**A systematic evidence synthesis of interventions to engage children and young people in health care consultations.**

**Abstract**

Children and young people with long-term conditions are not always provided with opportunities to engage fully in consultations. This systematic review examined the effectiveness or worth of methods used to engage children and young people with long-term conditions in their consultations. Searches were undertaken in October 2016 in eight databases and of the grey literature. Two reviewers independently screened the results, extracted data and assessed the quality of the studies using a validated and reliable checklist. A narrative synthesis of mixed method data was undertaken. Twelve studies were included in the review. Interventions used to engage children and young people mainly focussed on face to face outpatient consultations, with an emphasis on diabetes and asthma. Most of the interventions focussed on either improving health professionals’ communication skills or encouraging children’s and young peoples’ engagement through providing condition-related information or a structured way to be included in consultations. Fewer interventions were child-led or directed towards developing children’s and young peoples’ skills to become key reporters of their condition. This review has demonstrated that interventions targeted at children and young people with long-term conditions can improve their levels of engagement in consultations. There is a need for more systematic development and robust evaluation of interventions to improve children’s active participation in consultations.

**Introduction**

The words used to describe children’s involvement, participation and engagement in health care vary across time, settings, cultures and contexts. This diversity is important as the terms used can imply different levels of engagement ranging from a more passive involvement to a more agentic form of participation. In this review we purposively selected the term engagement to reflect that we wanted to include the diversity of children’s engagement within health care consultations. The term also underpins other reviews within this field (Feenstra et al 2014, Curtis-Tyler 2011) and is used within contemporary documents within the United Kingdom e.g. NHS Confederation (2011) Involving Children and Young People in Health Services.

It is important for children and young people to actively engage in their health care (Department of Health 2012, The Kings Fund 2013, American Academy of Pediatrics 2012, Moore & Kirk 2010) this engagement may take different forms depending on various factors such as children’s developmental level and their previous health care experiences. Children and young people have repeatedly expressed the value of being involved in their health care (Coyne 2008, Weil et al 2015) and specifically in relation to consultations (van Staa et al. 2011, Miller 2009). Evidence shows that active engagement in consultations can facilitate knowledge acquisition (Curtis-Tyler 2011) and the ability to communicate choices and decisions (Feenstra et al 2014). Despite this children and young people can be marginalised in consultations with health professionals and can find it difficult to have their voice heard above those of the adults (parents, health professionals) present (van Staa 2011, van Dulmen 1998, Beresford & Sloper 2003, Tates & Meeuwesen 2001, Coyne et al 2006, Savage & Callery 2007). This triadic communication between health professionals-parents-children/young people can often leave children and young people feeling excluded and struggling to become engaged in consultations and have the opportunity to be heard and listened to (Cahill & Papageorgiou 2007, Savage & Callery 2007, Callery & Milnes 2012, Raafe et al 2014). A recent review which focussed on triadic communication between medical providers, parents and children (Kodjebacheva et al 2016) identified that the majority of evidence focusses on improving *parent* engagement during health care interactions. If children are not given opportunities to develop their communication and decision-making skills within health care contexts they may struggle when they transition to adult services (van Staa et al 2011), this in turn can lead to lower levels of adherence to health regimens (Gardiner & Dorkin 2006, Levetown 2008) and lower levels of satisfaction and engagement with health care services (Ambresin et al 2013). Evidence has demonstrated that interventions can have a role in improving patient’s involvement in consultations (Henselmans, et al 2013), their ability to ask questions (Dimoska et al 2008, Smets et al 2012) and engage in decision-making (Feenstra et al 2014), but most of the interventional research within this field is based on adults (Gaston & Mitchell 2005) and the evaluation of targeted interventions to help children and young peoples’ engagement during consultations is lacking (Cunningham & Newton 2000, Milnes et al 2013, Gregory et al 2012).

There has been no systematic investigation of the current evidence which surrounds interventions, approaches or methods to enhance the engagement of children and young people in medical consultations about their long-term conditions. There is a need to systematically review the evidence regarding interventions to engage children and young people in their consultations. This review aimed to focus on interventions which had been subjected to evaluation in relation to effectiveness, influence or worth. Long-term conditions within this review refers to conditions which cannot be cured, but can be controlled by medication and therapies with a longevity of six months or more (Department of Health, 2012). The parameters of the intervention are defined within our inclusion criteria section in the methods section.

**Methods**

A systematic review was undertaken to locate, appraise and synthesise evidence of interventions to engage children and young people in health care consultations about their long-term conditions. The objectives were 1) to clearly define and critically examine the current evidence about which methods/interventions are designed to engage children and young people in health care consultations about their long-term conditions and 2) to explore what the evidence tells us about which methods are the most successful/effective in engaging children and young people in their health care consultations. The conduct and reporting of this study followed the PRISMA guidance for systematic reviews (Moher et al, 2009).

*Search strategy*

A comprehensive search strategy was undertaken in the following databases: Medline, Cinahl, PsychInfo, British Nursing Index, ChildLink, The Cochrane Library, Joanna Briggs Institute Database of Systematic Reviews and Implementation Reports, and Web of Science. All searches were initially undertaken in February 2016 and updated in October 2016. No date or language restrictions were applied to the searches. Both thesaurus and free-text terms were searched. Key terms searched include consultation terms (e.g., encounter, communication, conversation), health personnel terms (e.g. nurse, doctor, professional), child terms (e.g., child, adolescent, young person) and involvement terms (e.g. engagement, interaction, involvement). Truncation and proximity operators were employed to increase the sensitivity of the search (see Appendix for full Medline search).

In identifying innovative and emerging practice it was essential that grey literature was searched, since it is likely that literature relevant to this review may not be in the peer reviewed published domain. Grey literature was identified via Open Grey and Google. In addition, the Royal College of Paediatrics and Child Health, the Royal College of Nursing, National Institute of Health Research portfolio and the Department of Health websites were scanned for studies, conference papers and publications. Searches for grey literature were undertaken in February 2016 (and updated in January 2017).

*Inclusion criteria and study selection*

Studies were included in the review if they fulfilled all of the criteria identified in table 1.

**Table 1 (to be placed here): Inclusion criteria for studies included in the review**

Titles and abstracts were imported into Covidence.org (a specific system for systematic reviews designed by Cochrane) for screening. A two-stage approach to screening was adopted. Stage 1 involved the screening of titles and abstracts. References that clearly met the inclusion criteria, or in instances in which the relevance of the study was unclear, were taken forward to the next stage. Stage 2 involved the full-text screening of the studies against the inclusion criteria. We attempted to obtain full-text articles as this was seen as important in the quality appraisal process. We contacted authors directly to obtain the full-text articles not readily available via other sources. In order to minimise selection bias two reviewers were involved in both stages of the screening process. If consensus could not be agreed or uncertainty existed a third review was involved in screening.

*Data analysis and synthesis*

To provide consistency and transparency of the review process, a data extraction form was piloted and used to extract data specific to the aims and objectives of the review. The Mixed Methods Appraisal Tool (MMAT) (Pluye et al 2011) was used to assess the quality of the included studies. This tool was selected as it is a validated and reliable tool for the assessment of qualitative, quantitative and mixed methods studies for inclusion in a systematic review (Souto et al 2015). At least two reviewers independently extracted the data and quality assessed the included studies. The quality assessment of the included studies is detailed in Table 2. Due to clinical and methodological heterogeneity, a narrative approach to data synthesis was undertaken.

**Results**

The search located 14,265 references. Three hundred and thirty-six references were retrieved for full text analysis of which 14 papers (12 studies) met the inclusion criteria for the review (see Figure 1 for PRISMA flow diagram). The included papers are detailed in Table 3. Many of the papers were excluded as they only described the use of an intervention in practice with no evidence of evaluation. The results section of the paper is presented in two sections to reflect the main objectives of the systematic review; what methods and interventions are used to engage children and young people in consultations and which methods are effective in engaging children and young people in their consultation?

***What methods and interventions are used to engage children and young people in consultations?***

The first objective of the review was focused on clearly defining which methods/interventions are reported as being used to engage children and young people in health care consultations about their long-term conditions. Table 3 summarises the samples, methods, designs and outcomes of the included studies.

The studies detailed the use of a wide variety of interventions and methods to engage children and young people in their consultations, these could be seen to fit within the following headings of methods and intervention to prompt or open up communication, training to improve engagement and redesigning the consultation process to facilitate engagement.

Methods and interventions to **prompt or open up communication** between children and young people and health professionals: furniture to prompt and encourage children’s engagement (Chin et al 2014), drawings to prompt children’s engagement (Berger 1980); reflective consultation sheets completed by children and young people (Husted et al 2014); leaflets designed by young people to prompt discussion during consultation (Milnes et al 2013); written sheets for children and young people to define key topics to underpin consultations (Gregory et al 2011); structured questionnaire tools to underpin discussion during consultations (Petersen et al 2016); a computer based system to help children and young people define topics to discuss during consultations (Vatne et al 2013)

**Training to improve engagement** during consultations; consultation communication training for health professionals (Gregory et al 2011, Bejarano et al 2015); consultation communication training for young people (Husted et al 2014);

**Redesigning the consultation process** to facilitate engagement; shared medical appointment models (Bejarano et al 2015, Rijswijk et al 2016); two way text messaging interaction between health professionals and young people (Franklin et al 2006,2007, 2008, Yoo 2015) and a smart phone application to focus on condition management and interaction with health professionals (Haze & Lynaugh 2013).

Nine studies focussed on face to face consultations within an outpatient setting (Berger 1980, Bejarano et al 2015, Chin et al 2014, Rijswijk et al 2016, Vatne et al 2013, Gregory et al 2011, Milnes et al 2013, Husted et al 2014, Petersen et al 2016), with three papers focussing on remote engagement (Franklin et al 2006, 2007, 2008, Haze & Lynagh 2013, Yoo 2015). Studies addressed a range of long-term conditions, with more evidence for some conditions; diabetes (n=4), asthma (n=3), heart disease (n=1), palliative care (n=1), neuromuscular (n=1), allergy (n=1) and general paediatrics (n=2).

Study designs included qualitative (n=5), quantitative randomised controlled (n=1), quantitative non-randomised (n=1), quantitative descriptive (n=2) and mixed method studies (n=3). The qualitative studies focussed on gaining the perceptions and experiences of young people through interviews (Husted et al 2014, Milnes et al 2013, Petersen et al 2016) and observing interactions during the clinic consultation (Husted et al 2014, Rijswijk et al. 2016). In the quantitative studies, the assessment of engagement as a result of the intervention/method, was sometimes made within broader measures of long-term condition management, for example HRQoL and adherence (Gregory et al 2011). In some studies, the assumption appeared to be that improved levels of engagement could be demonstrated through increased knowledge levels and/or physiological measures of condition management (Bejarano et al 2015); there is limited evidence from our analysis to assert that these connections can be robustly made. Some studies utilised validated measures of engagement; Patient Enablement Inventory (young people >11yr) (Gregory et al 2011), Emotions Prior to Clinic Visit (children >7yo) (Gregory et al 2011), Diabetes Continuity of Care Scale (perceptions of diabetes team) (young people >11yr) (Gregory et al 2011), Healthcare Climate Questionnaire (Gregory et al 2011), Problem Areas in Diabetes (PAID) score) (Gregory et al 2011) and Self-Efficacy Diabetes Score (Franklin 2006, 2007, 2008). However, some studies used measures specifically developed for the particular study (Franklin et al 2006, 2007, 2008, Gregory et al 2011). Some studies assessed children’s and young people’s engagement by researchers analysing the videoed observations of consultations (Rijswijk et al.2016, Vatne et al 2013). Due to heterogeneity of outcome measures and methodological design across included studies it was not possible to undertake statistical analysis.

***Which methods are effective in engaging children and young people in their health care consultations?***

The second objective of the review focussed on exploring what the evidence presents about which methods are the most successful/effective in engaging children and young people in their health care consultations. The limited number of studies in the review (n=12) and the lack of robust quantitative methods used means that the evidence relating to ‘what works’ for children and young people is limited.

The studies included in the review provide evidence that the interventions helped children and young people to;

1. improve the **frequency** with which children and young people engaged in the dialogue during consultations through; a drawing to prompt discussion (Berger 1980), structured reflective sheets (Husted et al 2014), a pre-consultation guide (Milnes et al 2013), a computer based communication tool (Vatne et al 2013) and a smart phone app (Haze & Lynaugh 2013)
2. discuss a **wider range of their concerns** during consultations through; children choosing a style of chair to sit on to prompt them to express their emotions (Chin et al 2014), structured reflection sheets and communication training for young people (Husted et al 2014), a computer based communication tool (Vatne et al 2013), shared medical appointments with other young people (Rijswijk et al 2016)
3. talk **more openly and honestly** to health professionals through; targeted communication training for young people (Husted et al 2014) pre-consultation guide/leaflet designed by young people (Milnes et al 2013), a smart phone app (Haze & Lynaugh 2013)
4. be **more satisfied** with their engagement/consultation through; use of a shared decision-making aid (Bejarano et al 2015), attending shared medical appointments with other young people (Rijswijk et al 2016) and using a text messaging communication system (Franklin 2006,2007, 2008).

The quality review of the evidence, conducted using the MMAT tool (Pluye et al 2011), indicates that the overall quality of the studies was poor to fair. The only large scale RCT of children’s and young people’s engagement (Gregory et al 2011) failed to show any effect of intensive health care professional consultation training and materials for young people on their enablement scores, emotions about coming to clinic, continuity of care, Problem Areas In Diabetes (PAID) or their self-care.

The evidence from the review was challenging to synthesise due to the inconsistency in the terminology used, lack of definitions of the core elements of consultation or engagement, outcomes measured and the interventions being used in a range of settings with different professional groups.

**Discussion**

Despite using a broad search to try and capture the diversity of terms relating to children’s and young people’s engagement, only 12 studies met the inclusion criteria for interventions and methods to engage children and young people with long-term conditions in consultations. Although current evidence demonstrates some benefits of the interventions to engage children and young people with long-term conditions in their consultations, this evidence is disparate, inconclusive or drawn from single sites or single conditions. The authors recognise the difficulties inherent in designing and conducting a rigorous trial to appraise complex interventions such as those focussed on children’s and young peoples’ engagement during consultations.

As this is the first review to focus on children’s and young people’s engagement in consultations, we found it useful to consider the different levels of engagement afforded by the interventions and methods. The findings of the review are discussed in relation to the level of involvement model (Save the Children, 2010); the studies were categorised as low, medium or high involvement evident in the range of interventions and methods reported (see Figure 2).

**Figure 2 (to be placed in here): Application of the Save the Children, Putting Children at the Centre Involvement Model (2010)**

Most of the reported interventions and methods were categorised as ‘low level of engagement’ as they focused on providing children and young people with information and a structured method to encourage them to ‘talk more’ or voice their opinions and issues; children’s engagement was shaped and controlled by the adults in the consultation (Figure 2). Interventions categorised as ‘medium level of engagement’ were those that enabled children and young people to use technology to support their engagement. Although this review did not identify any child led initiatives (the highest level of engagement), some interventions were developed with young people (Milnes et al 2013) or focussed on developing long-term communication skills (Gregory et al 2011, Husted et al 2014, Vatne et al 2013) and as such these interventions were categorised as a ‘higher level of engagement’. It is hoped that as more health services recognise that children’s and young people’s agendas and priorities need to be at the centre of their care that new interventions and methods will be developed that are more participatory, engaging and child-centred. Interventions may be focussed on targeting specific age groups but need to recognise that children’s ability and preferences for engagement will be influenced by other factors including previous health care experiences.

This review focussed on children and young people with long-term conditions, as they often have protracted and ongoing contact and consultations with health professionals and therefore there can be multiple opportunities to build skills and positive experiences for this group of health care users. It is often assumed that children and young people with long-term conditions are experienced in communicating and interacting with health professionals, but this is not always the case (Bray et al 2012).

***Strengths/limitations***

This study aimed to minimise publication bias by undertaking a comprehensive search of both the published and grey literature. Two reviewers independently screened the results, data extracted and quality assessed the included studies. Due to the variable study designs, outcomes and quality of published reports we were not able to conduct a meta-analysis. As the studies reported a range of different interventions, within different settings and used with different groups of professionals this made the comparison of engagement challenging.

**Conclusion**

This review suggests that interventions can have a role in improving the frequency and range of children and young peoples’ engagement during consultations and can improve their satisfaction with their interactions, decisions and relationships with health professionals during consultations. There seems to be more work needed to explore the influence of consultation interventions and methods on children and young peoples’ health outcomes (physiological, psychosocially). This review has demonstrated that there is a need for a more systematic development and robust evaluation of interventions to improve children’s and young peoples’ skills and abilities and opportunities to actively participate in consultations and decisions about the care of their long-term condition.

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