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# What adolescents living with long-term conditions say about being involved in decision-making about their healthcare: A systematic review and narrative synthesis of preferences and experiences

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## Abstract

**Objective:** To understand the preferences and experiences of adolescents (age 10-19) with long-term conditions (LTCs) towards involvement in discussions and decisions regarding management of their condition.

**Methods:** A systematic review and narrative synthesis of mixed-methods, quantitative and qualitative and research was performed. Six databases were searched from inception to March 2017. The quality of the articles was assessed, and relevant data were extracted and coded thematically.

**Results:** The search yielded 27 articles which met the inclusion criteria. Decision-making involvement preferences and experiences were reported from the adolescents' perspectives. Adolescents often report that they do not have any choice of treatment options. Variability in preferences and experiences were found within and between individuals. Mismatches between preferences and experiences are common, and often with negative emotional consequences.

**Discussion:** Adolescent preferences for involvement in the decision-making process are situational and individualistic. Healthcare professionals can encourage involvement by ensuring that adolescents are informed of treatment options, and aware of the value of their contribution. Future research should explore adolescent perceived barriers and facilitators to SDM.

**Practical Implications:** Interventions are needed to effectively train HCPs in the delivery of shared decision-making, and to support the participation of adolescents with LTCs in shared decision-making.

# 1. Introduction

Adolescence is a critical period of psychosocial development in which people experience a change in interpersonal roles, responsibilities and identity [1, 2]. Unsurprisingly, these years can be more complex for those living with a long-term health condition (LTC). Adolescents with LTCs increasingly take on self-management responsibility, sometimes doing the majority of self-care tasks by the age of 13 [3-7]. However, self-management and health outcomes of patients with LTCs often decline during adolescence, which can lead to increased likelihood health complications and hospital admissions [7-9].

Current recommendations state that adolescents should be encouraged and supported to participate in healthcare decisions [10, 11], and the ability of adolescents with LTCs to make informed and thoughtful decisions about their healthcare has been documented [12, 13].

Healthcare decision-making around LTCs has been described as a continual process, with no clear beginning or end; where numerous decisions are taken, evaluated and often reevaluated [14]. Montori et al. emphasise the need for patients to take a more active role in treatment decision-making in a long-term care setting, which offers a longer window of opportunity to make decisions, and to revisit and reverse them without important loss, compared to patients in acute care settings where decisions are often urgent and may be irreversible [15]. Shared decision-making (SDM) provides the opportunity for patients with LTCs to evaluate the risks, benefits and costs of various management options and procedures for their condition, while enabling a shared understanding of preferences and possible issues, such as difficulties with side-effects or in performing self-management tasks [16]. SDM interventions in paediatric medicine have been found to be associated with improved knowledge and reduced decisional conflict [17].

Previous research in decision-making in paediatrics has predominantly focused on interactions between the parent and healthcare professionals (HCPs) [17]. The presence of a triadic relationship is an important distinction between child and adult consultations, where parent involvement can prevent SDM from occurring between the young patient and HCP [18]. A review [19], which identified literature addressing adolescents', parents' and HCPs' experiences of decision-making in paediatrics, found that adolescents' views in health consultations were rarely sought or acknowledged. However, most of the studies in the review did not actually explore the patients' perspectives. This is reflective of the exchange during a paediatric consultation, where adolescents' voices are rarely heard, and they tend to act as bystanders [20, 21]. It is important to understand how adolescents experience discussions and decision-making during consultations in a healthcare setting, as well as their preferences for involvement. Understanding the perspectives of adolescents with LTCs regarding their experienced and desired roles in the decision-making process can help us to further understand their support needs.

### 1.1 Aim & Objectives

The aim of this review was to collect and synthesise published research data on adolescent perspectives towards involvement. The objectives were to: (a) understand the preferences of adolescents with LTCs towards being involved in the decision-making process about their condition management; (b) understand the experiences of adolescents with LTCs with involvement in the decision-making process and (c) make recommendations regarding how SDM with adolescents with LTCs can be implemented.

## 2. Methods

The review applied a systematic search methodology following the PRISMA statement [22] and in accordance with the guidance on the conduct of a narrative synthesis [23]. The protocol was prospectively registered on PROSPERO [24] (CRD42017055650).

### 2.1 Eligibility Criteria

Included studies were English-language qualitative, quantitative and mixed-method papers which report empirical research about the preferences\_and/or experiences of adolescents living with one or more LTCs, from the patient perspective. No limitations were placed on the year of publication. An age range for adolescents of 10-19 years was stipulated in accordance with the WHO definition. Studies with participants of an age outside of the adolescent parameters were included if the measure of central tendency fell within the 10-19 year-old range. LTCs were defined as conditions requiring 'ongoing management over a period of years or decades' [25]; meaning conditions which require continuing clinical care and self-management. Examples include diabetes, asthma and cancer. Due to the small number of eligible papers, studies were not excluded if the sample also included acutely ill patients.

For inclusion, papers had to examine the decision-making process in a healthcare setting regarding decisions that are characteristic to LTC care. This means ongoing condition management discussions and decision-making, such as decisions about, diet, exercises, appointment scheduling, medication administration, or treatment plans. Papers which primarily examined other types of decisions such as research participation, fertility

preservation, or end of life decisions, were excluded. Studies containing mixed samples (e.g. perspectives of adolescents, parents and HCPs) were included if the adolescents generated data were reported separately or could be separated by the reviewers. Data which made comparisons between adolescent and HCP/parent responses were retained. Papers which reported studies with wholly parent or HCP samples were excluded.

## 2.2 Systematic search

Six electronic bibliographic databases (Embase, Medline, Cochrane Library, CINAHL, PsycINFO and Scopus] were searched systematically from inception to March 2017 in order to identify potentially eligible articles. Ethos, Open Grey, The New York Academy of Medicine Library and ADOLEC (Adolescent Health) were searched for grey literature, such as documents published by governments and non-governmental organisations. A comprehensive strategy was developed with key search terms across titles and abstracts, or as medical subject headings using the Boolean operators 'AND' to combine key concepts, and 'OR' for synonymous keywords (Fig 1). Key search terms included a string for 'adolescents', and combinations of strings for decision-making and HCPs, which was adapted from the Legaré et al. systematic review [26]. Relevant papers were also sought using the 'pearl-growing' technique, in which further studies are identified by examining the reference pages of relevant papers [27]. Papers identified from the initial database searches were imported to EndNote X8 [28] and duplicates removed. Remaining titles and abstracts were then screened for relevance by one author (AJ); those that did not meet the inclusion criteria were removed. The full texts of all the remaining records were assessed for eligibility

by two authors (AJ, VS) independently, and the reasons for exclusions stated (Fig 2).

Resolution of discrepancies was sought through discussion involving a third researcher (FW).

### 2.3 Critical appraisal of included studies

The quality of included studies was assessed using existing criteria designed for appraising the appropriate type of study (CASP/AXIS) [29, 30] (AJ). Ten per cent of the studies was quality assessed by a second author independently (VS). Both authors were in agreement, therefore it was decided no further duplication of effort was required. Due to the small number of eligible studies, none were excluded on the basis of overall quality, but important methodological issues were noted and taken into consideration during the data synthesis.

### 2.4 Data Extraction

The data from the studies were extracted according to basic study characteristics, including study aims, design, sample demographics, and care setting; definition of decision-making involvement and adolescent reported preferences and experiences (Table 1). Where necessary, corresponding authors of included studies were contacted to obtain specific information. Two authors extracted the data for all included studies independently (AJ, VS). The relevant data were entered into NVivo11 for coding support and quotation retrieval [31].



## 2.5 Data Synthesis

Due to the lack of homogeneity in the eligible studies, a meta-analysis of the results was impossible. The analysis was conducted following Popay et al's [23] guidance. This involves using words and text to summarise and explore data from differing methodologies, and organises the output as a synthesis to 'tell a story'. A preliminary synthesis was developed, involving the coding and organising the extracted data which were relevant to the research question. Braun and Clarke's [32] thematic analysis was used to extract, code, organise and report patterns or themes of the relevant data. The data set was coded inductively, and the codes were grouped into overarching themes. The themes were discussed and refined until a coherent pattern had been formed, and a summary of each theme was written out. The studies were then revisited to ensure the themes provided a sound representation of the relevant data.

## 3. Results

### 3.1 Systematic Search

We retrieved 10,388 studies; 6572 were assessed against the inclusion criteria after duplicates were removed, and 27 papers [33-59] were included in the review (Fig. 2.). Studies originated from seven countries: nearly half (n=11) from the United States, other countries of origin include Canada (n=2), Australia (n=2) and European countries (n=12). All except three were published between 2006 and 2016. Included studies employed qualitative (n=17), quantitative (n=6), and mixed methods (n=4). Study samples included adolescents with cancer [37, 40, 41, 45, 51-53, 56, 58, 59], diabetes [39], cerebral palsy [43, 57], immune thrombocytopenia [34], a mix of LTCs [33, 35, 44, 47, 49, 50, 55] or combined

LTCs and acute illnesses [37, 46, 54]. No studies focussing on mental health conditions met the inclusion criteria. Study characteristics are reported in Table 1.

### 3.2 Quality appraisal

All studies were appraised as including a clear statement of aims with an appropriate research methodology, design and recruitment strategy to address the aims. However, issues of reflexivity were only considered in one paper [56]. This is especially important due to the potential for perceived power imbalance between the researcher(s) and young participants, and it is important to consider the researcher(s) own role, potential bias and influence on the research outcomes. Furthermore, non-respondent characteristics were not reported in most studies. These data could be meaningful due to a potential association between those who participate in research and those who are involved during health consultations. Most papers provided clear and explicit findings, which add a valuable contribution to the area of literature [33-46, 48-52, 54-58].

### 3.3 Synthesis of findings

The data reflected involvement in the decision-making process from the adolescent perspective, where parents, adolescents and HCPs were involved at varying levels. This includes involvement in the exchange of information, as well as discussions and decisions. In response to the first two review objectives the data were grouped as either preferences or experiences. Preferences refers to the expressed wishes, views and opinions of the young patients towards the different decision-making stages. Experiences represents the young person's reality, what they have experienced and how it affects them. The grouping of data

into preferences and experiences allowed for comparisons to be made between what adolescents want, and what their reality is. Codes were created and grouped into three overarching themes, and are summarised below: variability in involvement preferences and experiences, power dynamics and involvement in the decision-making process, and mismatch between involvement preferences and experiences (number of studies coded at each theme). Table 2 provides examples of quotations coded at each of the themes.

### 3.4 Overarching Themes

#### 3.4.1 Variability in involvement preferences and experiences (n=24): From *'It's my body'* to *'Doctor knows best'*

Adolescents' involvement preferences and experiences vary substantially, which can depend on the individual, timing or the nature of the information or decision type. Adolescents differ in the amount of information they would prefer to receive regarding sensitive topics, such as survival rates and prognosis in cancer treatment [58]. Many report not wanting too much information when they are feeling acutely ill or too soon after diagnosis [38, 43, 46, 51, 55]. Adolescents generally do not want to be involved in decision-making when feeling unwell, and become dependent on their parents to communicate with HCPs for them [38, 45]. Relationship with and support of parents and HCPs, including trust, is often reported to effect experiences of involvement in decision-making [36, 45, 46, 55]. Furthermore, adolescents report that with increased familiarity with HCPs they were able to become more assertive about treatment preferences [37].

The preferred level of information and decision involvement is reported to evolve over time [33, 56], adolescents report wanting more information when they feel ready [51] and

decision-making involvement increases as more information is obtained [45]. Adolescents also state they would prefer more involvement as they get older [49]. Age may influence involvement preferences, although this difference was normally only noted with younger adolescents [33, 45, 46]. Adolescents under 11 years generally do not want the responsibility of being involved in decisions, and are satisfied with others making decisions for them, whereas those over 11 years report feeling frustrated when they are not involved [37]. However, some studies found that age had no effect on involvement preferences or experiences [33, 39, 48, 56].

Decisions are often categorised by adolescents as small or serious. Studies report that nearly all adolescents want and have input into smaller decisions such as medication administration or appointment scheduling [33-35, 37, 38, 45, 47, 51, 52, 56-58]. Some older adolescents feel they should be involved in all decisions, even if they are '*life or death*' [38, 47], although many state they would prefer to leave these decision to parents and HCPs [38, 40, 45, 47, 48, 51, 56, 58]. Experiences of involvement also depend on the types of treatment decisions being made. Adolescents whose primary treatments were oral medication regimes were more involved than with other types of treatment [47]. Although most adolescents feel that they should be involved in their treatment decision-making to some degree [37, 38, 40, 41, 43, 45, 46, 51, 53, 56, 58], many state a preference for taking a passive role, as they find involvement to be boring or unnecessary, and prefer to be represented by their parent who they feel would act in their best interest [37, 38, 43, 45, 47, 49, 51, 55, 58].

### 3.4.2 Power dynamics and involvement in the decision-making process (n=26): *'Because if it's about me then I should be part of it'*

Adolescents value being able to choose their level of involvement [51]. However, they generally see parents and HCPs as having this control, and look to them for validation of their role in the decision-making process [33, 34, 37, 40, 45]. Adolescents want to be taken seriously, and feel they have a right to be involved in discussions, to have been consulted on their treatment preferences, and that these preferences are viewed as important and considered during the decision [33, 36-38, 51-55, 58]. They recognise that their needs are different from both adults and children, and prefer their care to be adapted as such [59]. Although adolescents often do not usually want to make *'big'* or *'ultimate decisions'*, they feel they should *'have a say'*, and that treatment could be worse without their input [33, 34, 37, 38, 40, 43, 45-48, 54-56, 59]. Adolescents express a need for support and encouragement from others, in order to be empowered to be involved in decisions that affect their own healthcare [37, 39, 40, 46, 47, 49, 56, 58].

HCPs and parents are seen as the gatekeepers, controlling the amount and type of information exchanged [49]. Adolescents describe their parents as buffers or interpreters, holding the power over what information is relayed between themselves and HCPs [49, 55, 58]. Adolescents also report that parents can hinder their understanding by withholding information or by not supporting attempts to gain information, often to avoid worry [36, 37, 51, 55]. Most studies reveal that adolescents express a need to receive information, specifically regarding future treatment such as: length of stay in hospital, appointment times, details on treatment choices, and possible side effects [33]. This is in order for them to understand their illness and treatment in order to be involved in self-management, and to know what to expect [33, 34, 36-38, 43-47, 49, 51-59].

Discussions which exclude adolescents make them feel as though they need not or should not be involved [33]. Providing information encourages involvement [33, 36, 37, 39, 45], and encouraging involvement allows adolescents to feel empowered and validated; as a 13-year old remarked: *'they thought I was responsible enough to make a decision and I was'* [33]. Adolescents state that being provided with this type of information should be a *'normal thing to do'*, that it is their body and their right to know and be involved [37, 38, 40, 41, 43, 45, 46, 51, 53, 56, 58]. Adolescents feel they cannot be involved when they do not understand [37]. Ellis et al [41] found that the majority of adolescent patients with partial or inadequate understanding of their diagnosis felt little or no control over their treatment decision, which was not true of those who indicate complete understanding. Language is also related to control; technical jargon is described as is confusing, and can be seen as used to exert power and limit involvement [36, 37, 43, 46, 56, 58]. From accounts of adolescents' experiences, Knapp et al [47] identified lack of information about the future, poor understanding of diagnosis and/or treatment, and lack of choice between treatment options as the main barriers to involvement. Many adolescents, especially those with life limiting conditions, also state they had no control over decisions due to lack of options, that treatment *'has to be done'* [33, 35, 37, 38, 40, 45, 47, 53, 58].

Reported benefits of discussion and decision-making involvement include greater self-efficacy lower decisional conflict, feeling happier, less scared and more satisfied with decisions as well as increased appointment attendance [35, 39, 42, 45, 49]. Being part of treatment discussions provides an opportunity for young people to influence their situation by learning or applying self-management skills [40]. However, adolescents feel they should not have complete decisional control [49]. They voice concern about making the wrong decision [33, 35, 37], and trust the HCP's expertise to *'do what's best'* [33, 37, 38, 40, 43-45,

47, 49-51, 53, 54, 56-58]. Concern about making the wrong decision is expressed more when there is no attempt to involve the patient in the decision-making process [34].

### 3.4.3 Mismatch between involvement preferences and experiences (n=20): 'It hurts, one feels betrayed'

Adolescents appraise their positive and negative emotional, physical, coping, and knowledge responses to having their involvement preferences met (or not met) [38, 46]. When adolescents receive the desired level of information regarding their condition, they report benefits such as feeling valued, happy, less anxious, and more capable of illness management [36, 39, 46, 51, 56]. They consequently report feeling prepared and less worried about undergoing operations and treatment [36]. However, adolescents often report receiving insufficient information about treatment and procedures [35, 37, 40, 46]. Kelsey et al [46] describe the case of an adolescent boy who experienced pain and anger after being cannulated with no explanation. Seven other studies report the emotional consequences of not receiving sufficient information or explanation, which include feelings of fear and/or frustration, as though they were forgotten and depersonalised [34, 36, 37, 46, 51-53]. Dunsmore & Quine found a significant difference between to what degree adolescents would prefer each person to be involved in treatment decisions, and the degree they actually were; nearly half feel the decisions should be a collaboration between themselves, parent and HCP, whereas a very small number perceived this to have occurred; and the majority report the HCP as making the decision alone, which was generally not seen as appropriate [40].

On the other side, what is seen as too much involvement, such as receiving overly detailed information, is also reported to induce stress. Many adolescents want limited exposure to details about their condition that could be worrying and/or burdensome, which they feel they may not be able to remember [37, 43-45, 47, 51, 58, 59]. Adolescents sometimes experience distress from the pressure of being involved in decision-making, particularly when their treatment preferences do not coincide with those of their parents [51]. Studies which compared adolescent decisions and the factors affecting their choices, such as influences and values, with those of their parents frequently found disagreement between the two parties [33, 37, 38, 40, 48, 50]. This incongruity increases significantly with patient age [48]. Parents and adolescents also report symptom severity and overall wellbeing differently [37].

Adolescents report feeling annoyed when HCPs address their parents as though they were not in the room [36, 40, 44, 46, 56, 58]. They feel excluded from discussions and ignored, with questions and explanation directed only at parents [33, 45, 47]. They report HCPs requesting to speak to parents alone, which caused worry about a poor prognosis [37, 45, 51]. Some adolescents observed that HCPs would ask them questions which they felt were '*tokenistic*', or in turn ask the parents the same question, which made them feel as though their responses were not valued [36, 37]. Adolescents report feeling excluded from the decision-making process or that their treatment preferences were not considered [37]. They also feel that parents inhibit attempts to participate by withholding information, or answering questions on their behalf [37]. At times, adolescents report that they are not as involved as they would prefer because they feel rushed during consultations, and fear they may inconvenience HCPs by querying decisions or asking for more information [37]. When adolescents feel uninvolved in discussions and decisions, many report negative emotions



such as feeling powerless, rejected, disappointed, confused, angry, and betrayed [33, 37, 45-47, 51].

## 4. Discussion and Conclusion

### 4.1 Discussion

Developing an understanding of adolescent preferences and experiences in relation to involvement in healthcare discussions and decision-making is essential in order to improve healthcare delivery and to support participation in SDM. Although studies were diverse in terms of design and samples, the results were comparable, which allowed for the development of overarching themes.

Preferences between and within each individual can vary, and evolve over time. Preferences can depend on decision type and current health status. These findings reflect previous research with adolescents and adults with LTCs [60, 61], and highlight the need for HCPs to take an individual and flexible approach to involvement. Involvement preferences commonly go unmet, which adversely affect adolescent well-being, and their perceived ability to manage their condition.

Findings reveal that adolescents often feel they lack sufficient knowledge to be involved in decisions about their healthcare, and frequently report that there is no real choice. Elwyn et al's [62, 63] model of SDM iterates that the patients' understanding that treatment options exist, and how patient involvement is of value to the decision-making process, is the first step in the process. Provision of adequate information regarding diagnosis and treatment options, and ensuring patient understanding of the information has been documented as one of the essential elements of SDM [16]. However, it has been suggested that provision

of information, or knowledge alone, is not necessarily enough to promote involvement in SDM [64]. Patients also need to be provided the opportunity to participate, and have confidence in their own knowledge and ability to be involved in the decision-making process.

The core finding that adolescents exert little control over their level of involvement is in line with previous research on children's participation in consultations and decision-making within the healthcare setting [19]. Adolescents look to others to validate and encourage involvement. Support and guidance from others has been well documented as a motivator for adolescent behaviour [65, 66]. A large percentage of HCPs indicate that SDM was their usual approach to decisions with adolescents with LTCs [67], although other studies report otherwise [19, 68]. Adolescents with LTCs often feel ignored or left out of discussions, which gives them the impression that their views are not important. They are often delegated a passive role during consultations, which does not represent the role they need to play in self-management. However, they generally feel they should be involved to some degree.

Parents of children with LTCs expect to participate in SDM [69]. They can find it difficult to relinquish control over their child's LTC for fear of poor health outcomes [70]. Lack of parental support for their child's involvement, and attempt to control the information the adolescent receives may be also attributed to parents' protectiveness [61, 71]. This can be particularly troublesome as parents' treatment choices and values do not always coincide with those of their child [48]. Interventions which support SDM have been found to increase values congruence between child and parent, as well as child satisfaction with the decision-making process [72]. When adolescents do not participate in the discussion, important input that can contribute to the formation of a suitable self-management plan, which is

concordant with patient values, is not being considered. The 'three-talk' model for SDM includes 'deliberation', which outlines the importance of exploring patients' reactions to the information regarding their options in line with their own values and preferences [62, 63].

One of the strengths of this review is the inclusion of qualitative, quantitative and mixed-methods research. By acknowledging research from a variety of methodological approaches, a more complete overview of the current evidence can be provided. This review was conducted according to recognised systematic review standards [73]. By only including adolescent generated data in the narrative synthesis, this review attempts to tell the story of the adolescent from their perspective, which is often underrepresented in SDM research in paediatrics.

Due to the limited literature available, studies with some non-adolescent and acutely ill participant samples were also included, which can cause difficulty in ascertaining the studies' representativeness of adolescents with LTCs in general. However, there were no distinct differences in the findings of the papers which also include participants with acute illness. Further research is needed to establish whether these findings would be consistent for all adolescents with a variety of conditions. The nature of the research methods produced largely retrospective accounts of experiences which took place weeks, month, even years prior to the study.

Ten of the 27 reports included a sample of adolescents with cancer. Unlike many LTCs, cancer has the possibility of being cured, and the focus is therefore generally on curative as opposed to management decision-making. The seriousness of the condition and, consequently, the nature of the clinical decisions involved, perhaps decreases the likelihood of clinical equipoise

and may lessen opportunity for patient involvement in SDM. Although other studies include a sample of participants with various LTCs, only one [33] compared involvement level between the two conditions. In this study, participants who had a condition with less serious outcome possibilities report having more involvement than those with a potentially life-limiting condition [33]. Although this particular study had a small sample size, findings that show an association between a more serious prognosis and less patient involvement in decision-making have been reported elsewhere [74]. The lack of comparisons, and variability of LTCs across the studies included in this review limits the ability to make generalisations about all adolescents with LTCs. Further research is necessary to establish whether a connection between adolescent preferences/experiences and LTC characteristics, such as seriousness of complications, exists. Finally, due to limited resources, only English language articles were included in the synthesis.

## 4.2 Conclusion

Failure to involve adolescents in the decision-making process can cause feelings of exclusion and neglect. However, striving to make them fully informed and involved may also be counter to their preferred (often 'passive') way of being involved in decisions, which in turn, may itself trigger anxiety and distress. Adolescents' involvement preferences vary within and between individuals. Communication of treatment option information, as well as engaging patients in discussions which allow them to express and understand the benefits of articulating individual treatment preferences can prepare them for involvement in a shared decision. Many variables can influence the SDM process, particularly the role of the parent. Future research should further explore what may motivate or hinder adolescent participation in SDM, as well as possible reasons for the mismatch between adolescent

preferences and experiences in order for issues to be addressed and SDM involvement to be adequately supported.

### 4.3 Practical implications

Findings suggest that parents and HCPs may be limiting adolescent involvement by withholding information, and not providing opportunities. Adolescents report a high level of trust in HCP expertise, and may not acknowledge their own capability and potential contribution to the decision-making process. Current recommendations state that adolescents should be informed as fully as their developmental level allows, as soon as possible, and that involvement in discussions and decision-making should be encouraged and supported [75]. Research shows that adolescents benefit from SDM, and it can improve their wellbeing [17].

Although HCPs report using SDM with adolescents with LTCs, it was found that they often provide more detailed information about their preferred option with less information about other options, and minimal elicitation of preferences or treatment goals [67, 68]. Further skills training for HCPs could reinforce the delivery of SDM in line with current models [62, 63]. In adult care, current SDM training courses for HCPs vary widely in delivery, and evidence of their effectiveness is sparse [76]. It is suggested that providing HCPs with learning materials and decision aids would be helpful [76]. Decision aids have been found to improve patient knowledge and reduce passivity in the decision-making process [77]. However, little is known about the use of decision aids in a paediatric setting. Coyne et al. [78] set out to identify SDM interventions for young people with cancer, and retrieved no results. They suggest that educational interventions aimed at increasing HCPs' awareness of

young people's need for inclusion in the decision-making process could be useful. They also suggest that young people's preferences for how they want to be involved in the decision-making process should be assessed.

Adopting a flexible and individualised approach allows adolescents to participate in a way that fits with their preferences, needs and values. Striving to involve adolescents with LTCs beyond their preferences can lead to distress and confusion [61]. Adolescents might be asserting control by opting out of involvement [61], however, effective SDM involves fully informing patients about what involvement means, and why their contribution of values and preferences for treatment are important [62, 63]. SDM may be particularly important during adolescence, as this is a time when children are sensitive to authoritarian treatment [79].

These patients are at a critical time where they will be transitioning, or already have transitioned to adult services where encouraging and supporting communication and involvement is crucial [80]. In future, the parent may not always be a part of the consultation. Interventions which prepare and support involvement of adolescents with LTCs in SDM could be useful to promote and encourage active participation and improve care.

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## Fig. 1. Example Search Strategy: OVID- Medline

#1  
shared decision\*.ti,ab. or sharing decision\*.ti,ab. or informed decision\*.ti,ab. or informed choice\*.ti,ab. or decision aid\*.ti,ab. or ((share\*.ti. or sharing.ti. or informed\*.ti.) and (decision\*.ti. or deciding.ti. or choice\*.ti.))

#2  
\*clinical decision making/ or \*decision making/or \*decision support system/ or \*ethical decision making/ or \*family decision making/ or \*medical decision making/ or \*patient decision making/or decision making\*.ti,ab. or decision support\* ti,ab. or choice behaviour\*.ti,ab. or ((decision\*.ti. or choice\*.ti.) and (making\*.ti. or support\*.ti. or behaviour\*.ti.))

#3  
\*patient participation/ or patient participation\*.ti,ab. or consumer participation\*.ti,ab. or patient involvement\*.ti,ab. or consumer involvement\*.ti,ab. or ((patient\*.ti. or consumer\*.ti.) and (involvement\*.ti. or involving\*.ti. or participation\*.ti. or participating\*.ti.))

#4  
\*doctor patient relation/ or \*nurse patient relationship/or ((\*nurse/ or \*physician/ or nurse\*.ti or physician\*.ti or clinician\*.ti. or doctor\*.ti. or general practitioners\*.ti. or gps\*.ti. or health care professionals\*.ti. or healthcare professionals\*.ti. or health care providers\*.ti. or healthcare providers\*.ti. or resident\*.ti.) and (\*patient/ or patient\*.ti. or consumer\*.ti. or people\*.ti.))

#5  
\*child/ or \*adolescent/ or kid\*.ti,ab or \*minors/ or minor\*.ti, ab or child\*.ti,ab. or pediatric\*. ti,ab. or paediatric\*.ti,ab. or adolescen\*.ti,ab. or youth\*.ti,ab. or teen\*.ti,ab. or (young adj3 people).ti,ab. or (young adj3 person).ti,ab.

#6  
(1 or (2 and 3) or (2 and 4) or (3 and 4)) and 5

Fig. 2. PRISMA [21] flow diagram with reasons for exclusion

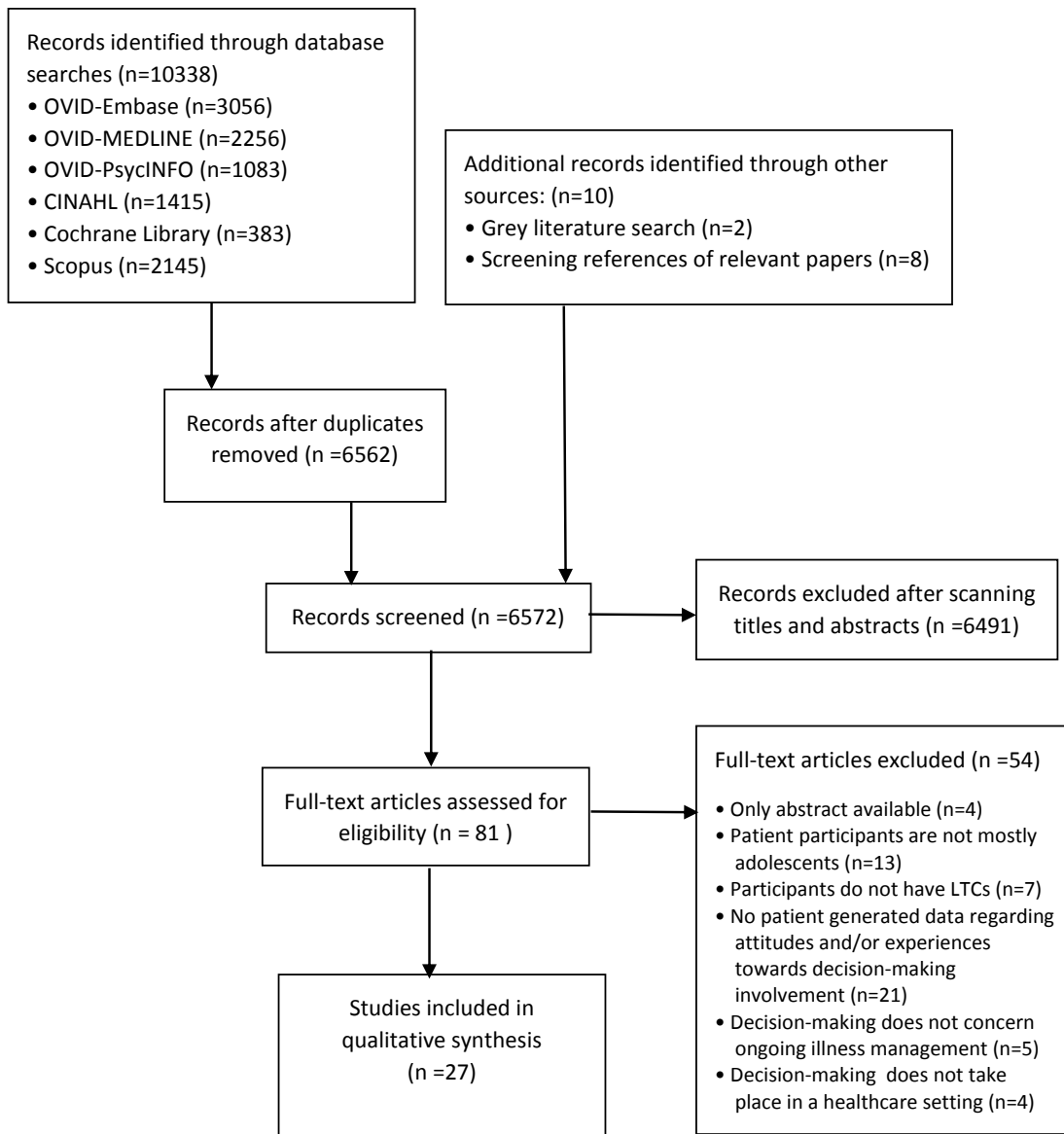


Table 1: Table of included studies

| Study:<br>Author, year,<br>Country                        | Study aims  | Design  | Patient<br>population<br>characteristics | Health Condition(s)<br>and setting   | Patient<br>Age<br>range | Definition of involvement  |
|---|---|---|--|--|-------------------------|--|
| <b>Angst and Deatrick, 1996 [33]<br/>United States</b>    | To describe how children with LTCs and their parents are involved in health care decisions through a secondary analysis of two data sets  | Qualitative:<br>interviews  | N=28<br>46% female                       | Cystic fibrosis (71%)<br>and scoliosis (29%)/<br>Secondary care                            | 7 to 19                 | Contribution towards decisions related to their health or illness  |
| <b>Beck <i>et al</i>, 2014 [34]<br/>Canada</b>            | To examine the treatment decision-making process for hospitalised children  | Qualitative:<br>focus groups  | N=7<br>14% female                        | Immune thrombocytopenia/<br>Secondary care   | 10 to 18                | SDM: exchanging information about medical evidence and patient's preferences, and identifying which course of action is most consistent with those preferences |
| <b>Bejarano <i>et al</i>, 2015 [35]<br/>United States</b> | To evaluate the feasibility and acceptability of SDM interventions  | Quantitative :<br>Pre-post<br>experimental<br>design                      | N=26<br>50% female                       | Environmental allergies (58%) and scoliosis (42%)/<br>Secondary care:<br>specialist clinic | 5 to 17                 | SDM: accommodating patient preferences and values in making decisions about their care   |
| <b>Coyne, 2006 [36]<br/>United Kingdom</b>                | To explore children's, parents' and nurses' views on participation in care in the healthcare setting                                      | Qualitative: in-depth interviews and participant observation              | N=11<br>64% female*                      | Various long-term and acute/<br>Secondary care:<br>inpatient                               | *7 to 14                | Being consulted and involved in decisions about their care   |
| <b>Coyne &amp; Gallagher, 2011 [37]<br/>Ireland</b>       | To explore hospitalised young people's experiences of participation in communication and decision-making                                  | Qualitative:<br>interviews and<br>focus groups                            | N= 55<br>44% female                      | Various long-term and acute/<br>Secondary care:<br>Inpatient                               | 7 to 18                 | Being active partners in decisions about their health and care and, where possible, being able to exercise choice  |
| <b>Coyne <i>et al</i>, 2014 [38]<br/>Ireland</b>          | To explore children's participation in shared decision-making.  | Qualitative:<br>interviews  | N= 20<br>45% female                      | Cancer/<br>Secondary care:<br>Inpatient and day care units                                 | 7 to 16                 | SDM: contribution to the decision-making process, independent of who makes the final decision.   |
| <b>Croom, 2011 [39]<br/>United States</b>                 | To examine the relationship between perceived patient-centred communication and patient empowerment and diabetes management.              | Quantitative:<br>Cross-sectional surveys and medical records              | N=190<br>52% female                      | Type 1 diabetes/<br>Secondary care:<br>specialist clinic                                   | 10 to 15                | Mutual exchange of information and reaching a shared understanding of patient problems and the treatments that are concordant with patient values.             |
| <b>Dumsmore &amp; Quine, 1995 [40]<br/>Australia</b>      | To identify patient's information, support and decision-making needs and preferences, and the extent to which those needs were being met. | Mixed Methods:<br>Questionnaire including open and closed-ended questions | N=51<br>47% female                       | Cancer/<br>Secondary care  | 12 to 24                | Information provision, and decision-making involvement.  |



|   |  |  |                     |  |           |   |
|---|--|--|---------------------|--|-----------|---|
| <b>Ellis &amp; Leventhal, 1993 [41]<br/>United States</b>   | To evaluate the information needs and decision-making preferences of children with cancer.   | Quantitative: surveys                              | N=50<br>40% female  | Cancer/<br>Secondary care  | 9 to 17   | Information needs and decision-making preferences   |
| <b>Feenstra <i>et al</i>, 2015 [42]<br/>Canada</b>          | to evaluate the feasibility and acceptability of decision coaching   | Quantitative: Pre-test/post-test                   | N=7<br>43% female   | Type 1 diabetes/<br>Secondary care:<br>specialist clinic                         | 9 to 17   | SDM: exchange of information on options and treatment preferences to reach an agreement on treatment plan.  |
| <b>Garth <i>et al</i>, 2009 [43]<br/>Australia</b>          | To explore how the doctor–parent–child partnership is experienced and if the child patient is considered a contributor                       | Qualitative: Interviews                            | N= 10<br>70% female | Cerebral palsy/<br>Secondary care  | 8 to 12   | Factors contributing to an effective partnership which include joint decision-making and open communication |
| <b>Jedeloo <i>et al.</i>, 2010 [44]<br/>The Netherlands</b> | To uncover preferences for self-management and hospital care of adolescents with various long-term conditions.                               | Mixed methods: Interviews Q-methodology            | N=31<br>48% female  | Various long-term /<br>Secondary care  | 12 to 19  | Involvement in consultations including decision-making styles.  |
| <b>Kelly <i>et al</i>, 2016 [45]<br/>United States</b>      | To better understand how children and adolescents viewed their treatment decision-making involvement   | Qualitative: interactive interviews                | N=29<br>48% female  | Cancer/<br>Secondary care  | 9 to 17   | Information provision and involvement in treatment decision-making  |
| <b>Kelsey <i>et al</i>, 2007 [46]<br/>United Kingdom</b>    | To explore young people's perceptions of their involvement in healthcare decisions affecting their management of care.                       | Qualitative: Interviews and recorded audio diaries | N=10<br>40% female  | Various long-term and acute/<br>Secondary care:<br>Inpatient                     | 13 to 16  | Involvement in healthcare decisions   |
| <b>Knapp <i>et al</i>, 2008 [47]<br/>United States</b>      | To explore adolescents involvement in and preferences about SDM  | Mixed methods: Surveys and interviews              | N=35<br>55% female  | Various long-term/<br>Various care settings                                      | 14 to 21  | SDM: participation in the decision-making by expressing preferences and coming to a mutual decision.        |
| <b>Knopf <i>et al</i>, 2008 [48]<br/>United States</b>      | To describe the decision-making preferences of adolescents with long-term conditions and their parents                                       | Quantitative: surveys                              | N=82<br>55% female  | Various long-term conditions /<br>Secondary care                                 | *11 to 19 | SDM: shared information and collaboration to reach a decision   |
| <b>Lipstein <i>et al</i>, 2013 [49]<br/>United States</b>   | To understand adolescents' roles and preferences in long-term condition treatment decisions, using biologic therapy decisions as an example. | Qualitative interviews                             | N=15<br>60% female  | Chron's disease (47%) and Juvenile idiopathic arthritis (53%)/<br>Secondary care | 12 to 17  | Participation in medical decision-making  |
| <b>Lipstein <i>et al</i>, 2016 [50]<br/>United States</b>   | To compare factors considered by parents to those considered by adolescents making decisions about long-term condition treatments.           | Qualitative interviews                             | N=13<br>62% female  | Chron's disease (54%) and Juvenile idiopathic arthritis (46%)/<br>Secondary care | 13 to 18  | Participation in LTC treatment decisions  |
| <b>Ruhe <i>et al</i>, 2016 (a) [51]<br/>Switzerland</b>     | To explore patient's perspectives in on participation in discussions   | Qualitative interviews                             | N=17<br>35% female  | Cancer/<br>Secondary care  | 9 to 17   | Participation in the form of receiving or providing information,  |

|   |   |  |                      |  |          |  |
|---|---|--|----------------------|--|----------|--|
|   | and decision-making surrounding their diagnosis.  |  |                      |  |          | contributing an opinion, or making healthcare choices  |
| <b>Ruhe <i>et al</i>, 2016 (b) [52] Switzerland</b>       | To explore how patient participation was put into practice in a paediatric oncology setting   | Qualitative interviews   | N=17<br>35% female   | Cancer/<br>Secondary care  | 9 to 17  | Participation in discussions and decision-making   |
| <b>Stegenga &amp; Ward-Smith, 2008 [53] United States</b> | To explore treatment decision-making from the perspective of the adolescent   | Qualitative interviews   | N=3<br>67% female    | Cancer/<br>Secondary care  | 13 to 15 | Participation in treatment decision-making   |
| <b>Taylor <i>et al.</i>, 2010 [54] United Kingdom</b>     | To investigate child and carers' attitudes towards child involvement in paediatric consultations  | Qualitative interviews   | N=20<br>75% female   | Various acute and long-term /<br>Secondary care:<br>inpatient and outpatient | 7 to 16  | Involvement during consultations including information sharing and ultimate decisions about treatment  |
| <b>Van Staa, 2011[55] The Netherlands</b>                 | To evaluate adolescents' preferences and competencies for communication during consultations.   | Mixed methods:<br>Interviews,<br>Q-methodology,<br>Observations,<br>Focus groups,<br>Web questionnaire | N=1021<br>55% female | Various long-term/<br>Secondary care   | 12 to 19 | Healthcare communication, including making decisions   |
| <b>Weaver <i>et al</i>, 2015 [56] United States</b>       | To investigate adolescent medical decision-making preferences and behaviours reported to be supportive of their preferred level of decision-making involvement. | Qualitative Interviews   | N=40<br>40% female   | Cancer/<br>Secondary care  | 12 to 18 | Treatment decision involvement and information access.   |
| <b>Young <i>et al</i>, 2006 [57] United Kingdom</b>       | To examine and compare children's, parents' and practitioners' perspectives and experiences of decision-making in community paediatric physiotherapy services   | Qualitative Interviews and focus groups  | N=11<br>45% female   | Cerebral palsy/<br>Community care  | 8 to 18  | SDM: involvement in the decision-making process by sharing information and expressing treatment preferences so that a decision is made and agreed by all parties |
| <b>Zwaanswijk <i>et al</i>, 2007[58] The Netherlands</b>  | To investigate communication preferences of childhood cancer patients, parents, and survivors of childhood cancer   | Qualitative Online focus groups  | N=7<br>57% female    | Cancer/<br>Secondary care  | 8 to 16  | Communication, including information exchange, decision-making and interacting.  |
| <b>Zwaanswijk <i>et al</i>, 2011 [59] The Netherlands</b> | To investigate communication preferences and variables associated with these preferences.   | Quantitative hypothetical:<br>Vignettes and questionnaires   | N=34<br>38% female   | Cancer/<br>Secondary care  | 8 to 16  | Level of involvement in decision-making  |

\*Author contacted directly for participant information which was not available in published report

Table 2: Overarching themes and exemplary quotations

| Theme and definition   | Exemplary Quotations  |
|--|---|
| <p><b>Variability in involvement preferences and experiences</b></p> <p>Involvement preferences and experiences can vary within and between individuals, and can depend on factors such as type of decision and current health status.</p>   | <p><i>'Like, small, if they were to ask you do you want tablets or medicine, yea, of course you can make them decisions, it's your body, you should decide what you want to do like.'</i> [37] (Female, aged 13).</p> <p><i>'In the beginning I did not care ... because I was so shocked. But then, after a while I realized that I have to know what I have and what is going on. And then I started to listen again.'</i> [51] (Male, aged 13-15).</p> <p><i>'I think that depends on the situation. Like for how much the decision will impact or affect me and how much it will impact or affect them [parents].'</i> [56] (Male, aged 17 with cancer).</p>  |
| <p><b>Power dynamics and involvement in the decision-making process</b></p> <p>Adolescents feel that it is their right to be involved and would like to be able to choose their level of involvement. However, they perceive parents and health professionals as having this control, and look to them to support and encourage their involvement.</p> | <p><i>'I think decisions are made most of the times before they come to me like the medicine and everything like, all the... they have already decided what to do before they come to me and ask me.'</i>[37] (Male, aged 18).</p> <p><i>'they don't explain everything. The first time I was getting it, I didn't know what it was. He didn't say it when I was there. He said it to Mam behind the curtains. I was upset because I don't know what it's for or anything like that...I wouldn't have the guts to say anything, he comes across as a very intimidating man.'</i> [37] (Female, aged 17).</p> <p><i>'They just tell you, they'd use big words and I wouldn't be able to understand them and then I'd ask my father what did they mean and he wouldn't really tell me. .... if the doctor is talking for nearly 15 minutes or so and your father only tells you a couple of seconds then there has to be more in the story. It makes you kind a worried.'</i> [37] (Male, aged 11 with cancer).</p> <p><i>'He could have told me what he possibly thought it was. What he thinks they'll need to do. He could have told me anything more because it was almost like I was sat dead on the bed. He was talking to my mum, and that, but he could have been talking to me.'</i> [47] (male aged 13-16).</p> |
| <p><b>Mismatch between involvement preferences and experiences</b></p> <p>Adolescents report a disparity between their preferences and experiences, which can cause anxiety, and feelings of being unvalued and excluded.</p>  | <p><i>'If they at least told me, I think I would feel a little better about why I'm taking this medicine...I think I'd feel more comfortable if I got to talk to them.'</i> [33] (female with cystic fibrosis).</p> <p><i>'It made me feel a bit...a slight bit...like a piece of machinery actually, they weren't actually talking to me...I thought hey I'm the patient here, talk to me, explain what are you going to do'</i> [36] (Female aged 14).</p> <p><i>'I feel real disappointed like, just disappointed because I don't feel, like I feel like I'm kind of rejected in a way.'</i> [37] (Male, aged, 13).</p> <p><i>'I wish maybe they would have listened to my opinion a little more'</i> [49] (Female, age 16 with junior idiopathic arthritis).</p> <p><i>'I prefer to represent myself. If I forget something, it's OK for my mum to step in, but I used to get so irritated when doctors addressed my parents instead of me, with me just sitting there!'</i> [55] (Female, aged 19 with cystic fibrosis).</p>   |

