon, S., A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit., Intensive & Critical Care Nursing, 27, 143-150, 2011	Population not in protocol - views of parents of children 0-17 with no way of discerning age.
Amin, A., Oragui, E., Khan, W., Puri, A., Psychosocial considerations of perioperative care in children, with a focus on effective management strategies, Journal of perioperative practice, 20, 198-202, 2010	Narrative review
Amsalem, D., Hasson-Ohayon, I., Gothelf, D., Roe, D., Subtle ways of stigmatization among professionals: The subjective	Population not in protocol - no way of identifying age of participant

Study	Reason for Exclusion
experience of consumers and their family members, Psychiatric rehabilitation journal, 41, 163-168, 2018	
Anderson, C., Lupfer, A., Shattuck, P. T., Barriers to receipt of services for young adults with autism, Pediatrics, 141, S300-S305, 2018	Population not in protocol - young adults with autism who had left high school in the past 15 years.
Anderson, C., Roy, T., Patient experiences of taking antidepressants for depression: A secondary qualitative analysis, Research in Social and Administrative Pharmacy, 9, 884-902, 2013	No qualitative data for under 18s
Anderson, E. S., Ford, J. S., Learning to listen: A patient led innovation to improve student's communication with patient feedback, Medical education, supplement, 2), 118-119, 2011	Conference Abstract
Angelopoulou, M. V., Oulis, C. J., Kavvadia, K., School-based oral health-education program using experiential learning or traditional lecturing in adolescents: a clinical trial, International dental journal, 64, 278-284, 2014	No qualitative data.
Angold, A., Erkanli, A., Copeland, W., Goodman, R., Fisher, P. W., Costello, E. J., Psychiatric diagnostic interviews for children and adolescents: A comparative study, Journal of the American Academy of Child and Adolescent Psychiatry, 51, 506-517, 2012	No qualitative data
Anonymous,, The development and analysis of feedback from a pilot chronic pain group at the Royal Manchester Children's Hospital, Rheumatology (united kingdom), 56 (Supplement 7), vii30, 2017	Conference Abstract
Ansmann, L., Kowalski, C., Ernstmann, N., Ommen, O., Pfaff, H., Patients' perceived support from physicians and the role of hospital characteristics, International Journal for Quality in Health Care, 24, 501-8, 2012	No qualitative data
Antao, V., Evaluation of post-diagnostic support to families and children with autism spectrum disorder, Developmental medicine and child neurology, 4), 69, 2010	Conference Abstract
Anttila, A., Rappaport, D. I., Tijerino, J., Zaman, N., Sharif, I., Interpretation Modalities Used on Family-Centered Rounds: Perspectives of Spanish-Speaking Families, Hospital Pediatrics, 7, 492-498, 2017	Views of parents with age of children not reported.
Arai, L., Bettany-Saltikov, J., Hamilton, S., Findings from a small-scale, exploratory content analysis of information provided to AIS patients and their parents from NHS Scoliosis Hospital Clinics, Scoliosis. Conference: 9th International Conference on Conservative Management of Spinal Deformities SOSORT, 8, 2012	Conference Abstract
Archibald, Mandy, Scott, Shannon, Hartling, Lisa, Mapping the waters: A scoping review of the use of visual arts in pediatric populations with health conditions, Arts & Health: An International Journal of Research, Policy and Practice, 6, 5-23, 2014	Systematic review - included studies checked for inclusion - 1 was identified.
Arheiam, A., Albadri, S., Laverty, L., Harris, R., Reasons for low adherence to diet-diaries issued to pediatric dental patients: A collective case study, Patient Preference and Adherence, 12, 1401-1411, 2018	No qualitative data for under 18s
Arheiam, A., Brown, S. L., Burnside, G., Higham, S. M., Albadri, S., Harris, R. V., The use of diet diaries in general dental practice in England, Community dental health, 33, 267-273, 2016	Views of healthcare professionals
Armitage, S., Swallow, V., Kolehmainen, N., Ingredients and change processes in occupational therapy for children: a grounded theory study, Scandinavian journal of occupational therapy, 24, 208-213, 2017	Not relevant to privacy and confidentiality

Study	Reason for Exclusion
Armoiry, Xavier, Sturt, Jackie, Phelps, Emma Elizabeth, Walker, Clare-Louise, Court, Rachel, Taggart, Frances, Sutcliffe, Paul, Griffiths, Frances, Atherton, Helen, Digital clinical communication for families and caregivers of children or young people with short- or long-term conditions: Rapid review, Journal of Medical Internet Research Vol 20(1), 2018, ArtID e5, 20, 2018	Systematic review - included studies checked for inclusion - 1 was identified
Armoogum, J., Cathcart, E., Cazenove, E., Knott, C., Mathambo, N., Tompsitt, L., Vevers, J., Wall, M., Bridging the gap: Giving information to young people undergoing bone marrow transplants using modern media, Bone Marrow Transplantation, 1), S421, 2011	Conference Abstract
Arnab, Sylvester, Brown, Katherine, Clarke, Samantha, Dunwell, Ian, Lim, Theodore, Suttie, Neil, Louchart, Sandy, Hendrix, Maurice, de Freitas, Sara, The development approach of a pedagogically-driven serious game to support Relationship and Sex Education (RSE) within a classroom setting, Computers & Education, 69, 15-30, 2013	Description of health education tool development
Arnott, J., Hesselgreaves, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Enhancing Communication about Paediatric Medicines: Lessons from a Qualitative Study of Parents' Experiences of Their Child's Suspected Adverse Drug Reaction, Plos one, 7 (10) (no pagination), 2012	Not related to privacy and confidentiality
Arnott, J., Nunn, A. J., Mannix, H., Peak, M., Pirmohamed, M., Smyth, R. L., Turner, M. A., Young, B., Communicating with parents following a suspected adverse drug reaction in a child: Who says what and when?, Archives of disease in childhood, 3), A10-A11, 2015	Conference Abstract
Arnott, J., Turner, M. A., Hesselgreave, H., Nunn, A. J., Peak, M., Pirmohamed, M., Smyth, R. L., Young, B., Parents' experiences of adverse drug reations in children: Qualitative study, Pharmacoepidemiology and Drug Safety, 21 (1), 112, 2012	Conference Abstract
Aronson, P. L., Shapiro, E. D., Niccolai, L. M., Fraenkel, L., Shared Decision-Making with Parents of Acutely Ill Children: A Narrative Review, Academic pediatrics, 18, 3-7, 2018	Systematic review - included studies checked for inclusion, no relevant studies
Ashcraft, L. E., Asato, M., Houtrow, A. J., Kavalieratos, D., Miller, E., Ray, K. N., Parent Empowerment in Pediatric Healthcare Settings: A Systematic Review of Observational Studies, Patient, 12, 199-212, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Aslam, A., Children's preference in selecting an emollient of their choice, British journal of dermatology, 1), 116, 2009	Conference Abstract
Astbury, R., Shepherd, A., Cheyne, H., Working in partnership: the application of shared decision-making to health visitor practice, Journal of Clinical Nursing, 26, 215-224, 2017	Not related to privacy and confidentiality
Aston, Hermione J., Lambert, Nathan, Young people's views about their involvement in decision-making, Educational Psychology in Practice, 26, 41-51, 2010	Setting not in protocol - Shared decision making in education only
Aston, J., Terry, D., Nusgen, U., Champaneri, N., Prescribed antimicrobial therapy: What parents/carers are told and what they would like to know, Archives of Disease in Childhood. Conference: 18th Neonatal and Paediatric Pharmacists Group, NPPG Annual Conference. Liverpool United Kingdom. Conference Publication:, 98, 2013	Conference Abstract
Aston, J., Wilson, K. A., Terry, D. R. P., The treatment-related experiences of parents, children and young people with regular prescribed medication, International journal of clinical pharmacy, 41, 113-121, 2019	Views of parents with no way of discerning age of children
Aston, J., Wilson, K., Terry, D., Starting a new medicine study, Archives of disease in childhood, 101 (9), A28, 2016	Conference Abstract

Study	Reason for Exclusion
Atkins, E., Colville, G., John, M., Finding the way to a 'new normal': Families' recovery in the year after a paediatric intensive care admission, Pediatric critical care medicine, 1), A3-A4, 2011	Conference Abstract
Aubugeau-Williams, P., Brierley, J., Consent in paediatric intensive care: A qualitative study of parental & professional views, Archives of Disease in Childhood. Conference: Great Ormond Street Hospital Conference, GOSH, 102, 2017	Conference Abstract
Audrey, S., Batista Ferrer, H., Ferrie, J., Evans, K., Bell, M., Yates, J., Roderick, M., Macleod, J., Hickman, M., Impact and acceptability of self-consent procedures for the school-based human papillomavirus vaccine: A mixed-methods study protocol, BMJ open, 8 (3) (no pagination), 2018	Published protocol
Azevedo, Avds, Lanconi, A. C. Junior, Crepaldi, M. A., Nursing team, family and hospitalized child interaction: an integrative review, Ciencia & Saude ColetivaCienc, 22, 3653-3666, 2017	Systematic review - included studies checked for inclusion - 1 was identified
Azzopardi, L. M., Serracino-Inglott, A., Zarb-Adami, M., Portanier, F. S., Evaluation of patient information leaflets for non-prescription medicines, International journal of pharmacy practice, 2), 81-82, 2010	Conference Abstract
Badri, P., Saltaji, H., Flores-Mir, C., Amin, M., Factors affecting children's adherence to regular dental attendance: a systematic review, Journal of the American Dental Association (1939), 145, 817-828, 2014	Systematic review - included studies checked for inclusion - 1 was identified
Bailey, J. V., Webster, R., Hunter, R., Freemantle, N., Rait, G., Michie, S., Estcourt, C., Anderson, J., Gerressu, M., Stephenson, J., et al.,, The Men's Safer Sex (MenSS) trial: protocol for a pilot randomised controlled trial of an interactive digital intervention to increase condom use in men, BMJ open, 5, e007552, 2015	Published protocol
Baird, Jennifer, Davies, Betty, Hinds, Pamela S., Baggott, Christina, Rehm, Roberta S., What impact do hospital and unit-based rules have upon patient and family-centered care in the pediatric intensive care unit?, Journal of pediatric nursingJ Pediatr Nurs, 30, 133-142, 2015	Population not in protocol - age >18 years old.
Baker, Erika, Baibazarova, Eugenia, Ktistaki, Georgia, Shelton, Katherine H., van Goozen, Stephanie H., Development of fear and guilt in young children: Stability over time and relations with psychology, Development and psychopathology, 24, 833-845, 2012	No qualitative data
Balato, N., Megna, M., Di Costanzo, L., Balato, A., Ayala, F., Educational and motivational support service: a pilot study for mobile-phone-based interventions in patients with psoriasis, British journal of dermatology, 168, 201â 205, 2013	No qualitative data.
Bancroft, V., Ganesan, V., Pistrang, N., Murphy, T., How adolescents and their parents understand and manage paediatric stroke, Developmental Medicine and Child Neurology, 3), 14-15, 2010	Conference Abstract
Banks, J., Cramer, H., Sharp, D. J., Shield, J. P., Turner, K. M., Identifying families' reasons for engaging or not engaging with childhood obesity services: a qualitative study, Journal of child health care, 18, 101â 110, 2014	Population not in protocol - parental views of children >5 years old. Children present in some interviews but no way of identifying which themes used data from them
Barber, S., Bekker, H., Marti, J., Pavitt, S., Khambay, B., Meads, D., Development of a Discrete-Choice Experiment (DCE) to Elicit Adolescent and Parent Preferences for Hypodontia Treatment, Patient, 12, 137-148, 2019	Description of questionnaire development. No qualitative data.

Study	Reason for Exclusion
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Assessment of information resources for people with hypodontia, Bdj Open, 4, 18001, 2018	Population not in protocol - views and experiences of healthcare professionals
Barber, S., Pavitt, S., Meads, D., Khambay, B., Bekker, H., Can the current hypodontia care pathway promote shared decision-making?, Journal of orthodontics, 46, 126-136, 2019	Not related to privacy and confidentiality
Boyden, P., Muniz, M., Laxton-Kane, M., Listening to the views of children with learning disabilities: An evaluation of a learning disability CAMHS service, Journal of Intellectual Disabilities, 17, 51-63, 2013	Not related to privacy and confidentiality
Brodsgaard, A., Pedersen, J. T., Larsen, P., Weis, J., Parents' and nurses' experiences of partnership in neonatal intensive care units: A qualitative review and meta-synthesis, Journal of Clinical Nursing, 28, 3117-3139, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Brown, Freddy Jackson, Guvenir, Jane, The experiences of children with learning disablilities, their carers and staff during a hospital admission, British Journal of Learning Disabilities, 37, 110-115, 2009	Not relevant to privacy and confidentiality
Byron et al, "You learn from each otherâ : LGBTIQ Young Peopleâ ™s Mental Health Help-seeking and the RAD Australia Online Directory. , 2016	Country: Australia
Cameron, M. A., Schleien, C. L., Morris, M. C., Parental presence on pediatric intensive care unit rounds, J Pediatr, 155, 522-8, 2009	Country: USA
Chaturvedi, Surabhi, Accessing psychological therapies: Homeless young people's views on barriers and facilitators, Counselling and Psychotherapy Research, 16, 54-63, 2016	Population not in protocol - age 16-25 with no further information.
Coker, T. R., Sareen, H. G., Chung, P. J., Kennedy, D. P., Weidmer, B. A., Schuster, M. A., Improving access to and utilization of adolescent preventive health care: the perspectives of adolescents and parents, J Adolesc Health, 47, 133-42, 2010	Country: USA
Comp, D., Improving parent satisfaction by sharing the inpatient daily plan of care: an evidence review with implications for practice and research, Pediatric nursing, 37, 237-242, 2011	Systematic review - included studies checked for inclusion, no relevant studies
Coyne, I., Children, parents, and healthcare professionalsâ ™ perspectives on childrenâ ™s participation in shared decision making, European Journal of Oncology, 15, 275-276, 2011	Conference abstract
Coyne, I., Amory, A., Kiernan, G., Gibson, F., Children's participation in shared decision-making: children, adolescents, parents and healthcare professionals' perspectives and experiences, Eur J Oncol Nurs, 18, 273-80, 2014	Country: Ireland
Coyne, I., Gallagher, P., Participation in communication and decision-making: children and young people's experiences in a hospital setting, J Clin Nurs, 20, 2334-43, 2011	Country: Ireland
Coyne, I., Kirwan, L., Ascertaining children's wishes and feelings about hospital life, J Child Health Care, 16, 293-304, 2012	Country: Ireland
Crowley, Making it matter: improving the health of homeless young people., 2012	Population not in protocol - age 16-25 with no further information.
Curtis-Tyler, K., Facilitating children's contributions in clinic? Findings from an in-depth qualitative study with children with Type 1 diabetes, Diabetic medicine, 29, 1303-1310, 2012	Not relevant to privacy and confidentiality
Daley, A. M., Polifroni, E. C., Sadler, L. S., "Treat Me Like a Normal Person!" A Meta-Ethnography of Adolescents' Expectations of Their Health Care Providers, Journal of pediatric nursing, 36, 70-83, 2017	Systematic review - included studies checked for inclusion, no relevant studies
Daniels, Karen, Cultural agents creating texts: A collaborative space adventure, Literacy, 48, 103-111, 2014	Not relevant to privacy and confidentiality

Study	Reason for Exclusion
Davey, A., Asprey, A., Carter, M., Campbell, J. L., Trust, negotiation, and communication: young adults' experiences of primary care services, BMC family practice, 14, 202, 2013	Population not in protocol - participants aged 18-25 years old.
Davies, Adam, Randall, Duncan, Perceptions of children's participation in their healthcare: A critical review, Issues in comprehensive pediatric nursing, 38, 202-221, 2015	Systematic review - included studies checked for inclusion, no relevant studies
Davies, E. B., Buchanan, H., An exploratory study investigating children's perceptions of dental behavioural management techniques, International journal of paediatric dentistry, 23, 297-309, 2013	No qualitative data.
Davies, Karen E., Marshall, Julie, Brown, Laura J., Goldbart, Juliet, Co-working: Parents' conception of roles in supporting their children's speech and language development, Child Language Teaching and Therapy, 33, 171-185, 2017	Not relevant to privacy and confidentiality
Davies-House, A., Ball, N., Balmer, C., Meeting and greeting in the clinical setting - are we doing what patients want?, British dental journal, 222, 457-461, 2017	No qualitative data
Day, E. R., Jones, L., Langner, R., Stirling, L. C., Hough, R., Bluebond-Langner, M., Teenagers' perspectives on their decisional involvement in the context of interactions with healthcare professionals, Archives of disease in childhood, 102 (Supplement 1), A2, 2017	Conference Abstract
Day, Emma, Jones, Louise, Langner, Richard, Bluebond-Langner, Myra, Current understanding of decision-making in adolescents with cancer: A narrative systematic review, Palliative Medicine, 30, 920-934, 2016	Systematic review - included studies checked for inclusion - 1 was identified
de Anstiss and Ziaian, Mental health help-seeking and refugee adolescents: Qualitative findings from a mixed-methods investigation, Aust Psychol, 45, 29-37, 2010	Country: Australia
De Vries MC, Bresters D, Kaspers GJL, et al, What constitutes the best interest of a child? Views of parents, children, and physicians in a pediatric oncology setting., AJOB Prim Res, 4, 1-10, 2012	Country: The Netherlands
Dean, L. A., An exploration of the experiences of young people who have been nursed on adult wards, Archives of disease in childhood, 1), A76, 2012	Conference Abstract
Dean, L., Black, S., Exploring the experiences of young people nursed on adult wards, British journal of nursing (Mark Allen Publishing), 24, 229-236, 2015	Not relevant to privacy and confidentiality
Deldar, K., Bahaadinbeigy, K., Tara, S. M., Teleconsultation and clinical decision making: A systematic review, Acta Informatica Medica, 24, 286-292, 2016	Population not in protocol - focus on medical professional views
DeLemos, D., Chen, M., Romer, A., Brydon, K., Kastner, K., Anthony, B., Hoehn, K. S., Building trust through communication in the intensive care unit: HICCC, Pediatric Critical Care Medicine, 11, 378-384, 2010	Population is parents with no way of ascertaining age of child.
Dewlett, S., Polychronakis, T., Ng, G. Y. T., Look who's talking: How well are we communicating with parents in the neonatal unit? A patient survey, Intensive Care Medicine, 37, S419-S420, 2011	Conference Abstract
Dhital, R., Whittlesea, C. M., Norman, I. J., Milligan, P., Community pharmacy service users' views and perceptions of alcohol screening and brief intervention, Drug and Alcohol Review, 29, 596-602, 2010	Age of respondents not given.
Dibley, L., Czuber-Dochan, W., Duncan, J., Artom, M., Burch, J., Wade, T., Verjee, A., Cann, D., Warusavitarne, J., Norton, C., Decision-making about emergency and planned stoma surgery for IBD: A qualitative exploration of patient and clinician perspectives, Journal of Crohn's and Colitis, 11 (Supplement 1), S487-S488, 2017	Conference Abstract

Study	Reason for Exclusion
Dickens, G., Picchioni, M., A systematic review of the terms used to refer to people who use mental health services: user perspectives, The International journal of social psychiatry, 58, 115-122, 2012	Systematic review - included studies checked for inclusion, no relevant studies
Dodoo, T., Murhad, Y., Batchelor, H. K., Stirling, H. F., Supporting young people to take their medication, Archives of Disease in Childhood, 102, A51, 2017	Conference Abstract
Donnellan, D., Murray, C., Harrison, J., An investigation into adolescents' experience of cognitive behavioural therapy within a child and adolescent mental health service, Clinical Child Psychology and Psychiatry, 18, 199-213, 2013	Not generalisable - specifically investigating attitudes to CBT-psychotherapy
Dovey-Pearce, Gail, Price, Christine, Wood, Helen, Scott, Tracy, Cookson, Jennifer, Corbett, Sally, Young people (13 to 21) with disabilities in transition from childhood to adulthood: An exploratory, qualitative study of their developmental experiences and health care needs, Educational and Child Psychology, 29, 86-100, 2012	Population not in protocol - age 13-21 with 82% over 16. No way of discerning age in results.
Downing, J., Gleeson, H., Clayton, P. E., Davis, J. R. E., Dimitri, P., Wales, J., Young, B., Callery, P., Communication with young people in paediatric and adult endocrine consultations: an intervention development and feasibility study, BMC Endocrine Disorders, 17, 33, 2017	Too specific - investigating if a forensic interview protocol aids BCYP with verbalising emotional reactions.
Drake, E. K., Urquhart, R., The Experiences of Young Adults Living with Metastatic/Advanced Cancer: A Scoping Review, Journal of Adolescent and Young Adult Oncology, 9, 145-156, 2020	Scoping review - included studies checked for inclusion, no relevant studies
Drewett, O., Hann, G., Price, N., Tipper, C., Devereux, E., A qualitative study to explore the use of the RCPCH epilepsy passport, Archives of disease in childhood, 102 (Supplement 1), A150, 2017	Conference Abstract
Duckett, Paul, Kagan, Carolyn, Sixsmith, Judith, Consultation and participation with children in healthy schools: Choice, conflict and context, American Journal of Community Psychology, 46, 167-178, 2010	Educational experiences of children and young adults.
Dugdale, E., Gerrard, G., Priestley, L., Mariappan, L., Choong, E. S., Follow up of low risk thyroid cancer patients by specialist nurse phone consultations rather than via clinic visits, European Thyroid Journal, 1), 165-166, 2014	Conference Abstract
Dunne, A., Carolan, R., Swords, L., Fortune, G., Patient and family perspectives of paediatric psychogenic non-epileptic seizures: A systematic review, Seizure, 71, 279-285, 2019	Systematic review - included studies checked for inclusion - 1 was identified
Duran, C., Curtis-Tyler, K., Exploring children's healthcare experiences of haematopoietic stem cell transplantation (HSCT)- a small scale study for service improvement, Bone Marrow Transplantation, 1), S257, 2016	Conference Abstract
Edbrooke-Childs, J., Jacob, J., Argent, R., Patalay, P., Deighton, J., Wolpert, M., The relationship between child- and parent-reported shared decision making and child-, parent-, and clinician-reported treatment outcome in routinely collected child mental health services data, Clinical Child Psychology & Psychiatry, 21, 324-38, 2016	No qualitative data
Edwards, M., Lawson, C., Rahman, S., Conley, K., Phillips, H., Uings, R., What does quality healthcare look like to adolescents and young adults? Ask the experts!, Clinical Medicine, Journal of the Royal College of Physicians of London, 16, 146-151, 2016	Age of participants 17-25 with no way of discerning age of individual quotes.
Egbunike, J. N., Shaw, C., Porter, A., Button, L. A., Kinnersley, P., Hood, K., Bowden, S., Bale, S., Snooks, H., Edwards, A., Streamline triage and manage user expectations: lessons from a qualitative study of GP out-of-hours services, British Journal of General Practice, 60, e83-97, 2010	No way of determining age source of data.

Study	Reason for Exclusion
El Miedany, Y., Lotfy, H., El Aroussy, N., Mekkawy, D., Nasef, S. I., Hassan, W., El Deriny, G., Farag, Y., Eissa, M., Almedany, S., El Gaafary, M., Facilitating patient centred care: The development of illustrated multidimensional patient reported outcome measure for children with juvenile idiopathic arthritis, Annals of the rheumatic diseases, 77 (Supplement 2), 502, 2018	Conference Abstract
Elwell, L., Grogan, S., Coulson, N., Adolescents living with cancer: the role of computer-mediated support groups, Journal of health psychology, 16, 236-248, 2011	Age of study population not reported.
Ely, B., Chen Lim, M., Becker, E., Wilson Jr, B., The pain experience of hospitalized youth: Assessment and management preferences, Journal of Pain, 1), S3, 2016	Conference Abstract
Ely, E., Chen-Lim, M. L., Carpenter, K. M., Wallhauser, E., Friedlaender, E., Pain Assessment of Children with Autism Spectrum Disorders, Journal of developmental and behavioral pediatrics : JDBP, 37, 53-61, 2016	Not relevant to privacy and confidentiality
Epstein, E. G., Arechiga, J., Dancy, M., Simon, J., Wilson, D., Alhusen, J. L., Integrative Review of Technology to Support Communication With Parents of Infants in the NICU, 46, 357-366, 2017	Duplicate
Epstein, Elizabeth G., Arechiga, Jaqueline, Dancy, Margaret, Simon, Jordan, Wilson, Daniel, Alhusen, Jeanne L., Integrative review of technology to support communication with parents of infants in the NICU, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 46, 357-366, 2017	Systematic review - included studies checked for inclusion - 2 were identified
Epstein, Elizabeth Gingell, Sherman, Jessica, Blackman, Amy, Sinkin, Robert A., Testing the feasibility of Skype and FaceTime updates with parents in the neonatal intensive care unit, American Journal of Critical Care, 24, 290-296, 2015	No qualitative data.
Evans, J., Rose, D., Flach, C., Csipke, E., Glossop, H., McCrone, P., Craig, T., Wykes, T., VOICE: developing a new measure of service users' perceptions of inpatient care, using a participatory methodology, Journal of Mental Health, 21, 57-71, 2012	Outcome not in protocol - validity study of experience measure
Evans, N., Experiences of a child and adolescent mental health service, Nursing Children and Young People, 29, 41-45, 2017	General article about first experience of accessing mental health services - no themes relevant to how healthcare staff should communicate with children and young people/parents of babies
Everley, S., Children's understanding of physical activity and health, Obesity facts, 10 (Supplement 1), 227, 2017	Conference Abstract
Fangstrom, Karin, Sarkadi, Anna, Lucas, Steven, Calam, Rachel, Eriksson, Maria, "And they gave me a shot, it really hurt"-Evaluative content in investigative interviews with young children, Children and Youth Services Review, 82, 434-443, 2017	Too specific - investigating if a forensic interview protocol aids BCYP with verbalising emotional reactions.
Fawcett, R., Porritt, K., Stern, C., Carson-Chahhoud, K., Experiences of parents and carers in managing asthma in children: A qualitative systematic review, JBI Database of Systematic Reviews and Implementation Reports, 17, 793-984, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Fazel, M., Garcia, J., Stein, A., The right location? Experiences of refugee adolescents seen by school-based mental health services, Clinical Child Psychology and Psychiatry, 21, 368-380, 2016	Not relevant to privacy and confidentiality
Flett, A. M., Hall, M., McCarthy, C., Marshman, Z., Benson, P. E., Does the British Orthodontic Society orthognathic DVD aid a	Not related to privacy and confidentiality

Study	Reason for Exclusion
prospective patient's decision making? A qualitative study, Journal of orthodontics, 41, 88-97, 2014	
Flynn,D., Knoedler,M.A., Hess,E.P., Murad,M.H., Erwin,P.J., Montori,V.M., Thomson,R.G., Engaging patients in health care decisions in the emergency department through shared decision-making: A systematic review, Academic Emergency Medicine, 19, 959-967, 2012	Systematic review - included studies checked for inclusion, no relevant studies
Fortier, M. A., Chorney, J. M., Rony, R. Y. Z., Perret-Karimi, D., Rinehart, J. B., Camilon, F. S., Kain, Z. N., Children's desire for perioperative information, Anesthesia and Analgesia, 109, 1085-1090, 2009	Not relevant to privacy and confidentiality
Foster, M. J., Whitehead, L., Maybee, P., Cullens, V., The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: a metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Systematic review - included studies checked for inclusion, no relevant studies
Foster, Mandie Jane, Whitehead, Lisa, Maybee, Patricia, Cullens, Victoria, The parents', hospitalized child's, and health care providers' perceptions and experiences of family centered care within a pediatric critical care setting: A metasynthesis of qualitative research, Journal of Family Nursing, 19, 431-468, 2013	Systematic review - included studies checked for inclusion - 1 was identified.
Franck, L. S., Oulton, K., Bruce, E., Parental involvement in neonatal pain management: an empirical and conceptual update, J Nurs Scholarsh, 44, 45-54, 2012	Not relevant to privacy and confidentiality
Franck, L. S., Oulton, K., Nderitu, S., Lim, M., Fang, S., Kaiser, A., Parent involvement in pain management for NICU infants: A randomized controlled trial, PediatricsPediatrics, 128, 510-518, 2011	No qualitative data
Freer, Y., McIntosh, N., Teunisse, S., Anand, K. J., Boyle, E. M., More information, less understanding: a randomized study on consent issues in neonatal research, Pediatrics, 123, 1301â 1305, 2009	No qualitative data.
Gates, M., Shulhan-Kilroy, J., Featherstone, R., MacGregor, T., Scott, S. D., Hartling, L., Parent experiences and information needs related to bronchiolitis: A mixed studies systematic review, Patient Education and Counseling, 102, 864-878, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Giambra, B. K., Stiffler, D., Broome, M. E., An integrative review of communication between parents and nurses of hospitalized technology-dependent children, Worldviews on evidence-based nursing / Sigma Theta Tau International, Honor Society of Nursing, 11, 369-375, 2014	Systematic review - included studies checked for inclusion - 1 was identified
Gibson, Faith, Aldiss, Susie, Horstman, Maire, Kumpunen, Stephanie, Richardson, Alison, Children and young people's experiences of cancer care: A qualitative research study using participatory methods, International journal of nursing studies, 47, 1397-1407, 2010	Not related to privacy and confidentiality
Gondek, D., Edbrooke-Childs, J., Velikonja, T., Chapman, L., Saunders, F., Hayes, D., Wolpert, M., Facilitators and Barriers to Person-centred Care in Child and Young People Mental Health Services: A Systematic Review, Clinical Psychology & Psychotherapy, 24, 870-886, 2017	Systematic review - included studies checked for inclusion, no relevant studies
Graham, R., Pemstein, D., & Curley, M. , Experiencing the pediatric intensive care unit: Perspective from parents of children with severe antecedent disabilities. , Critical Care Medicine, 37, 2064-2070, 2009	Country: USA
Grainger, H., Joyce, C., Beuschel, S., Davies, A., Shreeve, K., Super blood! development of a child patient information leaflet, Transfusion Medicine, 2), 45, 2014	Conference Abstract

Study	Reason for Exclusion
Grealish, A., Tai, S., Hunter, A., Morrison, A. P., Qualitative exploration of empowerment from the perspective of young people with psychosis, Clinical Psychology & Psychotherapy, 20, 136-148, 2013	Outcomes not in protocol â " No themes relating to shared planning or decision making
Gregory, J. W., UK: Communication in patient-centered care, Pediatric diabetes, 18), 8, 2013	Conference Abstract
Grist, Rebecca, Porter, Joanna, Stallard, Paul, Mental health mobile apps for preadolescents and adolescents: A systematic review, Journal of medical internet research, 19, 153-166, 2017	No qualitative data.
Guest, J., Cheal, H., Welcome to Ward 3 at the Great North children's hospital-a fun guide to your first two days with us (DVD format patient family information), Bone Marrow Transplantation, 1), S519, 2016	Conference Abstract
Gund A, Sjoqvist BA, Wigert H, Hentz E, Lindecrantz K, Bry K, A randomized controlled study about the use of eHealth in the home health care of premature infants, Neonatal Intensive Care, 26, 42-50, 2013	Country: Sweden
Gurung, G., Richardson, A., Wyeth, E., Edmonds, L., Derrett, S., Child/youth, family and public engagement in paediatric services in high-income countries: A systematic scoping review, Health expectations : an international journal of public participation in health care and health policy, 23, 261-273, 2020	Systematic review - included studies checked for inclusion, no relevant studies
Gutman, T., Hanson, C. S., Bernays, S., Craig, J. C., Sinha, A., Dart, A., Eddy, A. A., Gipson, D. S., Bockenhauer, D., Yap, H. K., Groothoff, J., Zappitelli, M., Webb, N. J. A., Alexander, S. I., Goldstein, S. L., Furth, S., Samuel, S., Blydt-Hansen, T., Dionne, J., Michael, M., Wenderfer, S. E., Winkelmayer, W. C., Currier, H., McTaggart, S., Walker, A., Ralph, A. F., Ju, A., James, L. J., Carter, S., Tong, A., Child and Parental Perspectives on Communication and Decision Making in Pediatric CKD: A Focus Group Study, American Journal of Kidney Diseases, 72, 547-559, 2018	Countries: Australia, Canada and USA
Hajivassiliou, E. C., Hajivassiliou, C. A., Informed consent in primary dental care: patients' understanding and satisfaction with the consent process, British dental journal, 219, 221-224, 2015	Population not in protocol - adults with capacity.
Hamama, Liat, Ronen, Tammie, Children's drawings as a self-report measurement, Child & Family Social Work, 14, 90-102, 2009	Country: Israel
Hamann, J., Kohl, S., McCabe, R., Buhner, M., Mendel, R., Albus, M., Bernd, J., What can patients do to facilitate shared decision making? A qualitative study of patients with depression or schizophrenia and psychiatrists, Social psychiatry and psychiatric epidemiology, 51, 617-625, 2016	Adult population only, aged 18-65 years old.
Harper, B., Dickson, J. M., Bramwell, R., Experiences of young people in a 16-18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Population not in protocol
Harper, Ben, Dickson, Joanne M., Bramwell, Ros, Experiences of young people in a 16â "18 Mental Health Service, Child and Adolescent Mental Health, 19, 90-96, 2014	Duplicate
Hartling, L., Scott, S., Pandya, R., Johnson, D., Bishop, T., Klassen, T. P., Storytelling as a communication tool for health consumers: development of an intervention for parents of children with croup. Stories to communicate health information, BMC pediatrics, 10, 64, 2010	Narrative description of intervention development.
Harvey, M. E., Redshaw, M. E., Analysis of audio-recordings of discussions between parents and clinicians regarding scanning results, Archives of Disease in Childhood: Fetal and Neonatal Edition, 99, A57, 2014	Conference Abstract

Study	Reason for Exclusion
Heath, G., Greenfield, S., Redwood, S., The meaning of 'place' in families' lived experiences of paediatric outpatient care in different settings: A descriptive phenomenological study, Health and Place, 31, 46-53, 2015	Not related to privacy and confidentiality
Heinemann, A. B., Hellstrom-Westas, L., Hedberg Nyqvist, K., Factors affecting parents' presence with their extremely preterm infants in a neonatal intensive care room, Acta Paediatr, 102, 695-702, 2013	Country: Sweden
Hemsley, B., Bastock, K., Baladin, S., Davidson, B., Scarinci, N., Worrall, L., Communication during hospitalization: The path to better healthcare for children and adults with cerebral palsy, Developmental Medicine and Child Neurology, 54, 31-32, 2012	Conference Abstract
Hill, C., Knafl, K. A., Santacroce, S. J., Family-Centered Care From the Perspective of Parents of Children Cared for in a Pediatric Intensive Care Unit: An Integrative Review, Journal of pediatric nursing., 16, 2017	Systematic review - included studies checked for inclusion - 6 were identified
Hill, J., Masding, M. G., The development of an innovative mobile phone App for Type 1 diabetes alcohol education, Diabetic medicine, 1), 112, 2013	Conference Abstract
Hinton, D., Kirk, S., Paediatric multiple sclerosis: A qualitative study of families' diagnosis experiences, Archives of disease in childhood, 100, 623-629, 2015	Not related to privacy and confidentiality
Hughes, B., O'Brien, M. R., Flynn, A., Knighting, K., The engagement of young people in their own advance care planning process: A systematic narrative synthesis, Palliative Medicine, 32, 1147-1166, 2018	Systematic review - included studies checked for inclusion, no relevant studies
Hughes, V. C., Phillips, S., Exploring the pre-hospitalisation needs of parents of children with cystic fibrosis, Journal of Cystic Fibrosis, 13, S115, 2014	Conference Abstract
Hunt, A., Brown, E., Coad, J., Staniszewska, S., Hacking, S., Chesworth, B., Chambers, L., 'Why does it happen like this?' Consulting with users and providers prior to an evaluation of services for children with life limiting conditions and their families, Journal of child health care : for professionals working with children in the hospital and community, 19, 320-333, 2015	Not relevant to privacy and confidentiality
Ignatowicz, Agnieszka, Slowther, Anne-Marie, Elder, Patrick, Bryce, Carol, Hamilton, Kathryn, Huxley, Caroline, Forjaz, Vera, Sturt, Jackie, Griffiths, Frances, Ethical implications of digital communication for the patient-clinician relationship: Analysis of interviews with clinicians and young adults with long term conditions (the LYNC study), BMC Medical Ethics Vol 19 2018, ArtID 11, 19, 2018	Population not in protocol - clinicians and patients (16-24) with chronic physical and mental health conditions. No way of determining source of data.
Ion, R., Cropper, J., Walters, H., Involving young people in decision making about sequential cochlear implantation, Cochlear Implants International, 14, S44-S47, 2013	No qualitative data
Jacob, J., Edbrooke-Childs, J., Holley, S., Law, D., Wolpert, M., Horses for courses? A qualitative exploration of goals formulated in mental health settings by young people, parents, and clinicians, Clinical child psychology and psychiatry, 21, 208-223, 2016	Too specific - individual goal examples used.
Jacob, J., Edbrooke-Childs, J., Law, D., Wolpert, M., Measuring what matters to patients: Using goal content to inform measure choice and development, Clinical Child Psychology and Psychiatry, 22, 170-186, 2017	No qualitative data
Jansen, R., Reid, M., Caregivers of adolescents with mental health issues using communication technology: a systematic review, JMIR mHealth and uHealth, 2020	Systematic review - included studies checked for inclusion, no relevant studies
Jefferies, K., Haest, J., Edge, J., Admission pack for newly diagnosed diabetes: Help or hindrance?, Archives of disease in childhood, 1), A120, 2012	Conference Abstract

Study	Reason for Exclusion
Jenkins, Peter, Having confidence in therapeutic work with young people: Constraints and challenges to confidentiality, British Journal of Guidance & Counselling, 38, 263-274, 2010	Narrative review
Joanne, C., Deepa, P., Emily, W., Vanessa, M., An evaluation of the views of adolescent patients with a learning disability and their carers on a medicines information leaflet, Archives of Disease in Childhood. Conference: 22nd Annual Conference of the Neonatal and Paediatric Pharmacists Group. United Kingdom, 103, 2018	Conference Abstract
Jobbins, A., Baily, C., Wilkinson, G., Menzies, J., Mildner, R., Adolescents in PICU: Are we meeting their needs?, Pediatric critical care medicine, 1), A37-A38, 2011	Conference Abstract
Kean, S., Children and young people visiting an adult intensive care unit, Journal of advanced nursing, 66, 868-877, 2010	Reports experiences of BCYP visiting family members in ICU
Kerri, O., Byron, P., Improving strategies to better support adolescents with cancer: The creation of an "adolescent-friendly oncology ward", Pediatric Blood and Cancer, 53 (5), 751-752, 2009	Conference Abstract
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decision-making for people with asthma, Cochrane Database of Systematic Reviews, 2017 (10) (no pagination), 2017	No qualitative data.
Kew, K. M., Malik, P., Aniruddhan, K., Normansell, R., Shared decisionâ making for people with asthma, Cochrane Database of Systematic Reviews, 2017	Duplicate
Latour, Jos M., van Goudoever, Johannes B., Schuurman, Beatrix Elink, Albers, Marcel J. I. J., van Dam, Nicolette A. M., Dullaart, Eugenie, van Heerde, Marc, Verlaat, Carin W. M., van Vught, Elise M., Hazelzet, Jan A., A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units, Intensive care medicineIntensive Care Med, 37, 319-325, 2011	Country: The Netherlands
Law, H., Gee, B., Dehmahdi, N., Carney, R., Jackson, C., Wheeler, R., Carroll, B., Tully, S., Clarke, T., What does recovery mean to young people with mental health difficulties?- "It's not this magical unspoken thing, it's just recovery", Journal of Mental Health, 2020	Not related to privacy and confidentiality
Lawrence, M., Young adults' experience of stroke: a qualitative review of the literature, British journal of nursing (Mark Allen Publishing), 19, 241-248, 2010	Population not in protocol - adults 18-65
Lawton, J., Waugh, N., Noyes, K., Barnard, K., Harden, J., Bath, L., Stephen, J., Rankin, D., Improving communication and recall of information in paediatric diabetes consultations: A qualitative study of parents' experiences and views, BMC pediatrics, 15 (1) (no pagination), 2015	Population not in protocol - parents of children with Type 1 diabetes. Only 2 quotes gave age of patients, both over 5.
Lea, S., Martins, A., Morgan, S., Cargill, J., Taylor, R. M., Fern, L. A., Online information and support needs of young people with cancer: A participatory action research study, Adolescent Health, Medicine and Therapeutics, 9, 121-135, 2018	Age range 13-24, no way of determining source of data
Lerch, Matthew F., Thrane, Susan E., Arnett, Babler Baucom Bishay Borus Dashiff Gaston Heath Hilliard Kayle King Knopf Miller Polfuss Sanders Sawicki Seiffge-Krenke Skinner Stevens Vygotsky Williams, Adolescents with chronic illness and the transition to self-management: A systematic review, Journal of Adolescence, 72, 152-161, 2019	Systematic review. References checked for possible included studies - none were identified.
Levin, A. B., Fisher, K. R., Cato, K. D., Zurca, A. D., October, T. W., An Evaluation of Family-Centered Rounds in the PICU: Room for Improvement Suggested by Families and Providers, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric	Country: USA

Study	Reason for Exclusion
Intensive and Critical Care SocietiesPediatr Crit Care Med, 16, 801-7, 2015	
LGBT Youth Scotland et al, Life in Scotland for LGBT young people: Health Report, 2013	Grey literature survey
Lindberg, Birgitta, Axelsson, Karin, Öhrling, Kerstin, Taking care of their baby at home but with nursing staff as support: The use of videoconferencing in providing neonatal support to parents of preterm infants, Journal of Neonatal Nursing, 15, 47-55, 2009	Country: Sweden
Lion, K. C., Kieran, K., Desai, A., Hencz, P., Ebel, B. E., Adem, A., Forbes, S., Kraus, J., Gutman, C., Horn, I., Audio-Recorded Discharge Instructions for Limited English Proficient Parents: A Pilot Study, Joint Commission Journal on Quality and Patient Safety, 45, 98-107, 2019	No qualitative data.
Liossi, C., Noble, G., Franck, L. S., How parents make sense of their young children's expressions of everyday pain: A qualitative analysis, European journal of pain (united kingdom), 16, 1166-1175, 2012	Not relevant to privacy and confidentiality
Lipstein, E. A., Brinkman, W. B., Britto, M. T., What is known about parents' treatment decisions? A narrative review of pediatric decision making, Medical decision making : an international journal of the Society for Medical Decision Making, 32, 246-258, 2012	Narrative review
Little, P., White, P., Kelly, J., Everitt, H., Gashi, S., Bikker, A., Mercer, S., Verbal and non-verbal behaviour and patient perception of communication in primary care: An observational study, British journal of general practice, 65, e357-e365, 2015	No qualitative data
Livesley, J., Long, T., Children's experiences as hospital in-patients: Voice, competence and work. Messages for nursing from a critical ethnographic study, International journal of nursing studies, 50, 1292-1303, 2013	Not related to privacy and confidentiality
Loewenstein, K., Barroso, J., Phillips, S., The Experiences of Parents in the Neonatal Intensive Care Unit: An Integrative Review of Qualitative Studies Within the Transactional Model of Stress and Coping, The Journal of perinatal & neonatal nursing, 33, 340-349, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Lowes, L., Eddy, D., Channon, S., McNamara, R., Robling, M., Gregory, J. W., The experience of living with type 1 diabetes and attending clinic from the perception of children, adolescents and carers: analysis of qualitative data from the DEPICTED study, Journal of pediatric nursing, 30, 54â 62, 2015	Not related to privacy and confidentiality
Macdonald, M. E., Liben, S., Carnevale, F. A., Cohen, S. R., An office or a bedroom? Challenges for family-centered care in the pediatric intensive care unit, J Child Health Care, 16, 237-49, 2012	Country: Canada
Martin-Kerry, J. M., Knapp, P., Atkin, K., Bower, P., Watt, I., Stones, C., Higgins, S., Sheridan, R., Preston, J., Horton Taylor, D., Baines, P., Young, B., Supporting children and young people when making decisions about joining clinical trials: Qualitative study to inform multimedia website development, BMJ open, 9 (1) (no pagination), 2019	Population not in protocol - age of protocol range from 6-19 which no way of discerning age of quotes
Masoumi, M., Shahhosseini, Z., Self-care challenges in adolescents: A comprehensive literature review, International Journal of Adolescent Medicine and Health, 31, 0152, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Mc Manus, V., Savage, E., Cultural perspectives of interventions for managing diabetes and asthma in children and adolescents from ethnic minority groups, Child: Care, Health and Development, 36, 612-622, 2010	Systematic review - included studies checked for inclusion, no relevant studies
McCormack, A., Norrish, S., Parker, L., Frampton, I., Consulting with young people about healthcare. Part 2: Experience of long-term health conditions, Pediatric Health, 4, 167-175, 2010	Not related to privacy and confidentiality

Study	Reason for Exclusion
McKenna, K., Collier, J., Hewitt, M., Blake, H., Parental involvement in paediatric cancer treatment decisions, Eur J Cancer Care (Engl), 19, 621-30, 2010	No qualitative data
McMillan, S. S., Wilson, B., Stapleton, H., Wheeler, A. J., Young people's experiences with mental health medication: A narrative review of the qualitative literature, Journal of Mental Health, 2020	Systematic review - included studies checked for inclusion, no relevant studies
McPherson, G., Jefferson, R., Kissoon, N., Kwong, L., Rasmussen, K., Toward the inclusion of parents on pediatric critical care unit rounds, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care SocietiesPediatr Crit Care Med, 12, e255-61, 2011	Country: Canada
Miller, V. A., Parent-child collaborative decision making for the management of chronic illness: a qualitative analysis, Fam Syst Health, 27, 249-66, 2009	Country: USA
Mimmo, L., Harrison, R., Taking time to care: Meta narrative review of the experience of parents with a child with intellectual disability in hospital, Journal of Intellectual Disability Research, 63, 812, 2019	Conference abstract
Mimmo, L., Woolfenden, S., Travaglia, J., Harrison, R., Partnerships for safe care: A meta-narrative of the experience for the parent of a child with Intellectual Disability in hospital, Health Expectations, 22, 1199-1212, 2019	Systematic review - included studies checked for inclusion, no relevant studies
Mitchell, Wendy, Parents' accounts: Factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making, Children and Youth Services Review, 34, 1560-1569, 2012	Not related to privacy and confidentiality
Nair, T., Savulescu, J., Everett, J., Tonkens, R., Wilkinson, D., Settling for second best: when should doctors agree to parental demands for suboptimal medical treatment?, Journal of medical ethics, 43, 831-840, 2017	Empirical and ethical analyses only
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parent's information seeking in acute childhood illness: what helps and what hinders decision making?, Health expectations : an international journal of public participation in health care and health policy, 18, 3044-3056, 2015	Systematic review - included studies checked for inclusion - 1 was identified
Neill, S. J., Jones, C. H., Lakhanpaul, M., Roland, D. T., Thompson, M. J., Parents' help-seeking behaviours during acute childhood illness at home: A contribution to explanatory theory, Journal of child health care : for professionals working with children in the hospital and community, 20, 77-86, 2016	Not relevant to privacy and confidentiality
Neill, S., Roland, D., Jones, C. H. D., Thompson, M., Lakhanpaul, M., Information resources to aid parental decision-making on when to seek medical care for their acutely sick child: A narrative systematic review, BMJ open, 5 (12) (no pagination), 2015	Systematic review - included studies checked for inclusion, no relevant studies
Nelson, P. A., Kirk, S. A., Parents' perspectives of cleft lip and/or palate services: A qualitative interview, Cleft Palate-Craniofacial Journal, 50, 275-285, 2013	Too specific â " experiences of cleft lip and/or palate services.
Ngo-Metzger, Q., Hayes, G. R., Yunan, Chen, Cygan, R., Garfield, C. F., Improving communication between patients and providers using health information technology and other quality improvement strategies: focus on low-income children, Medical Care Research & ReviewMed Care Res Rev, 67, 246S-267S, 2010	Systematic review - included studies checked for inclusion, no relevant studies
Nicholls, S. G., Southern, K. W., Parental selection and use of information when learning about newborn bloodspot screening, Pediatric Pulmonology, 46, 427, 2011	Conference Abstract

Study	Reason for Exclusion
Nik-Hussin, N. M. H., Saleem, Y., Sivayoham, E., Rothera, M. P., A survey of parent's attitudes towards viewing intraoperative photographs used as an educational tool, International journal of pediatric otorhinolaryngology, 73, 585-588, 2009	No qualitative data
O'Reilly, M., Karim, K., Taylor, H., Dogra, N., Parent and child views on anonymity: 'I've got nothing to hide', International Journal of Social Research Methodology: Theory & Practice, 15, 211-223, 2012	Context not in protocol - confidentiality and privacy in the context of research only
Obeysekera, M., Tanney, K., Picture books to improve the quality of communication in newborn intensive care, Archives of Disease in Childhood, 102, A88, 2017	Conference Abstract
Ochieng, B. M., Black African migrants: the barriers with accessing and utilizing health promotion services in the UK, European Journal of Public Health, 23, 265-269, 2013	Population not in protocol - above 18 years old.
October, Tessie W., Fisher, Kiondra R., Feudtner, Chris, Hinds, Pamela S., The parent perspective: "being a good parent" when making critical decisions in the PICU, Pediatric critical care medicine : a journal of the Society of Critical Care Medicine and the World Federation of Pediatric Intensive and Critical Care SocietiesPediatr Crit Care Med, 15, 291-298, 2014	Country: USA
O'Hare, L., Santin, O., Winter, K., McGuinness, C., The reliability and validity of a Child and Adolescent Participation in Decision-Making Questionnaire, Child: care, health and development, 42, 692-698, 2016	No qualitative data.
Oulton, K., Wray, J., Carr, L., Hassiotis, A., Jewitt, C., Kerry, S., Tuffrey-Wijne, I., Gibson, F., Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families, BMJ open, 6, 2016	Published protocol, no experimental data
Page, C. J., Dunkley, L., Edgerton, J., Hawley, D., Tattersall, R. S., Don't lose your HEADSS in the adolescent clinic: An evaluation of how an adolescent rheumatology service counsels young people's issues, Rheumatology (United Kingdom), 3), iii6, 2014	Conference Abstract
Pallotta-Chiarolli, Maria, Martin, Erik, â œWhich Sexuality? Which Service?â : Bisexual Young People's Experiences with Youth, Queer and Mental Health Services in Australia, Journal of LGBT Youth, 6, 199-222, 2009	Country: Australia
Pellerin-Leblanc, A. A., Derynck, M., Dow, K., Improving communication in the NICU: Parental perceptions and knowledge about resident physicians, Paediatrics and Child Health (Canada), 23 (Supplement 1), e47-e48, 2018	Conference Abstract
Pepper,D., Rempel,G., Austin,W., Ceci,C., Hendson,L., More than information: a qualitative study of parents' perspectives on neonatal intensive care at the extremes of prematurity, Advances in Neonatal Care, 12, 303-309, 2012	Country: Canada
Petrie, K., McArdle, A., Cookson, J., Powell, E., Poblete, X., 'Let us speak'-children's opinions of doctors, Archives of Disease in Childhood, 102 (Supplement 1), A200-A201, 2017	Conference Abstract
Pini, S., Education mentoring for teenagers and young adults with cancer, British journal of nursing (Mark Allen Publishing), 18, 1316-1319, 2009	Not relevant to privacy and confidentiality
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Duplicate record - Phenomenon of interest of included studies not in protocol. Included studies checked for inclusion

Study	Reason for Exclusion
Pyke-Grimm, Kimberly A., Franck, Linda S., Kelly, Katherine Patterson, Halpern-Felsher, Bonnie, Goldsby, Robert E., Kleiman, Ari, Rehm, Roberta S., Albritton, Alsous Barakat Bhatia Bhatia Bleyer Bluebond-Langner Britto Britto Broome Broome Butow Coccia Coyne Coyne Coyne Coyne Day de Vries Dunsmore Ellis Hinds Jacobs Joffe Kelly Knopf Lyon Martenson Masera Miller Miller Miller Miller Moher Noblit Pace Pearce Pluye Read Ruhe Ruhe Smith Snethen Spinetta Stegenga Stewart Tenniglo Unguru Unguru Weaver Whittemore Young Zwaanswijk Zwaanswijk, Treatment decision-making involvement in adolescents and young adults with cancer, Oncology Nursing Forum, 46, E22-E37, 2019	Systematic review. References checked for possible included studies - none were identified.
Read, N., Schofield, A., Autism: are mental health services failing children and parents?, The journal of family health care, 20, 120-124, 2010	No qualitative data for under 18s.
Redley, M., Prince, E., Bateman, N., Pennington, M., Wood, N., Croudace, T., Ring, H., The involvement of parents in healthcare decisions where adult children are at risk of lacking decision-making capacity: A qualitative study of treatment decisions in epilepsy, Journal of intellectual disability research, 57, 531-538, 2013	Population not in protocol - parents' views with no way of discerning age of child
Rennick, J., Lambert, S., Childerhose, J., Campbell-Yeo, M., Filion, F., & Johnston, C. , Mothers' experiences of a touch and talk nursing intervention to optimize pain management in the PICU: A qualitative descriptive study. , Intensive & Critical Care Nursing, 27, 151-157, 2011	Country: Canada
Richards, C. A., Starks, H., O'Connor, M. R., Doorenbos, A. Z., Elements of Family-Centered Care in the Pediatric Intensive Care Unit: An Integrative Review, Journal of hospice and palliative nursing : JHPN : the official journal of the Hospice and Palliative Nurses Association, 19, 238-246, 2017	Systematic review - included studies checked for inclusion â “ 4 were identified
Richardson, C., Paslakis, G., Men's experiences of eating disorder treatment: A qualitative systematic review of men-only studies, Journal of psychiatric and mental health nursing, 2020	Systematic review - included studies checked for inclusion, no relevant studies
Riddell, R., Lewis, A., Tuthill, D., PN for children-information leaflet, Archives of disease in childhood, 101 (9), A13, 2016	Conference Abstract
Robards, F., Kang, M., Usherwood, T., Sanci, L., How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review, Journal of Adolescent Health, 365-381, 2018	Not related to privacy and confidentiality
Robert, Marie, Leblanc, Line, Boyer, Thierry, When satisfaction is not directly related to the support services received: Understanding parents' varied experiences with specialised services for children with developmental disabilities, British Journal of Learning Disabilities, 43, 168-177, 2015	Country not in protocol: Canada
Robertson, A. O., Tadic, V., Rahi, J. S., Transition from paediatric to adult ophthalmology services: what matters most to young people with visual impairment, Eye, 32, 406-414, 2018	Exclusion as per protocol - child to adult healthcare transition.
Rosenthal, S. A., Nolan, M. T., A Meta-Ethnography and Theory of Parental Ethical Decision Making in the Neonatal Intensive Care Unit, Jognn-Journal of Obstetric Gynecologic and Neonatal Nursing, 42, 492-502, 2013	Systematic review - included studies checked for inclusion, no relevant studies
Rubin,S.E., McKee,M.D., Campos,G., O'Sullivan,L.F., Delivery of confidential care to adolescent males, Journal of the American Board of Family Medicine: JABFM, 23, 728-735, 2010	Country: USA
Russell, G., Sawyer, A., Rabe, H., Abbott, J., Gyte, G., Duley, L., Ayers, S., Parents' views on care of their very premature babies in neonatal intensive care units: a qualitative study, BMC Pediatrics, 14, 230, 2014	Population not in protocol - strongly on parent's views only. Not a good proxy for unders 5s.

Study	Reason for Exclusion
Saaltink, R., MacKinnon, G., Owen, F., Tardif-Williams, C., Protection, participation and protection through participation: young people with intellectual disabilities and decision making in the family context, J Intellect Disabil Res, 56, 1076-86, 2012	Country: Canada
Sanders, C., Pritchard, E., Bray, L., McKenna, J., Exploring young people's expectations and experiences of discussing sexual and relationship health with professionals in a children's hospital, Journal of clinical nursing, 20, 1705-1712, 2011	No qualitative data
Sayal, Kapil, Mills, Jonathan, White, Kate, Merrell, Christine, Tymms, Peter, Predictors of and barriers to service use for children at risk of ADHD: Longitudinal study, European child & adolescent psychiatry, 24, 545-552, 2015	No qualitative data.
Schaeuble, K., Haglund, K., Vukovich, M., Adolescents' preferences for primary care provider interactions, J Spec Pediatr Nurs, 15, 202-10, 2010	Country: USA
Scholefield, B., Gosney, J., Callens, C., Duncan, H., Morris, K., Draper, H., Consultation with children regarding deferred consent in emergency care research, Pediatric critical care medicine, 1), A44, 2011	Conference Abstract
Sharkey, S., Lloyd, C., Tomlinson, R., Thomas, E., Martin, A., Logan, S., Morris, C., Communicating with disabled children when inpatients: barriers and facilitators identified by parents and professionals in a qualitative study, Health expectations : an international journal of public participation in health care and health policy, 19, 738-750, 2016	Not related to privacy and confidentiality
Sherratt, F. C., Beasant, L., Crawley, E. M., Hall, N. J., Young, B., Enhancing communication, informed consent and recruitment in a paediatric urgent care surgical trial: A qualitative study, BMC Pediatrics, 20, 140, 2020	Not related to privacy and confidentiality
Sime, D., 'I think that Polish doctors are better': Newly arrived migrant children and their parents' experiences and views of health services in Scotland, Health and Place, 30, 86-93, 2014	Not relevant to privacy and confidentiality
Sisson, Helen, Jones, Catriona, Williams, Rhona, Lachanudis, Lisa, Metaethnographic synthesis of fathers' experiences of the neonatal intensive care unit environment during hospitalization of their premature infants, Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns, 44, 471-480, 2015	Systematic review - included studies checked for inclusion, no relevant studies
Smith, L. A. M., Critoph, D. J., Hatcher, H. M., How Can Health Care Professionals Communicate Effectively with Adolescent and Young Adults Who Have Completed Cancer Treatment? A Systematic Review, Journal of Adolescent and Young Adult Oncology, 2020	Systematic review - included studies checked for inclusion, no relevant studies
Stafford, V., Hutchby, I., Karim, K., O'Reilly, M., "Why are you here?" Seeking children's accounts of their presentation to Child and Adolescent Mental Health Service (CAMHS), Clinical child psychology and psychiatry, 21, 3-18, 2016	Not relevant to privacy and confidentiality
Starkman, Harold, Fisher, Kathleen, Pilek, Nicole L., Lopez-Henriquez, Gloria, Lynch, Laura, Bilkins-Morgis, Briana L., Listening to adolescents with uncontrolled diabetes, their parents and medical team, Families, systems & health : the journal of collaborative family healthcare, 37, 30-37, 2019	Country not in protocol: USA
Stenberg, U., Haaland-Overby, M., Koricho, A. T., Trollvik, A., Kristoffersen, L. G. R., Dybvig, S., Vagan, A., How can we support children, adolescents and young adults in managing chronic health challenges? A scoping review on the effects of patient education interventions, Health expectations : an international journal of public participation in health care and health policy, 2019	Scoping review - included studies checked for inclusion, no relevant studies

Study	Reason for Exclusion
Stickney, C. A., Ziniel, S. I., Brett, M. S., Truog, R. D., Family participation during intensive care unit rounds: goals and expectations of parents and health care providers in a tertiary pediatric intensive care unit, J Pediatr, 165, 1245-1251.e1, 2014	Country: USA
Sunderland, E., Wood, K., Barwick, S., What do looked after young people think about the specialist health services they use?, Archives of disease in childhood, 3), A184, 2015	Conference Abstract
Sutcliffe, P., Martin, S., Sturt, J., Powell, J., Griffiths, F., Adams, A., Dale, J., Systematic review of communication technologies to promote access and engagement of young people with diabetes into healthcare, BMC endocrine disorders, 11 (no pagination), 2011	No qualitative data.
Taylor, S., Haase-Casanovas, S., Weaver, T., Kidd, J., Garralda, E. M., Child involvement in the paediatric consultation: a qualitative study of children and carers' views, Child: care, health and development, 36, 678-685, 2010	Not related to privacy and confidentiality
Templeton, Lorna, Novak, Claire, Wall, Sarah, Young people's views on services to help them deal with parental substance misuse, Drugs: Education, Prevention & Policy, 18, 172-178, 2011	Not relevant to privacy and confidentiality
Ulph, F., Cullinan, T., Qureshi, N., Kai, J., Informing children of their newborn screening carrier result for sickle cell or cystic fibrosis: qualitative study of parents' intentions, views and support needs, Journal of Genetic Counseling, 23, 409-20, 2014	Not relevant to privacy and confidentiality
Van Cleave, A., Roosen-Runge, M., Miller, A., Karkazis, K., Magnus, D., Quality of communication in interpreted versus non-interpreted pediatric ICU family meetings, Critical Care Medicine, 1), A177, 2013	Conference Abstract
Van De Vijver, M., Bertaud, S., Nailor, S., Marais, G., Baby diaries: A tool to improve parental communication in the neonatal unit, Archives of Disease in Childhood, 99, A81-A82, 2014	Conference Abstract
van de Vijver, M., Evans, M., A tool to improve communication in the neonatal unit, BMJ Quality Improvement ReportsBMJ qual, 4, 2015	Study design not in protocol - close ended, yes/no questionnaire
Waite-Jones, J. M., Majeed-Ariss, R., Smith, J., Stones, S. R., Van Rooyen, V., Swallow, V., Young People's, Parents', and Professionals' Views on Required Components of Mobile Apps to Support Self-Management of Juvenile Arthritis: Qualitative Study, JMIR MHealth and UHealth, 6, e25, 2018	Not relevant to privacy and confidentiality
Wales, Jackie, Brewin, Nicola, Raghavan, Raghu, Arcelus, Jon, Exploring barriers to South Asian help-seeking for eating disorders, Mental Health Review Journal, 22, 40-50, 2017	Population not in protocol - >18 years old
Walsh, J., Scaife, V., Notley, C., Dodsworth, J., Schofield, G., Perception of need and barriers to access: The mental health needs of young people attending a Youth Offending Team in the UK, Health and Social Care in the Community, 19, 420-428, 2011	Not relevant to privacy and confidentiality
Watts, R., Zhou, H., Shields, L., Taylor, M., Munns, A., Ngune, I., Family-centered care for hospitalized children aged 0-12 years: A systematic review of qualitative studies, JBI Database of Systematic Reviews and Implementation Reports, 12, 204-283, 2014	Not relevant to privacy and confidentiality
White, B., Tuschl, K., Walker, J., Segal, T., Viner, R. M., Confidentiality, consent and privacy: A challenge even in a specialist young person unit, Archives of disease in childhood, 1), A65, 2010	Conference Abstract
Whittingham,Koa, Boyd,Roslyn N., Sanders,Matthew R., Colditz,Paul, Parenting and prematurity: Understanding parent	Country: Australia

Study	Reason for Exclusion
experience and preferences for support, Journal of Child and Family Studies, 23, 1050-1061, 2014	
Wiering, B. M., Noordman, J., Tates, K., Zwaanswijk, M., Elwyn, G., De Bont, E. S. J. M., Beishuizen, A., Hoogerbrugge, P. M., Van Dulmen, S., Sharing decisions during diagnostic consultations; an observational study in pediatric oncology, Patient Education and Counseling, 99, 61-67, 2016	No qualitative data
Wong et al, Risk discourse and sexual stigma: Barriers to STI testing, treatment and care among young heterosexual women in disadvantaged neighbourhoods in Toronto, Can J Hum Sex, 21, 75-89, 2012	Country: Canada
Wood, D., Geoghegan, S., Ramnarayan, P., Davis, P. J., Pappachan, J. V., Goodwin, S., Wray, J., Eliciting the experiences of the adolescent-parent dyad following critical care admission: a pilot study, European Journal of Pediatrics, 177, 747-752, 2018	Not related to privacy and confidentiality
Wyatt, K. D., Prutsky Lopez, G., Domecq Garces, J. P., Erwin, P., Brinkman, W. B., Montori, V. M., LeBlanc, A., Study protocol: a systematic review of pediatric shared decision making, Systematic reviews, 2, 48, 2013	Published protocol for quantitive systematic review
Yamaji, Noyuri, Suto, Maiko, Takemoto, Yo, Suzuki, Daichi, Lopes, Katharina da Silva, Ota, Erika, Supporting the Decision Making of Children With Cancer: A Meta-synthesis, Journal of pediatric oncology nursing : official journal of the Association of Pediatric Oncology Nurses, 1043454220919711, 2020	Systematic review - Included studies checked for inclusion, no relevant studies
Ye, Jiali, Rust, George, Fry-Johnson, Yvonne, Strothers, Harry, E-mail in patient-provider communication: A systematic review, Patient Education and Counseling, 80, 266-273, 2010	Systematic review - Included studies checked for inclusion, no relevant studies

Economic studies

No economic evidence was identified for this review. See supplementary material 6 for details.

Appendix L – Research recommendations

Research recommendations for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

No research recommendations were made for this review question.

Appendix M – Evidence from reference groups and focus groups

Reference and focus group evidence for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Methods for the reference and focus groups and details of how input was obtained from the children and young people are described in Supplement 4.

Table 11: Evidence from reference groups and focus groups

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
• I would like the doctor to tell me what they were going to do before they did it (9/12) because: ○ 'I don't know so I want them to tell me what they'll do first' ○ 'I want to know what will happen'	• What does consent mean? ○ 'Doctors shouldn't close the curtains and give treatment you don't know why' ○ Not being given medicine without permission' ○ 'I think it means something personal' ○ 'I know what a concern means' ○ 'Initials and signing something' ○ 'To make sure we are allowed' ○ 'Asking for permission' ○ 'Something personal' ○ 'Is it anything about your senses?' ○ 'Give them, a child if they think you feel good, they take you to the teachers' ○ 'Telling an adult you don't feel well and you keep it to yourself' ○ 'Maybe when you go to hospital' ○ 'Permission to get into the hospital' ○ 'Asking the doctors or nurses if you can do something or not' • What does privacy mean?	• What does confidentiality mean? ○ 'Private' (MH services) ○ 'Not exposed area' (MH services) ○ The group struggled to define this; they got it confused with confidence • What does consent mean? ○ 'Giving permission'' ○ 'Permission you have given for someone to do something – asking my permission to share information with my school' • How would you like to be made aware about what your rights around consent are? ○ Face to face (4/6) - 'Because you can sort it out in person', - 'It is just best for them to do this in the moment, when you need it, whenever you start to access those services' ○ Over email ○ Reading a booklet (2/6) ○ Over the phone (2/6)	• Low

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	○ 'It's if like I want to be alone' ○ 'I'm not sure' ○ 'Something private, like a bank' ○ 'When you go to the doctors and talk to them' ○ 'Toilets' ○ 'When you see a doctor you don't know' ○ 'It's if like I want to be alone' ○ 'Leaving people be' ○ 'Your own space' ○ 'In your tummy' ○ 'When going to the loo' ○ 'Parts of your body' ○ 'When you need some private space' ○ 'When you have private parts of your body as well' ○ 'Respecting when people want privacy you have to leave them be' ○ 'It's in my tummy' ○ 'When you want to be in private and you don't want people to see' ○ 'There are private bits of your body' • What does confidentiality mean? ○ 'Comfortable' ○ 'Give someone a piece of information' ○ 'When you feel confident and comfortable sharing your business with people, when you give someone a piece of information and they keep it private, but after 1 - 2 months they have to throw it away very careful, it would happen when you have a wedding' ○ 'Something you are confident with' ○ 'You are confident and a bit nervous at the same time'	- 'You are talking which is better, I don't like typing or anything' - 'Better to have a chat' ○ Texting (3/6) - 'You can read it when you want' ○ One young person really didn't want it to be face-to-face because 'I just don't like leaving the house' • If you had a face to face or over the phone meeting, who would you want to talk to you about confidentiality and privacy? ○ Your own doctor (2/6) - 'Better because they're going to give us more information and detail [than parents]' - 'Definitely my own doctor would be best but this has changed over time. Would have picked my parent when I was younger' ○ Your parent/guardian (3/6) - 'Because I know them more and it would just a feel bit more private because I tell everything to them… I feel like they would be a lot more supportive' - 'More supportive and you're more comfortable with your parents' - 'I'd pick my mum… she makes me comfortable, she could tell me anything and I could tell her anything' ○ No one 1/6) - 'I would want to read about it online or in a booklet' ○ Other options offered were: a nurse, a different kind of healthcare worker, a school/college /university nurse or a teacher but none of the young people selected any of these options. • Who would you want in the room with you when a healthcare professional talks to you about private things?	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	○ 'It's when you're quite brave' ○ 'NHS' ○ 'Treatment' ○ 'Privacy' ○ 'Hospital' ○ 'Doctors' ○ 'Telling doctors what is happening' ○ 'Health care' ○ 'Does it mean having confidence?' ○ 'Doctors' ○ 'Hospitals' ○ 'Treatment' ○ 'When you tell the doctor how you are feeling' ○ 'Does it involve the NHS?' • When a doctor is talking about something private, I want to be by myself ○ 4 disagreed - 'I want my parents or someone to be with me' - 'I pick no because I want my parents to be with me' - 'I think the same because I need someone to be with me, I want my parents to be with me' - 'I am standing by no because my mum is really special to me and I really love her and I wouldn't want anyone else. I would want to bring my mum with me' - 'I just want my dad to know to help me and if my dad is not there he cannot hear my private conversation' ○ 5 agreed	○ Parent/guardian (5/6) - 'I would want my mum and the doctor' - '[My parents] are very supportive and can help you understand what is going on' - 'They [parents] could probably help you understand better' - 'To help you understand and relax a bit so it's a bit more comfortable with your parent in the room' - 'So you don't have to go out [of the room] and then repeat what the doctor has said' - 'Mum to help you understand and relax a bit' ○ Just myself (1/6) - 'Definitely I would rather be by myself but I'm not sure if I could as there is a requirement not to be on your own if you are under 16 I think' ○ Other options offered were: a sibling, carer or support worker but none of the young people selected any of these options. • Do you think a healthcare professional should communicate to children and young people directly about consent and privacy, or should they speak to your parent/guardian? ○ Talk to both of us (6/6) - 'To make sure there is general awareness' • Do you feel able and confident to choose who you would like to share your private health information with? ○ Yes (5/6) - 'I can make up my own mind' - 'I feel confident in what I want' ○ No (1/6) - 'I would want a bit of support from my parents with this'	

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	- 'My mum gets too worried and is annoying, I don't like it when mum worries' - 'I get really funny sometimes if I am with other people and I need to talk about something private and if someone hears I can get angry and hurt someone. With everybody else there' - 'I really like doctors' - 'If it was private, I would not want anybody to know because it is a secret' ○ 2 unsure - 'I think I would need my mum with me but at the same time, when the doctor says something like you're coming down with something my mum will be like 'Oh my god you need to do this you need to do that' - 'I like when my mum worries about me sometimes but at the same time I feel like she does it a bit too much.' - 'Sometimes yes, it depends what it was about' • I would prefer it if the doctors spoke to my parents about privacy and consent than myself ○ 1 disagreed - 'Sometimes when they make me leave I don't think the doctors will keep everything confidential. I feel like sometimes they kind of like, they'll say can you leave the room and I don't like that because my mum is making decisions on my behalf and then some things they don't keep everything private and confidential, sometimes things can leak' (they = the doctors) ○ 2 agreed - 'I don't understand what the doctor says, I don't like knowing if I have illness.'		

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	- ‘I pick yes because I don’t understand things the doctors say so my mum will tell me. I don’t like knowing if I have illness so I don’t like to know.’ ○ 1 unsure - ‘I don’t know, sometimes I don’t want to know if I have an illness but sometimes I do. Would not want to be with my mum and dad when they talk about it.’ • I like it when the doctors ask me if they can speak to my parents before they do. ○ 1 disagreed - ‘If I say no then I might get in trouble, I would be worried about getting in trouble with my parents’ ○ 4 agreed - ‘I like it because my mum gets to know what’s happening and it makes me feel brave, if I had the virus I would not want my mum to know.’ - ‘I like it because then I get to know what is happening and it gives me a chance to brave. If I had the virus or something I would not want my parents to know. I want to know before they do if there is something wrong with me.’ - ‘I like it when the doctor cares about my opinion so I want them to ask me ○ 2 unsure - ‘Sometimes I don’t like it because when doctors do stuff like it feels more serious that they have to ask me to do it.’ - ‘Depends on what it’s about’ • I get worried if I tell the doctor something, they will tell my parents or my school ○ 3 disagreed		

Age < 7 years	Age 7-11 Years	Age 11-14 years	Overall quality of the evidence
	- ‘It’s fine because my family won’t tell other people, because it’s your family and I trust them.’ - ‘I won’t get worried because I don’t know. My family would never say it to anyone else. I’m not worried because it’s my mum, it’s just my mum. Its someone I can trust.’ ○ 3 agreed - ‘I am worried because if I have a temperature and I might have the virus, it makes me worried because I can die and get worried if the doctor will tell my parents they will tell everyone and get worried.’ - ‘This worries me a lot’ - ‘If they did tell someone I would never go to the doctors again’ - ‘I like doctors and I don’t want people to find out that I have something bad with me’ ○ 5 unsure - ‘if they don’t tell them, they might not be sure’ - ‘It depends what they would tell them’ - ‘I don’t know’ - ‘If it was bad, I would be worried they would tell my parents. If it is good then I don’t mind’ • Who would you want to help you make decisions about your consent? ○ ‘Mummy or daddy or the doctor’ x2 ○ ‘People who know about your healthcare’ ○ ‘Mum is good at helping me’ ○ ‘Dad because he is a doctor’ ○ ‘Mum and dad because they know me’ ○ ‘I would ask other nurses because other nurses help other people so they can help me’		

Appendix N – Evidence from national surveys

Evidence from national surveys for review question: How should issues about consent, privacy and confidentiality be addressed with babies, children and young people?

Methods for the grey literature review of national surveys and details of the surveys included are described in Supplement 5.

Table 12: Evidence from national surveys

Survey	**Findings**	**Overall quality of the evidence**
Association for Young People's Health. Young people's views on involvement and feedback in healthcare 2014	• No relevant findings were identified for this question	• N/A
Care Quality Commission. Children and young people's inpatient and day case survey 2018	PRIVACY: • 80% of 0-15 year olds reported they were always given enough privacy • 90% of 12-15 year olds were able to talk to a doctor or nurse without their parent or carer being there if they wanted to.	• Low
Child Outcomes Research Consortium. Child- and Parent-reported Outcomes and Experience from Child and Young People's Mental Health Services 2011-2015	• No relevant findings were identified for this question	• N/A
Health and Social Care Information Centre. Children's Dental Health Survey 2013. (Country specific report for England, published 2015)	• No relevant findings were identified for this question	• N/A
HM Inspectorate of Prisons. Children in Custody 2016-2017	• No relevant findings were identified for this question	• N/A
National Children's Bureau.	CONCERNS OF ETHNIC MINORITIES REGARDING MENTAL HEALTH SUPPORT:	• Moderate

Survey	Findings	Overall quality of the evidence
Listening to children's views on health provision 2012	• A consultation with young people aged 12-24 from a range of ethnic backgrounds and including some for whom English was a second language, refugees and asylum seekers, found that few mainstream public services were mentioned as sources of support by these young people, who were more likely to rely on family, social networks and community organisations. Influences on the decision to seek help (and from whom) were: ○ Knowing that confidentiality will be respected ○ Trust in the person ○ A good relationship ○ Feeling at ease, understood and feeling safe with that person.	
Opinion Matters. Declare your care survey 2018	• No relevant findings were identified for this question	• N/A
Picker Institute. Children and Young People's Patient Experience Survey 2018.	• No relevant findings were identified for this question	• N/A
Picker Institute. Paediatric Emergency Department Survey 2015 and Children and Young People's Outpatient Survey 2015	• No relevant findings were identified for this question	• N/A
Picker Institute/NHS England/Bliss. Neonatal Survey 2014 *Results for individual questions were converted into scores on a scale of 1 to 100, with 100 representing the best possible outcome (the scores are not percentages).*	PRIVACY FOR CONVERSATIONS: • Were you given enough privacy when discussing your baby's care on the neonatal unit with staff? Score = 84 PRIVACY FOR BREASTFEEDING: • Were you given enough privacy in the neonatal unit for expressing milk and/or breastfeeding your baby? Score = 88	• Moderate

Survey	Findings	Overall quality of the evidence
Word of Mouth Research and Point of Care Foundation. An options appraisal for obtaining feedback on the experiences of children and young people with cancer 2018	• No relevant findings were identified for this question	• Low

N/A: not applicable