Clinical Doctorate in Paediatric Dentistry (DDent)

INVOLVING CHILDREN IN ORAL HEALTH RESEARCH: ARE WE DOING ENOUGH?

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Declaration of Originality

I hereby declare that the work represented in this thesis is the result of my own investigations, except where otherwise stated. Information imitative from the published and unpublished work of others had been acknowledged in the text and the relevant references are included in this thesis.

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Abstract

Background: Actively involving children in decisions made about them in research is of growing interest. In paediatric dentistry, it is still relatively rare for children to be co-researchers or be involved in clinical feedback.

Aims: To determine existing methods used to engage with children in order to develop and shape research design. To develop a satisfaction tool for paediatric dentistry with children and compare the outcomes to the standard adult survey already in use.

Method: A systematic review done through electronic databases searches for literature on the involvement of children (aged 4-12 years) either in the design of the research question, or in development of the methods.

Children attending the Paediatric Dentistry Unit were interviewed to capture their views about the important areas to include in a satisfaction questionnaire. Several versions of the questionnaire were piloted with children, until the final version was deemed acceptable by children. This was then validated against the standard survey.

Results: The systematic review reported four examples of children as researchers with insufficient data about the best method to be used.

The final questionnaire contained 7 questions and a comments section, using writing and facial images to record children’s views. The questionnaire was different in content and interest to an adult version. Differences were noted when compared to standard are questions text, type, design, response and outcome.

Recommendation: More involvement is needed for children in research in paediatric dentistry. Focus groups/ interviews in combination with questionnaires may be an effective method.

The satisfaction scale developed can be used for service improvement, however multi centre, larger sample studies are required for testing and modification.

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List of abbreviations

NHS	National Health Service
PRP	Policy Research Program
NCB	National Children's Bureau
PHRC	Public Health Research Consortium
PEAR	Public health, Education, Awareness, Research
DoH	Department of Health
UCLH	University College London Hospital
NSF	National Service Framework
U&EC	Urgent and Emergency Care
PREM	Patient Reported Experience Measure
SDM	Shared Decision Making
NIHR	National Institute for Health Research
NICE	National Institute for Clinical Excellence
SCIE	Social Care Institute for Excellence
AMRC	Association of Medical Research Charities
PRA	Participatory Rural Appraisal
PAR	Participatory Action Research
SRA	Social Research Association

Chapter One:

Introduction

1.1 Background

Children make up more than a quarter of the total consultations in general medical practice and have become important users of health care services (Hart and Chesson, 1998). Following increased appreciation of children rights over the last decade, both nationally and internationally, the importance of listening and consulting children in health care related decisions is now recognised. Nowadays, there is a greater emphasis on involving children directly in research (Hill, 1997). In this research we looked at two important elements of this:

1. the involvement of children in research
2. the involvement of children in the measurement of patient satisfaction.

1.2 Child involvement in research – recognising the problem

The best sources of information about children are children themselves (Bearison, 1991); therefore, any research should involve children from the outset. Article 12 of the United Nations Convention on the Rights of the Child (UNCRC, 1989), states that “all children and young adults who are capable of forming their own views, have a right to express those views freely in all matters affecting them, with the views of the child being given due weight in accordance with their age and maturity. Even a three-year-old child can provide a graphic report and great recall related to events (Alex and Ritchie, 1992). In the past, children’s participation was considered as either part of family research, or guided by a responsible adult making decisions on their behalf. This resulted in parents being the major decision makers in research concerning children. This was adopted because of the impression that a child or young adult's feedback may not be reliable, or that children are either immature or cannot understand (Gerison, 2011).

There is now agreement that the aim of research concerning children should concentrate on involving them in the design. Listening to children will yield greater benefits for both the child and the researchers. However, there is an obvious gap between what we expect and the reality, achieving active involvement may be more complicated than it appears. Research topics may to be picked by the researchers themselves, with funding bodies acting in a responsive mode (Nuffield Council on Bioethics, 2015). In 1996, the director of research and development in the Department of Health, set up a group involving consumers in the National Health Services. This organization defined public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (http://www.invo.org.uk/about-involve/).

1.2.1 Projects involving children

Seven years later, this group was renamed as "INVOLVE" (http://www.invo.org.uk/), to promote public involvement for service users through the INVOLVE initiative. The purpose of the group was further extended to include the Policy Research Program (PRP). The main purpose of PRP is "public health research and social care, where people's involvement in research and development will improve the way the research is organised, appointed, taken on and disseminated. INVOLVE believes that the involvement of people who use services in the research process leads to a research that is more relevant to people in general, where it is more likely to be used. When research reflects the needs and views of the 'end user', it is more likely to produce results that can be used to improve practice in health and social care "(http://www.invo.org.uk/).

INVOLVE have undertaken several projects including young people in research, mostly health related. Examples of involvement include people with disabilities (Robinson, 2005), children suffering from illness (Lightfoot and Sloper, 2001), children involved in clinical audit and its potential (Moules, 2002), mental health needs in children aged 10 to12 years of age (Brooks, 2005) and looked after children (Hobbiss, 2005).

Another project relating to young people is the PEAR project (http://www.ncb.org.uk/pear). This project was originally run by The National Children's Bureau (NCB), which is a charity improving lives for children and young people for over 50 years. In collaboration with the Public Health Research Consortium (PHRC) and INVOLVE, a small project was run in London from 2005-2007, including a conference for over a hundred researchers interested in health, more specifically the public and social health. Children helped in organising and appointing their own projects, and received research skills and public health training.

The sample size for the PEAR project was 20 young people from London and Leeds aged between 13-18 years of age. The researchers summarised the ways in which children and young adults can be involved in research as:

1. Working alongside with adults as young advisors.
2. As young researchers or evaluators – working alongside adult researchers to design tools, collect data, analyse and/or report on findings
3. As co-researchers – being supported to do their own research alongside adult researchers
4. Coming up with research ideas and helping to choose the best adult researcher.

The authors concluded that children may be involved in any stage of research starting from the research proposal, methods and writing up the research. Benefits gained by children are that the child has the chance to make a difference, develop more skills and gain more knowledge. It helps researchers to meet patients' needs, improve understanding (Patient and public awareness), leads to better recruitment and outcome design (Thomas et al., 2007) and enhanced implementation of findings (Hanely, 1999).

Following on from PEAR, the Wellcome trust (http://www.wellcome.ac.uk/) funded a two group project in London and Leeds from 2008 to 2010. Whilst they had explored how young people could be involved in the first project, they took this a step further in the second study, where they trained the children about the concept and process of research. Furthermore, they allowed children to help in the conference organization, where their opinions were heard and taken into consideration (http://www.wellcome.ac.uk/).

In the recent Nuffield Report on Bioethics of Research in Children they made the following recommendation: 'We recommend that research ethics committees should routinely require researchers to have involved children, young people and parents, as appropriate, in the design of their studies. Researchers who have not sought input in this way should be required to justify to the research ethics committee why this was not appropriate in their case, and be able to demonstrate an appropriate knowledge of relevant literature and guidance.' (Nuffield Council on Bioethics, 2015).

In 2001 The United States Institute of Medicine recognised the importance of Shared Decision Making (SDM) for health care providers in the clinical setting. SDM introduced an effective way to involve and motivate the patient. Mayall summarised the child-centered approach as" concerning child capability in reporting their own experience, take what children say in a serious manner, working with and for children rather than on them." (Mayall, 2004)

According to the United Nations Convention on the Rights of the Child in 1989, there has been a huge increment in the past five years to include youngsters in decision making (Oldfield and Fowler, 2004). Consulting children is now a key policy issue that is recognised and actively promoted by many non-government and voluntary organizations such as Action for Sick Children, Barnardo's, Carnegie Young People Initiative, National Children's Bureau (2004) and Save the Children (2004). In 1991, the UK government ratified the united nation rights of child, which clearly states the rights of every child to make an informed decision and be respected. However, there appears to be an obscurity about the concept of child involvement, as children are seen to be in need of protection in contrast of being active participants in research methodology (Jans, 2004).

Rights have been reported to be a complex issue (Martin and Nickel 1980). In addition, the United Nations Conventions on the right of the child (UNCRC) concerned about children's rights as a source of information. They launched this in 1989 and it came into force in 1990.

The United Kingdom significantly changed towards more involvement of children in taking decisions affecting them after the UNCRC and Children Act in 1989, in departments such as the Department of Health 2006 and Department of Education and Skills. Authors have stated that: 'if all our children are to enjoy the rights enshrined in the UNCRC, then research and practice in England needs to fundamentally reshape its paradigm to become more inclusive and participatory' (Pascal and Bertram, 2009).

1.3 Child as active partners in research

When children's actual opinions, perspectives, perceptions and contribution are taken in consideration, this is defined as research with children (Punch, 2002).

To date dentistry has lagged behind the rest of medicine in this regard. A systematic review of child involvement in oral health research found children were treated as the 'object' rather than actively involved in the research process with no good examples of practice noted (Marshman, 2007). Fear of involvement was a concern, as were different opinions among parents and professionals about the benefits of involving children in the research process (Coyne, 2008). In a recent narrative review (Gilchrist et al, 2013) potential methods for involving children were noted, including focus groups and interviews.

The new model is to consider children as research advisors, changing the traditional approach to research with children.

1.4 Public participation

The public has a passive role in the process of research conduction, even though they are the main source for data collection in research. When research is planned to involve members of the public, several questions needs to be considered; what are the benefits of involving these members in the study? What are the reasons behind the selection criteria? And what is the degree of involvement? As knowledge and experience may differ between patients, a 'standard' set of questions may not be appropriate (National Institute of Health Research, INVOLVE, 2010).

There are many examples available that explain and clarify how children and young people can be involved in research. The National Institute for Health Research (NIHR, 2010) summarized this as follows:

- Involve people as early as possible - so they feel part of the research and have a sense of ownership
- Be clear with the people you want to involve - so there is a shared and clear understanding of what they are being invited to do
- Be accessible - consider who you are going to involve and if they reflect the diversity of people or cultures in the research
- Resource public involvement in research - think about how you resource involvement in terms of budget and the additional time required to involve the public in your research
- Offer training and support
- Clarify organizational responsibilities
- Document and record public involvement in your research
- Contact the Research Design Service for advice and support in developing your public involvement or see how we can help you (NIHR, 2010).

Other research organization follows the same rules as NIHR such as National Institute for Health and Care Excellence (NICE), Social Care Institute for Excellence (SCIE) and the Association of Medical Research Charities (AMRC).

It appears that the inclusion of service users in research is not only a research agenda; it is also a participation agenda (Hart and Chesson, 1998). Any knowledge about young people that does not involve them is considered as incomplete.

1.4.1 How are children involved in research?

Children's involvement could happen at any stage of the research such as in decision making, developing research idea or proposal, research period, data providing, data collection and analysis and finally reporting". (Gerison, 2011). Research that considers children as participants can be classified into four categories with each category having its own sub categories. This was clear in the 2015 systematic review undertaken by Marshman et al from the University of Sheffield. The four main categories are:

- children as the objects of research
- proxies used on behalf of children
- children as the subjects of research with some involvement
- children as active participants with their perspectives explored

This review concentrates mainly on the last three categories.

While the percentage of studies involving children actively involved in dental research has increased from 0.3% of 3266 papers between year 2000 and 2005 to 0.6% out of 2950 papers between year 2006 and 2014, numbers are still low. What are the barriers to involving children in research and what are the problems we need to overcome? (Marshman et al, 2007 and 2015)

1.5 Methodological issues

1.5.1 Children vs. adult in research

Adult researchers may find it difficult to understand the child's world (Fine and Sandstorm, 1988). As they were children for a period of time; adults think they are aware of childhood. This assumption may lead to an inappropriate understanding of childhood. The belief that adult's knowledge is superior to that of a child must be abandoned (Reamer et al, 1992).

The question is how can researchers involve children in their studies in the best manner? (Hill, 1997). Recent studies have created different approaches such as Participatory Rural Appraisal (PRA) and Participatory Action Research (PAR). Studies found these methods empowered participants to positively participate in society and make decisions (Boyden and Ennew, 1997; Hart, 1997).

Participatory Rural Appraisal:

Is an approach used by non-governmental organizations (NGOs) and other agencies involved in international development. The approach aims to incorporate the knowledge and opinions of rural people in the planning and management of development projects and programs. The evidence obtained from people through PRA compared with data from more traditional methods showed high validity and reliability of information (Robert, 1997). Most techniques used in PRA can fit in one of the following: Group dynamics, sampling, interviewing and information visualization (Mukherjee, 1993).

Participatory action research:

PAR is an approach to research in communities that emphasizes participation and action. It is a set of principles and practices for originating, designing, conducting, analysing and acting on a piece of research (Kindon et al, 2007). The aim of these techniques is to allow free participation of children in research (e.g. O'Kane, 2000). Within a PAR process, "communities of inquiry and action evolve and address questions and issues that are significant for those who participate as co-researchers" (Reason and Bradbury, 2008). An example of how participation action research is used as a practical and reliable methodology for research is a study undertaken by Cooper in 2005.

1.5.2 Validity and reliability

Another concern with involving children in research is the assumption that children may lie to researchers for different reasons (Morrow, 1999). In fact, the same could happen with adults (Hood et al, 1996; Mauthner, 1997). Building a close and harmonious relationship with the child during the research will increase his/her trust in the researcher thus increasing the reliability (Ennew, 1994).

1.5.3 Clarity of the language

Language may be a barrier, as children may not be able to express their feelings as accurately as adults. Clarity of language is vital in any formulated study. However, adult researchers underestimate children in this aspect (Mahon et al,1996). The language difficulty is mutual, as children can use a different language that adults cannot understand. Researchers should be accurate in understanding and interpreting the feelings, attitude and feedback of the child to complex words, such as medical words (Punch, 2002).

1.5.4 Research context and setting

The context and setting when children are involved in research should be as important as it is for adults. Nevertheless, most research environments are mainly controlled by adults who may affect the children negatively. The environment for data collection may have an impact on the response of the child. Many aspects including the location, size and atmosphere may affect the procedure. It's critical to have control over the environment and minimize its effect on research (Shaw et al, 2011).

1.5.5 Building rapport

A good relationship between researchers and subjects, either adults or children, is a vital factor for a successful study (Harden et al, 2000). However; many researchers lack the skills to build harmonious rapport with children for several reasons; such as fear of being patronising and not finding suitable ground for building a good relationship. In this aspect, researchers need to follow guidelines for developing rapport with children and react to them positively (Cosaro, 1997; Punch, 2002). This skill should not be limited to the children's subjects but also applied with the adult gatekeepers (Morrow, 1999).

1.6 Analysis of the data

Children can be actively involved in analysing data, provided sufficient training and support is provided.

1.7 Giving feedback to participants in the findings

To make sure that research findings reach the participant, it is important to keep communicating with those who wish to receive the results of the study. Secondly, the findings should be accessible to all children in an appropriate format (Ritchie and Lewis, 2003).

1.8 Sampling

The age of the participant plays a major role in the method and research design. For those who are at secondary school, adult approaches can be used such as questionnaires and one-to-one interviews. For younger age groups i.e. children in primary school, the formal methods may not be appropriate. As there is no lower age limit for children to participate; methodology should be prepared appropriately to meet their cognitive level, understanding ability as well as their language. More consideration must be given for very young children; how can they understand the aim of the research? How will they contribute? This means there is a need to use numerous methodological approaches, which can affect and alter the time for study, as data collection may require more than one visit (Shaw et al, 2011).

Dealing with special needs children may require careful thought. When dealing with vulnerable children researchers should use creative methods and more flexible techniques. The Council for Disabled Children and other disability charities is a good source of advice where they might be able to offer additional advice and guidance in this respect (United Nation, 1989).

1.9 Resourcing and cost

Adequate resources are the cornerstone of the research process, as insufficient resources may require some modification and alterations to plans. Costs do not only include finance, but also resources such as time and energy. First the researcher needs to recruit younger researchers and this is not an easy procedure, in addition to that it is time consuming. Time is required to contact and enroll youngsters, and support specialists in the field may also be required (Kirby, 2004). The young researchers may need support in order to understand what participation means as well as the meaning of personal support. This personal support may include help while travelling to the research site or during the attempt to reach the meetings locations. This also could include the cost for children with disability that are in need for special arrangements (Shaw, 2011).

Without proper training, we cannot assume that a child acting as a young researcher is capable of providing a good and valid interview or questionnaire or focus group exercise. This training is most likely to be a critical point to the whole research process, and demands both skill and resources for it to be undertaken effectively (Lockey et al, 2004).

1.10 Ethics and its issues

Ethical issues are the major reason for not involving children in the research process. Social Research Association (SRA) ethical guidelines are available as a reference (www.the-sra.org.uk). Staff dealing with children in research may need criminal checkup record before the initiation of the project. In 2000, the declaration of Helsinki: ethical principles for medical research involving human subjects demanded a special justification for including children in research, which resulted in a limitation into the involvement of children in research (World Medical Association, 2000). However, over the last 10 years the literature regarding practice and ethics in relation to research with children has increased and good practice guidelines have been developed (Alderson, 1995). Issues around the ethics of involving children in research include

- Negotiating the relationship between the carer and the child
- Power imbalance between the researcher and the child
- Informed consent

- Confidentiality
- Avoiding harm

1.10.1 Negotiating the relationship between the carer and the child

Going via parents or an adult gatekeeper is essential to gain children consent, this leads to a concern that we need to ensure that children have a chance to express their emotions or refuse to participate at any time (McCrum and Bernal, 1994). This is an example of how the ethical process is different if we consider child participants (Punch, 2002). Gatekeepers or parents may take an action as protector and the child may miss the chance to participate. On the other hand, they could encourage their child to be involved (Harden et al, 2000). Children rely mostly on adults in day to day activity so they tend to assume adult power over them (Mayall, 2000).

From the parent's aspect, giving informed consent is allowing the researcher to approach the child (Broome et al, 2001). Munhall claims that consent/assent should be an on-going process in qualitative studies. One issue facing the researchers is how to explain to the children what it means to take part in research and what benefits are likely to be directly on them (Mauthner, 1997). Every effort should be done to make sure that the explanation process is child-centred and to his/her appropriate level and the child understand and willing to participate (Knox and Burkhart, 2007).

1.10.2 Power imbalance

The second issue is around the power imbalance between children and the adult researcher in the research process (Harden et al, 2000). Research with children is assumed to be different due to un-equal power and dissimilar understanding ability by the younger age group (Kirk, 2007). While it is easy to recognise that children are more vulnerable to un-equal power issues, ethics can help control the debate about research methodology and it's concerns (Punch, 2002). This imbalance has led to concerns about how children feel about refusing to participate or withdraw during any stage of the study or even to reject giving their feedback to the adult researcher, as well as for their experience (McCrum and Bernal, 1994).

Children may also be less able to explain their discomfort towards a particular question, due to the amount of pressure felt by the child to provide the researcher with the answer that they think he wants rather than offering their own opinion (Kirk, 2007). Children are more likely to expect that the adult has power over them, due to the manner of inequality that they are treated with in most daily situations (Punch, 2002). Even when the adult researcher or the gatekeepers are there to protect the child, they may deny children the chance of participating or they might reflect their concern to be part of the research (Harden, 2000). Therefore, the researcher should monitor the child's attitude and behaviour during the experience of involvement. If there is a change of behaviour, this may give the responsible adult a clue that the child is trying to escape from the situation (Helseth and Slettebo, 2004).

While it's impossible to avoid power imbalance, various steps can be done to minimize its effect. Several approaches were raised by the researchers to overcome problems associated with power imbalance. A literature review undertaken by Kirk in 2007 recommends the following:

I. Using methods that allow children to feel part of the research process and which give them the maximum opportunity to provide their views
II. Being responsive to children's own agendas
III. Involving children as part of the research team
IV. Using group interviews
V. Checking on children's willingness to participate throughout the interview (including being aware of nonverbal cues such as body language)
VI. Rehearsing with children how to decline participating or answering particular questions
VII. In interview studies giving children control over tape recorders

Other approaches may be useful include using a yellow card as a stop sign if the child is uncomfortable and red card if they wish to stop totally (Helseth and Slettebo, 2004). Lastly, it should be made clear to the child researcher that withdrawal from the study is allowed any time with no need to give any reason or explanation (Westcott and Davies, 1996).

1.10.3 Informed consent

Informed consent is defined as: "an interactive process between subject and researcher involving disclosure, discussion and a complete understanding of a proposed research activity, and which culminates in the individual freely expressing a desire to participate"

(Beresford, 1997; Davis, 1998). Informed consent is divided into three parts; firstly, possible participants gain knowledge about information that they can understand. Secondly, that consent is given willingly. Lastly, the potential participant has the competence to give consent. This can be summarised using simpler words: given information, competency and voluntary (Beresford, 1997). Gaining informed consent from participants is mandatory, this can sometimes be difficult with younger children, as a result, consent is obtained from the accompanying adult (Gilchrist et al, 2013). Even if the adult accompanying the child confirms the consent, child agreement is still required. This is termed as “Assent “and it is defined as: “an expression of the child by their desire to be a participant in the research" (Helseth and Slettebo, 2004). Child friendly materials and simple language must be used in order to make the process easier for younger people. When an individual has a mental capability to understand the nature and purpose of what it is he or she are intended to do, that is considered as competence.

The Nuffield report for biostatistics discussed the ethical issues around involving children in clinical research. The report ended by giving 19 recommendations and it was published in a small magazine format (Nuffield Council on Bioethics, 2015). In addition, an animation version was provided on YouTube called “health research: making the right decision for me” (https://www.youtube.com/watch?v=6yaKwLG_vlE). The evidence was taken from all age groups, young people and children, parents, and field professionals in UK and abroad. The report recommended that “where children and young people have sufficient maturity and understanding, but are not yet treated as fully ‘adult’ by the law of their country, professionals should, wherever possible, seek consent from both the children and young people and from their parents”. The Royal College of Paediatrics and Child Health, commented: “Decisions involving children are never easy but this should not be an excuse for inaction; the danger of not developing the evidence base is far greater than the risks of recruiting infants, children and young people to well-run carefully regulated clinical trials and other research studies. A poor evidence base is a patient safety issue. Children, young people and parents must be centre-stage. They must be partners in the process and have a leading role in advocating for research to reduce uncertainties in their treatments and to assure the care they receive.” (https://www.rcpch.ac.uk).

The Norwegian regional research ethics committee (2003) recommended that children older than 12 years should be provided with written information about the study, while those between 7-12 years old would obviously face difficulties to manage these claims. The American Academy of Paediatric Dentistry (AAPD) suggested that children aged 7 years of age and above are competent to understand research participation (AAPD, Committee on Drugs, 1995). In the United Kingdom research, active paediatricians participation is consider little compared to adults. Of the 2 million children admitted to the National Health Services, less than 2.5% each year are recruited to be part of research (Nuffield Council on Bioethics, 2015).

Usually, children have been asked to provide a written consent by signing a form. This process makes children more comfortable most of the time, this has two justifications. The first, this process gives them the feeling that their opinion counts regarding their approval of participating. Second, it gives them feeling of significance about the situation (Helseth and Slettebo, 2004). Regarding the minimum age needed to gain child assent, this is still a debate. The following questions can be used to measure the child ability and compatibility (Hammersley, 2015):

- When does a child know what it means to be part of research?
- Is the child aware of the right to withdraw?
- Is the child able to understand the described study?

1.10.4 Confidentiality

Confidentiality and privacy are absolute in the research process. Confidentiality should be stated in the information provided about the research, and should be reinforced at the consent stage. Participants must be informed about the available different methods of confidentiality including any audio or video tape, written and computerised information.

When family research is the topic, confidentiality is seen as a challenging issue (Kirk, 2007). According to research ethics guidelines, participants in research have the absolute right of confidentiality and privacy. If some or all the family members are involved in the study, interviewing them separately or together can be a sensitive issue. Most of the time children prefer to be interviewed without their parents present. They might feel more at ease and comfort to express their emotions without their parents listening. It is considered part of good practice if the researcher could give an explanation about some limitation faced in the confidentiality procedure, and provides information on how the research team managed disclosures (Punch, 2002).

1.10.5 Avoiding harm

Researchers are responsible to ensure the welfare and safety of any young person involved in the research process. Help and support should be available any time the child needs it. In contrast, researchers should maintain their professional boundaries and recognize the limits acceptable when providing assistance or aid to children. Support services could be available when help is required; when research contains question targeting sensitive or painful experience to discuss support services are consulted in order to minimize harm and manage the situation (Grieg et al, 2007).

1.11 Methods of involving children in research

Most of the methods mentioned and used in the literature are described below:

1.11.1 Interviewing and Focus Group

An Interview is a conversation between two or more people where questions are asked by the interviewer to elicit facts or statements from the interviewee "questioning of a person". It is the most important component in conducting qualitative research. This technique could be applied to children of different ages. A good example of this approach is "Better together", which is a Scotland health development initiative (2008), using focus groups with children between 6 to 16 years (Docherty and Sandelowski, 1999; Fine and Sandstrom, 2011). NHS Scotland wanted patients to see themselves not as receivers of services, but as partners in care. In 2008, they developed “Better Together” a new program for patient experience; which will aid patients to work in collaboration with staff as partners to ensure the optimal care and treatment is provided, and received.

Another example is the method applied by Steward and Steward in 1996, where children responded easily when asked about their morning; their breakfast and getting ready for school. The same strategy was described by Hamond and Fivush in 1990, for children between 2.5 and 4 year of age describing a special day event. The child's ability to remember and communicate is directed by the purpose of the interview or the interest of the researcher. Saarni in 1984 declared in his study of 45 children found that girls between 6 to 10 years tend to mask their frustration, while Cole found that boys between 4 to 9 years tend to hide any undesirable response.

Some key principles can be considered when interviewing a child: the number of children in each group (optimum ranging between 6-8 children), pairing is most helpful specially when it is a friendship pair, avoid wide age ranges in the same group (closer age differences in the same group should be no more than 2 to 3 years apart), seek advice regarding the group gender (single sex VS multiple), short question formats should be adopted like interactive ones, and the interview should encompass a short time frame. Some barriers and disadvantages may be associated to this technique; parents may be the first Barrier to their child's involvement (Shaw, 2011).

Interviews are different from questionnaires as they involve social interaction. Interviews involves two people, where the interviewer tries to comprehend, report and draw the personal experiences of the interviewee (Kvale, 1996; Schwandt, 2001). Personal experiences include the beliefs, attitudes, wishes, perceptions, feelings, knowledge and skills related to the subjects life (Parker, 1984). The effectiveness and power of an interview is directly related to the ability of the interviewer to acquire the other sides ideas and views (Hatch, 1990), therefore when the informant is a young adult or a child with restricted language skills, this may decrease the reliability of the interview to an extent.

Furthermore, when it comes to a child, personal experiences are built as a reflection of the world they are part of. A child builds their world of experiences perpetually in terms of a specific theme or in their own words, thus designing their personal frame of reference (Kortesluoma et al, 2003). Therefore, the situations that surround the child during the time of the interview may be important. Furthermore, the majority of the available data presented in the literature dealt with child interviewing as a method of data collection instead of means to collect research data (Kortesluoma et al, 2003).

I. Theoretical approaches used in a child interview:

There are a variety of methods used to interview children but the exact methodology to be used should be based on the researcher’s close observation, judgment and the understanding about children and childhood (Wimpenny and Gass, 2000).

II. Skills required:

The basic and most important quality in an interviewer is that he/she shows deep interest in children and their stories. Every person has a child-like quality in them regardless of their age. Hellsten (1992) also explained some typical features that may be found in these child-like qualities; feelings, needs, simplicity and being puzzled and amazed. In plain, the action of properly capturing and understanding children's experiences depend solely on the child present in the adult interviewer (Hellsten, 1992). In fact, some researchers consider this quality as an absolute mandatory element for interpreting children's experiences. This element is essential in creating the theory or hypothesis of children's experience.

III. Interview undertaking:

Motivating children: Ideally, children should be given full information about what the research and interview will entail, and should be given a chance to consider these before settling on a choice to participate (Hill et al, 1996). Some motivational factors depend on their stage of development. Small children do not co-operate if the purpose of the research is explained to them using concepts of abstract, altruistic rewards in the future or from utilitarian points of view, such as increasing scientific knowledge (Rheingold, 1982; Price, 2002). At the point when kids have a privilege to give assent they should likewise have a privilege to decline (Lowden, 2002). School children may agree to be interviewed because they wish to please adults. On the other hand, they get an immediate prize from being an object of full focus in the interview (Gunther, 1991).

Interactive relationship: researchers' prior encounters of children and their techniques for alleviating anxiety can help in setting up collaboration (Yarrow, 1960; Greig and Taylor, 1999). Apart from establishing interaction, the success of the interview also depends on how well researchers can maintain the interaction and co-operate with children (Hughes, 1989).

To supplement qualitative interviews, it is possible to use quantitative measures, drawings, small group discussions and projective/ reflective techniques. According to Hughes (1989), if the interview is carried out in a natural context, using open ended questions and concrete accessories, children give more adequate and meaningful answers than when answering structured questions.

The validity of interviews is linked to the quality of the verbal communication. Therefore, the poorer the quality of verbal interaction between the interviewer and the child, the more unreliable and invalid the results will be. Accordingly, interviewing young children who have limited verbal abilities to talk about their own perspectives and thoughts has always been an issue of concern. Interviewing young children is challenging in many ways. For instance, research has shown that young children are highly suggestible (Moston, 1990) and difficult to be approached by an adult stranger (Parker, 1984). Hatch (1990) notes four major problems in interviewing very young children. The first problem is the "Adult-Child problem" that emerges from the nature of adult-child relationship, meaning both interviewer and informant to have different culturally defined roles and expectations towards each other. Such predefined expectations make it harder for the interviewer to "build more equal role relationships and to avoid giving children any sense that their superior adult status is being used (p.255)." Hatch indicates that children develop firmed perceptions of the way they should deal with adults that makes them concerned about having appropriate behaviour.

The next difficulty in interviewing young children is "the right answer problem". As such, the young child pictures the adult interviewer as someone who should approve every single word he is saying. Therefore, a tiny extra feedback from the interviewer makes the child follow what he believes to interest the interviewer than what he himself believes. This problem might be more expected among school children (Punch, 2002). The third common difficulty in interviewing younger children is "the Pre-Operational thought problem" that pertains to limited cognitive abilities of 2-7-year-old children. Jean Piaget (Piaget, 1997) counts many characteristics for pre-operational thought such as ego-centrism and lack of abstract thinking that makes the child not able to understand other people's point of view or formulate a multi-faceted reason.

The fourth difficulty that Hatch addresses is the "Self-As-Social-Object problem" that underscores children's belief in which they can be the objects of their own actions.

1.11.2 Questionnaire

They are the most commonly used quantitative method used to involve children and young people in research. Previously children completed questionnaires designed by adult researchers. More recently, children have become more involved in the research by taking part in questionnaire development. Several oral health related quality of life measures was designed with the active involvement of children in the research process, namely The Child Perceptions Questionnaires and The Child Oral Impacts on Daily Performance (Gherunpong et al, 2004; Jokovic et al, 2004). Questionnaires offer an objective means of collecting people's knowledge information as well as attitudes, behaviour, experience and beliefs (Boynton and Greenhalgh, 2004). Questionnaires can be used alone as a research instrument to address specific areas e.g. cross sectional surveys or within trials clinically and theoretically (Boynton and Greenhalgh, 2004). They can evaluate new or existing systems, in addition to assessing patient's satisfaction (Gilchrist et al, 2014). Some advantages of questionnaires (Carter and Williamson,1996):

- Standard way of collecting the responses so it is certainly more objective
- In general, it is a quick way of collecting information
- Questionnaire information can be collated

Some disadvantages of questionnaire (Carter MP and Williamson D.,1996):

- Like other methods, it happens after an event or situation and participant may forget some information
- Open ended style questions can result in large amount of data that take a longer time to analyse and process
- Participant may not like the question or refuse to participate for many reasons as they might think that there is no benefits from participating.

To date, there is no validated questionnaire to measure children patient satisfaction and overall experience about the dental visit. Therefore, using another method like interview to develop your own survey is feasible in this situation (Gilchirst et al, 2013). In the last few years, social researchers have come to understand the importance of conducting survey research with children without adult help from an adult proxy (Scott, 1997).

Designing questionnaires for children

The research team must have some basic assumptions about the design of these (Widerszal-Bazyl and CieSlak, 2000). Children will go through four challenging skills in this process which are (Schwarz and Sudman, 1996):

- Understanding both the task he or she is assigned to and the questions given
- Retrieving information to answer
- Making judgment
- Evaluation of the answers

Simplicity in all aspects is one key when designing material for children. Straightforward questions and short ones are advisable (Gray, 2002). As children need more time than adults to process information, an introduction can be an advantage (Kail, 1991) and can make it easier for the children (De Leeuw et al, 2004). Complexity in structure tends to be a problem for children. For example, a question with a negative formulation which leads the participant to deliver a positive response should be avoided (De Leeuw et al, 2004). If the aim of designing the questionnaire is to measure children's behaviour, it is important to keep in mind that their recall period is different from adults (Tourangeau et al, 2000).

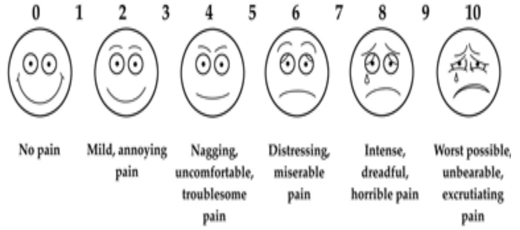
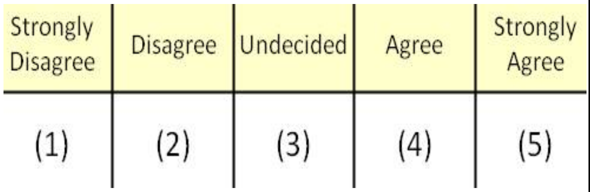
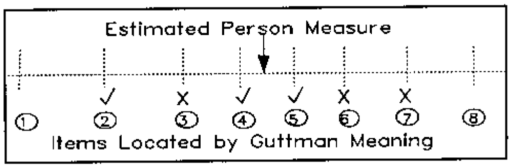
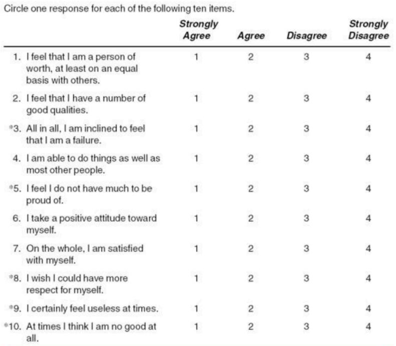
1.11.3 Scales

This qualitative method is used as an alternative approach to the questionnaire. The age of the child should be considered in the process while selecting the most suitable method. The Visual Analogue Scale (VAS) is a psychometric response scale; it is a measurement instrument for subjective characteristics or attitudes that cannot be directly measured (Reips and Funke, 2008). It is a good example in the field of paediatric dentistry; it has been used successfully for several years for recording the feedback from children.

Other scales include:

1) Likerts Scale: is a psychometric scale commonly used in research as an alternative to questionnaires. It is the most widely used approach to scaling responses in survey research.
2) Guttman Scale: In statistical surveys conducted by means of structured interviews or questionnaires, a subset of the survey items having binary (e.g., YES or NO) answers forms.
3) Phrase Completion Scale: Phrase completion scales are a type of psychometric scale used in questionnaires.
4) Rosenberg self-esteem Scale (RSES): is designed similar to social-survey questionnaires. It is a ten-item Likert-type scale with items answered on a four-point scale - from strongly agree to strongly disagree.

Examples of these scales are shown in figure 1.1.

VAS	Likerts Scale
	
Guttmann Scale	**RSES**
	

Circle one response for each of the following ten items.

	Strongly Agree	Agree	Disagree	Strongly Disagree
1. I feel that I am a person of worth, at least on an equal basis with others.	1	2	3	4
2. I feel that I have a number of good qualities.	1	2	3	4
*3. All in all, I am inclined to feel that I am a failure.	1	2	3	4
4. I am able to do things as well as most other people.	1	2	3	4
*5. I feel I do not have much to be proud of.	1	2	3	4
6. I take a positive attitude toward myself.	1	2	3	4
7. On the whole, I am satisfied with myself.	1	2	3	4
*8. I wish I could have more respect for myself.	1	2	3	4
*9. I certainly feel useless at times.	1	2	3	4
*10. At times I think I am no good at all.	1	2	3	4

Figure 1.1 Example of scales used with children

(VAS; Wong and Whaley, 1996/ Likerts Scale; The Research Bunker, 2010/ Guttmann Scale; Linacre and Wright, 1996/ RSES; Rosenberg, 1989)

1.11.4 Time-line exercises and life grids

They are often used to chart a special or important event of an individual life (Stewart et al, 2006). It is a familiar technique for historical events (history classes) and exploring distinguished events by using stickers. A more relevant example of this is the cleft lip and palate study done by the University of Sheffield that aimed to explore children's experience about this defect, as shown in figure 1.2.

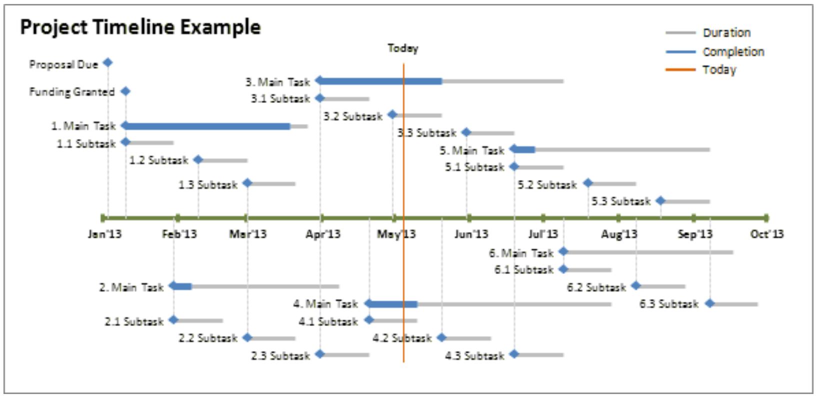


Figure 1.2 Example of timeline exercise used with children

1.11.5 Drawing

This method is suitable for all age groups. It is the most enjoyable approach where even the youngest participants are familiar with it; it ends up meeting the wishes of these participants and more importantly expressing their opinion in a non-verbal manner. This method has become very popular in health related research issues (Oakley et al, 1995). Despite its limitation; some children may not have the confidence in their skills, the subjectivity of interpretation done by adults and difficulties with analysis, makes this approach less favorable to some researchers (Marshman, 2008).

1.11.6 Diaries

Written or video diaries are used to explore day-to-day activities or activities in a children's life. In video diaries, participants can be given a camcorder to document events in their day through a specific period of time (range from 4-8 weeks). This may reveal information that couldn't be obtained in the clinical interview. Written diaries; gives the child the space to express their thoughts through a written account away from external influences. A two-week diary was developed which included open and closed questions with space to include drawings to investigate the impact of gender, visible dental differences and self-reported satisfaction with dental appearance on children (Rodd et al, 2011).

As the world develops and progresses, technology is becoming an integral part of our lives. Interactive media based decisions may be considered as a high quality technique used to enhance the child's ability to communicate and express their feelings. Raymond et al 2010, established that the use of percentages and pie charts is the most attractive and logical approach in comparison to others.

1.12 Involving children in research - summary

Children are often involved in research as objects. But very rarely do they participate in the design of research, nor are they involved in the development of research ideas. What is the best method to involve children in research? There is no single method that appears to be more effective and practical than the others, or if one specific method can be used in a certain situation. Therefore, the aim of this part of the project was to determine existing methods used to engage with children in order to develop and shape research design and ideas.

Chapter Two:
Involving Children in Research:
Systematic Review

2.1 Aims

To determine existing methods used to engage with children in order to develop and shape research design and ideas.

2.2 Methods

2.2.1 Review of the literature

Pilot work suggested that there were no examples in oral health of children being involved in the design of clinical research. Therefore, we made the decision to expand the search to consider medical as well as dental research - this avoided the production of an 'empty' review which has limited utility.

2.2.2 Research question

What is the most effective method for involving children (12 years and under) in developing research questions and designing research studies?

An electronic search was conducted in conjunction with the institute librarian, using the following databases; PubMed, Scopus, Web of science and Medline Ovid to identify relevant studies (starting from earlier to newer studies). The search terms found in tables 2.1 and 2.2, includes the terms child, dental research, patient participation, questionnaires, patient centered care, ethics, paediatric dentistry, youth. Following this a manual search for systematic and narrative reviews on the topic was done of the following journals: British Dental Journal, International Journal of Paediatric Dentistry, European Journal of Paediatric Dentistry, Journal of Paediatric for Children Health, Health and Human Rights, Health and Society, Paediatrics, Health, Culture and Society, Children and society, Childhood, Adolescent health, medicine and therapeutics, Journal of Adolescence and Journal of Adolescent Health. In addition, Google scholar search engine was also searched. Reference lists of eligible studies were screened for further eligible studies.

Term	Definition
Child	Persons who have not attained the legal age for consent to treatments or procedures involved in the research, under applicable law of the jurisdiction in which the research will be conducted. Generally the law considers any person under 18 years old to be a child.
Research	The Department of health defines research as work designed to provide new knowledge, whose finding are potentially of value to all, that is general is able.
Development	The testing and evaluation of new ways doing things.
Participation	the action of taking part in something, – children and young people joining in decision making, from giving their views in a consultation through to more active involvement.
public involvement in research	research being carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them

Table 2.1. Research term definition

Criteria	English language articles only
Data Basis	Midline ovid 1964-2014 Scopus 1960-2014 Web of science 1900-2014 PubMed
Words used to identify database index terms	audit biomedical research dental research empirical research education research medical research non-therapeutic human experimentation nursing education research outcome assessment (health care) community-based participatory research consumer participation dental patient-centered care dental care for children public pediatric dentistry qualitative research qualitative research questionnaires research design research subjects therapeutic human experimentation ethics, research health health services research human experimentation interviews as topic
Key search terms	biomedical research/ or dental research/ or health services research/ or human experimentation/ or non-therapeutic human experimentation/ or therapeutic human experimentation/ or nursing research/ or nursing education research/ or "outcome assessment (health care)"/ or community-based participatory research/ or empirical research/ or qualitative research/ or research design
limit used	Limit 14 to ("preschool child (2 to 5 years)" or "child (6 to 12 years)")

Table 2.2 Research terms and key words

2.2.3 Eligibility criteria:

All studies targeting active involvement of children and young people in research at any stages of development, were included. Only English language studies were included. Both quantitative and qualitative studies were included, preferably studies done in a health care situation or sitting. Table 2.3 provides details on both inclusion and exclusion criteria.

Inclusion criteria	• Any studies describing how children were involved in the design or methodological process of a study in a health related setting. • Any studies describing how children were involved in the development of research ideas or themes in a health related setting. • Studies were included irrespective of design or type. Both quantitative and qualitative studies were included.
Exclusion criteria	• Articles targeting or involving parents or caregiver or any other adults only. • Articles that aim to educate, teach or motivate children. • Articles that involve children in any of the research stages rather than design. • Articles related to quality of life. • An article does involve children in the design of the study with not enough details. • Studies that are not English language.

Table 2.3. Review inclusion and exclusion criteria

2.2.4 Study Selection and Data extraction:

Two reviewers independently scanned each abstract and full text from potentially relevant citations. Screening of studies was done using a data extraction form developed for this process (Appendix- data extraction forms). The form was piloted on a random selection of 10 studies. During piloting, we noted that we are missing a lot of relevant information stated in the discussion part of the study. As a result, we added (points from the discussion) to the extraction form. Furthermore, it is very important to us to know from the study if any help were giving to the children by adults so we added this question as well.

Final data extraction was undertaken by two reviewers with a third reviewer used in case of disagreement. The extraction form contained general information about the study (title, journal, author…), Study Demographic data (Age, Sample and sitting), Study type and its inclusion/exclusion criteria, how the study obtained ethical approval, Data collection (retrospective or prospective, duration) and analysis (outcome measures, results), method used, sampling technique, conclusion and future recommendation.

NEWCASTLE - OTTAWA QUALITY ASSESSMENT SCALE (Wells GA. et al, 2000) was used to assess the quality of the studies. Although the overall methodological quality of the studies was low, they reported an example of involving children as research partners. It was not easy to evaluate the quality of the studies because there were not enough details reported in the papers. However, papers reported relevant information to our review despite the overall study aim and outcome. A blank sample of the data extraction form is shown in table 2.4.

Date:	Publication (year/ Volume/ Pages):
Title:	
Authors:	
Source / Journal:	
Eligibility	
Is it Health Related	☐Yes ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐Yes ☐ No
Study Eligible	☐Yes ☐ No
General	
Demographics	☐ Age range: ☐ Other measure of age: ☐ Males vs. females:
Location/ Setting	
Conflict of interest statement:	☐ Yes ☐ No
Funding	☐ Non-governmental ☐ Governmental ☐ The specific institute and source for funding is not clear
Type of Study	☐ Research with children ☐ Research by children
Aim	
Inclusion criteria	
Exclusion criteria	
Ethical measures included	☐ Yes ☐ No
Describe ethics	
Data collection	☐Prospective ………………………………………………………. ☐ Retrospective

	……………………………………………………………
Study duration	☐ Days ☐ Weeks ☐ Months ☐ Years ☐ Not Mentioned
Sampling technique (How selected)	
Research Method	☐ Interview ☐ Written questionnaire ☐ Focus Group ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ Literature Review ☐ Methodology ☐ Select research subjects ☐ Data Collection, process and analysis ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used:	
Outcome measure	☐ Degree of involvement. ☐ Degree of child's acceptance and cooperation. ☐Degree of guardian acceptance and cooperation. ☐ Other, children were subjects in the research where no involvement occurred

Was any help given to children when designing or conducting the research	☐ No ☐ Yes. If yes by whom? (Specify: parent, teacher, etc...) ………………………………………………………
Results of the study	
Future recommendation	

Table 2.4. Data extraction form

2.3 Results and Analysis

The literature search resulted in 2231 papers in total, including 34 papers from manual searching in related journals, 23 by looking at the references. After going through the title and abstract, only 157 were related to subject. Of these, only 4 studies (0.18%) were categorized as research by children of 12 years and under (Table 2.5) (Figure 2.1). The data extraction form was used for final data extraction of four eligible studies in addition to five studies they were extracted due to information relevancy. Data was extracted from these five studies due to the active involvement of children in research in their method and availability of relative information to the field, however, they failed to meet the age restriction in our inclusion criteria (below 12 years).

The use of Meta-analysis to report the result was not feasible as studies reported different ways of involving children (focus group and questionnaire, interview and diaries).

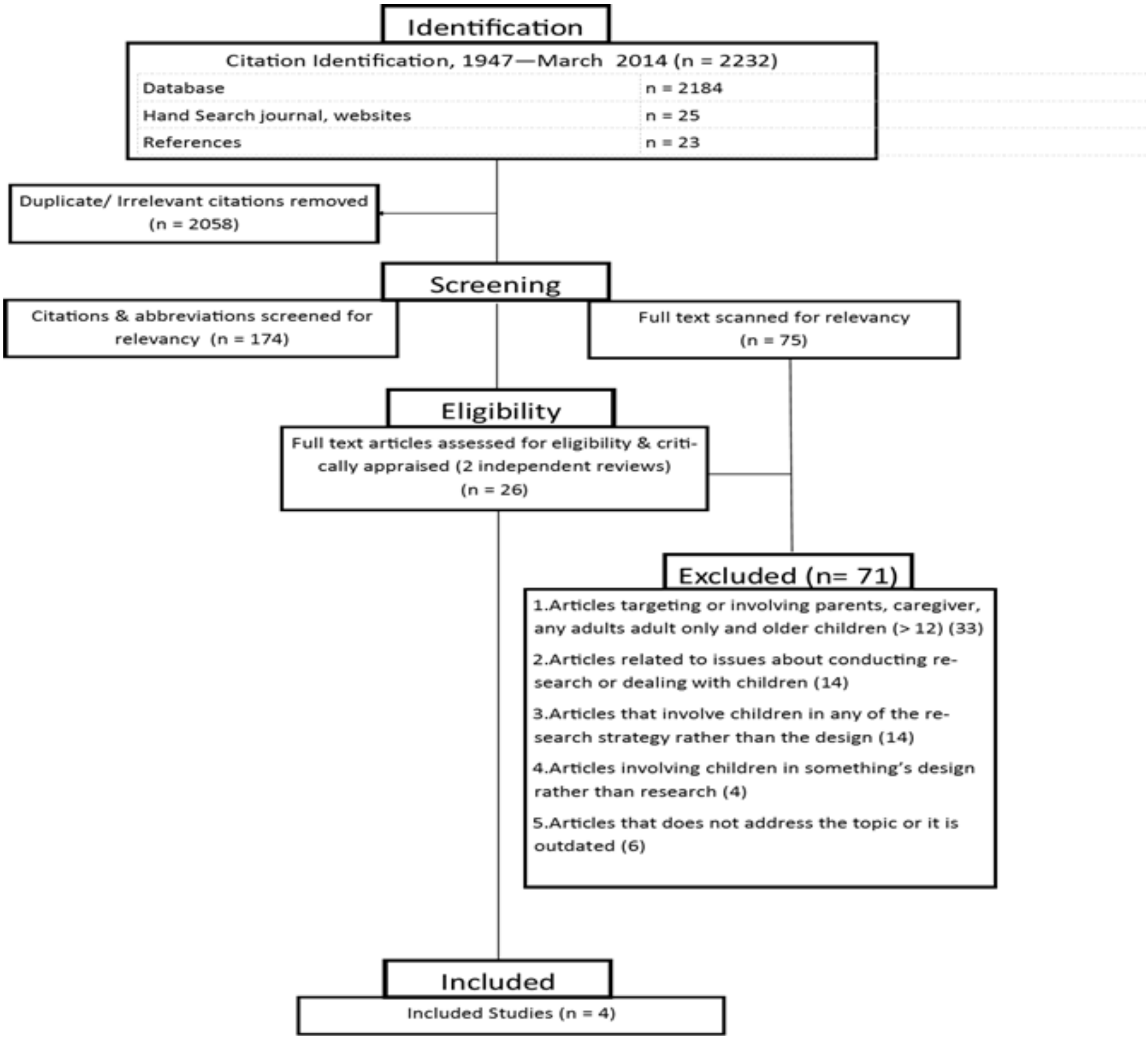


Figure 2.1 Consort flow diagram showing result of literature search

Study Title	Study author / Year of publication	Setting / age and Gender	Active involvement method / Sample size	Method used	Results
Children as Advisers of Their Researchers: Assuming a Different Status for Children	**Ferran Casas et al 2013**	The Alt Empordà county district of Girona province of Catalonia-Spain. 8-12 years old boys and girls	Written questionnaire Focus Group. 24 children were involved	Explanation about study in the first stage then suggestion and option chosen for 14 items questionnaire.	When children were asked to help the researchers, they all became impressively cooperative and highly motivated to do both the individual work and the group discussion. They actively tried to find alternative wording and solutions to any difficulty raised.
Small Shoes, Big Steps! Empowering Children as Active Researchers	**Mary Kellett 2010**	University of Milton Keynes, UK. 11 year old girl	Diaries. 1 child was involved	Help by staff from university	This style of child-led research generates valuable knowledge about children's lived experiences otherwise inaccessible to adults, knowledge that those who advocate for children's meaningful participation cannot be ignored

Involving Children in the Design and Development of Research Instruments and Data Collection Procedures: A Case Study in Primary Schools In Northern Ireland	**Kellie Turtle et al 2010**	Primary Schools in Northern Ireland. 5-10 years old (9) boys and (10) girls	Written questionnaire Focus Group. 19 children were involved	Stage one include explanation and introduction about the subject. Phase two is feedback and discussion.	This research has implications for the development of practice and policy, particularly at this time when there is a concerted strategic drive to improve practice.
The management of dental caries in primary teeth involving service providers and users in the design of a trial.	**Zoe Marshman et al 2012**	Dentist and team: either in their dental practices, in the local dental school or at the dentists' homes. Children age 4-8 were interviewed at their home.	Interview 4 children were involved	Data Saturation was done after individual interview.	Overall, more research is needed into existing barriers to involving patients and the public in dental research and exploration of approaches to improve their involvement. limited number of children involved in this study did not allow full exploration of children's experiences of the different interventions The findings have provided

					valuable recommendations and are being used to refine the main trial and improve the recruitment of dental practices and patients, training and support for dentists and engagement of children and parents.

Table 2.5. Included studies result

Decision for exclusion was based on several reasons; firstly, reason was that some articles involved adults in the research process, e.g. parent/ care giver as proxy for the child (n=27). Secondly, articles that involved children in the research but not in the design process (n=14). Twenty articles were excluded from the study because they only discussed the issues for engagement of young people as a participant in research process. Other reasons for exclusion involving children in design of anything rather than research (n=4) and six studies were excluded because they were outdated or did not address the topics.

All four papers included demonstrated active children involvement in the research process. These four papers showed a variety of aims to be achieved by asking children to be involved. Casas et al. used a method of involving children in improving the questionnaire that other children will be asked to respond to in the future. A detailed description regarding children in design of research was provided by Turtle K. et al (2010). A youth friendly interview and research done by 11 years old girl was described in the last two studies by Marshman et al (2012) and Kellett (2010).

2.3.1 Children participation:

Two studies (Turtle et al, 2010 and Casas et al, 2013) had two stages in their research. In the study by Turtle et al these were consultation and the feedback. The consultation session took the children's opinion about the questionnaire and how to make it better. While the feedback concerned suggestions about phase one and evaluation of the experience. Casas et al stages were first training then the actual research. In both studies, the first session took approximately an hour. Sessions started by giving written and verbal instruction to the children. The research team and teaching assistance hosted the children and facilitated the session.

Manasa Patil in the Kellett study (2010), the girl who did the research ''getting around as the child of a wheelchair users'' received training by the university staff about the nature and different stage of the research process. While the four children in the Marshman (2012) study were interviewed separately from their parents although they were sitting in the same room.

Useful tips obtained from the included studies for involving children in research are summarised in the table 2.6.

What make the process easier What to tell	What make the process harder What not to tell
Individual explanation briefly about the process with a written explanation.	Longer time
Ask the children for help and advice	Repeating questions
Explanation given by another child lead to faster understanding than the one given by adult.	Long introductory page with no pictures
Shading alternate lines makes questions much easier to read.	Using same text design and size for heading and subheading
Faces/emotions are easy to understand	Considering critical details
Establishing a trusting relationship with the research team	Giving the questionnaire only without reading it allowed by researchers
Feel relaxed, there is no one can pass or fail	Feeling like an exam
Thank everyone and take feedback	Formal opening of the session
Instruction about how to answer questions on to pages where question are presented	Writing their names
Giving children an envelope to place their questionnaire and feedback	Ignoring children's cognitive skills and different ability of participation
Answer the best you can, there is no right or wrong answers	Using in appropriate method or not giving enough time to apply good methods.
Fun and ice breaker activity are important to use	Using emails, power point presentation and internet a lot

Table 2.6. Tips for involving children in research

2.3.2 Methods used:

I. *Focus Group and Questionnaire:*

Along with a questionnaire, focus group were used in two studies (Casas et al, 2013 and Turtle et al, 2010). Focus groups reported a positive outcome in term or behaviour of young people and recruiting child participants. And when focus group were used, most of the participants reported having enjoyed the experience. Before administrating a questionnaire to children, a pilot test is needed. Changes may include:

- Make it easier or more difficult
- Increase or decrease possible types of error
- Visually more pleasant or unpleasant
- Comfortable or non for the respondent

At the end of each stage, the questionnaire was used to get the participants experience of the process as well, children could answer both by written and picture format.

II. *Interview:*

Marshman et al in 2012 reported that the interview is the most appropriate qualitative method for parents and children to give their experience individually.

III. *Diaries:*

The last method used was diaries. Written or video diaries can be used to explore day-to-day activities or specific events in a child's life. They can be used to gain contemporaneous insights into participant's disease and treatment experiences, negating the effects of inaccurate recall.

The four papers could not decide what is the most appropriate method to engage children in the research process. A combination of focus groups and questionnaires appeared popular with children. Working with their peer group and enjoying team work with the research team lead to positive experience and better response to the questionnaire part. Feeling listened to, being safe; taking their feedback and act upon their recommendation could be achieved and feels more pleasant by combining these two methods together than the other methods.

Studies:

Two of the studies were published in 2010 and the remaining two in 2012 and 2013 in different journals (Table 2. 5).

IV. Sampling:

There was a variation in sampling technique and sample size between studies. This might be due to multiple factors include accessibility, ethical issues, parent agreement and environmental problems. A total of 48 children presented by 4 papers were actively involved in the design process. The youngest age was 4 years old and the eldest was 12 years old. The majority of the children are aged above 8 years (75%) and 12 children were between age 4-8 years. In Casas et al. 2013 study, children were divided into three sample group depending on their age (8, 10 and 12 year) for both girls and boy. In Turtle (2010) study, equal weight was given to both boys and girls participants (10 girls and 9 boys). The children were the least group involved in Marshman (2012) study (only 4) as their involvement was considered as a pilot. More about sampling in table 2.5.

Apart from the study that was done by an 11-year-old girl (Kellet, 2010), children samples were achieved by contacting schools that are willing to participate in research projects. Researches almost always faced difficulties in contacting schools, where the presence of many factors may complicate the situation. Such factors like the schools may be participating in other projects, the limitation of time and resources that they could offer, school council availability at the time of recruitment and no response to invitation letter and phone calls.

A purposive sampling strategy (Denzin and Lincoln, 2000) by inviting all schools available to nominate their council to consider involvement was used by Turtle et al. 2010. Although Marshman study in 2012 involved dentist and dental team member in her study, she managed to include four children to be a part of designing her trial. These four children were recruited by dentists taking part in the trial.

In addition to school availability, age was selected after advice from the school staff or teachers or health care provider or findings of international research project ISCWEB.

Children experience as research partners:

The important consideration for their involvement is the outcome of their research, making difference and changes to the research field to help other children. This is a quote from a child researcher: ‘’ Doing the research helped with my confidence. I was quite shy, but I stood in front of people at the conference and told them about the research. (Girl aged 9) ‘’

So, doing research by children could reflect benefits for children researchers as well as the research process. From our review we can point out potential benefits for children Elevation of self esteem

- Increase sense of personal worth
- Developing their analytical thinking critical skills
- Increasing ethical awareness in their life situation
- Promotes increased participation in other issues

The majority of children reported enjoyment during their experience, feeling listened to during sessions and stages and they felt good about the whole process.

For research, children could help to develop more useful instruments for research and adolescents to be suitable for all age ranges. This could be achieved by construction of a tool with both child and adult researchers involved in the trial.

2.4 Discussion

This systematic review represents a hierarchy of the involvement of children as an active part of the research process ranging from involvement as co-researchers to a study done totally by them (Kellett, 2010). This study raises the importance of conducting more research in the future done by children as service users, and the positive effect it has for these health services. This highlights the importance of considering their experience about health related issues and transferring these experiences and opinions into words to be listed to.

Generally, children’s active participation in the research process has increased in the last few years (Grant and Ramcharan, 2006). From this review, looking at the papers discussing the methodological issues involving children; ethical ones have been the vast majority of problems cited. Research Ethics Committees and Grant-awarding Bodies require evidence explaining the level of involvement of participants throughout the research process. Following the recommendation of the article number 12 of The United Nations which stressed the point of the children’s rights to be listened to and acted upon their needs. For child-centred research, this occurs when the responsible adult or the health care provider challenges the children in a safe and respectful manner to develop (together and individually) their own solutions to problems given, thus encouraging co-operation, the development of life skills, their analysing power, their capacity to organize themselves (Rogier Van‘t Rood, 2004). This leads for a more thorough consideration for children undergoing treatment or those needing health care to be considering their own perspective, expectations and desires.

Using the child-centered approach is not only a method to be used by researchers in research, but it is also an aid to help them define the research question and to disseminate the findings back to them. To date, most of the guidelines available for involving young people in research are designed for children over 12-year-old. Examples of such guidelines include; A Guide to Actively Involving Young People in Research (Kirby, 2004) and more recently Guidelines for Research with Children and Young People in 2011 (Shaw et al., 2011).

This systematic review presents four papers in which they successfully involved children actively in research. When children were asked to help and advise the researchers, they became impressively cooperative and highly motivated to do both the individual work and the group discussion. They actively tried to find alternative terminologies and solutions to any difficulty raised or faced. When a questionnaire is designed by children for children, this helps to produce a better research method – even if the changes seem minor. In Casas et al study children found that the different shades in the questionnaire used were actually helpful when repeating the question that was considered boring in the past. The reaction would be different between the sample groups due to different cognitive abilities, however, the children claimed that better understanding occurred when help was provided by another child.

The quality of evidence this review identified was low. About quality of children participation process, Sinclair in 2004 reported the following: ''there has not been enough evaluation of the outcomes of participation and it is important that researchers write in greater depth and more transparently about the participative processes in young people's research'' (cited in Franks, 2009, p. 9). Marshman et al. in 2012 considered the children involvement in their trial as a pilot participation. Casas et al. in 2013 reported that the same study should be done with a larger sample group.

The search strategy was really challenging for the research team. As this field is now expanding, our aim was only to include children involved in the research process with relation to health. As a result, some papers were excluded due to their reporting involvement in other fields such as, Education (e.g. McDonald et al, 2008; Cook and Hess, 2007) and social care (O'Kane, 2000), or papers involving children to develop a tool or service (e.g. Nic Gabhainn and Sixsmith, 2006; Croghan et al, 2008). Another issue that was faced in this project were the terms of involvement and participation. In the literature, involvement reflects both research with and on children in addition to by children. The term participation should reflect how the research involved children and young people (Hart, 1998). Participation was first described by Roger Hart 1979 in a project to mark the international year of the child. They demonstrated eight categories that describe the increasing levels of agency that children and young people may have when engaging in participation projects and activities. Participation activities include various models and each model has its own ethical issues and application.

Last but not least there were issues around the age limits for the included papers (12 years and under). The review excluded papers involving older children above 12-year-old in their trial design (e.g. Flicker et al 2010, Porter et al 2010, Holland et al 2010, Evans, 2012) even if younger children may also have been included in the study. According to Piaget’s (1972) theory, children aged either less than 4 or above 11 should be excluded. For the ones under four, eliciting information from them or give rise to challenge and may require different approaches. For the ones aged over 11, involving them in the participation process is not a problem like their younger peers, as they could be considered like adults to some extent when they chose to be the research sample. Therefore, children aged 4–11 years are the most challenging because of the stage of their linguistic development. This review presents the need for greater involvement of younger aged children in the participation process.

Children aged 7-11 can report their experience about something, while the younger group aged 6 years and under have limited use of language. They can answer questions accurately but in one sided way (Piaget’s, 1972). Although competence is not defined by chronological age, children’s experience about something could affect their understanding (Alderson and Montgomery, 1996). Therefore, the need for a specific method and different approach to different age group is essential. Addressing the different age and ability of the children, one of the studies included in this review (Casas et al, 2012) managed to involve three different age groups in their design. In addition, they gave a special recommendation on how to deal with each single group (8, 10 and 12 year) and tips to make their involvement more pleasant. They pointed out that the questionnaire could be done in many different formats, and when youth feel comfortable with this type of technique, quality of the answer could increase as well as the reliability. Their results reported that formats are considered in a different way according to age group. However, it is surprising how younger children could react and understand the tasks given, better than their older peers.

The limitation of this review includes that it was restricted to electrical journals and English language articles only.

Children participation in research is not a new model. It has been common for several years now. Children can participate to some limits in design and methodology. But when children receive in-depth training is research process to apply their knowledge and skills, they can give the initial choice of research question, topic, method and design from their views and need.

When a chance is available children's perspective should be considered. Depending on this review, children were considered as an object in almost all the papers found. In addition, children were seen as a homogenous age group where they should be seen as individuals having the right to express and be listened to. When studying health research including children, social and psychological perspective of individuals should be considered (Engel, 1977). In health research, children are usually considered as a source for data (research with children) and their involvement is limited. Questionnaire or interview is mostly used to take their opinion (Jongudomkarn et al, 2006; Lipstein et al, 2013; Coyne, 2008).

In paediatric dentistry research, qualitative research type still faces resistance (Blinkhorn, 2005). Marshman Z. et al. in 2012 concluded that ''The findings provided valuable recommendations to improve the method of recruitment of dental practices and patients, the timing and content of the training, the type of support dentists would value and ways to further engage children and parents in the FICTION main trial''. A systematic review about children in dental research was done by the same author (Marshman et al, 2007) she stated: ''It should be acknowledged that not all research in paediatric dentistry lends itself to child-centred approaches; however, there is considerable scope to access children's perspectives of their oral health and care.

Actively involving children in research is critical to this endeavour. A summary and conclusions of this part of the project are described in Chapter 4.

Chapter Three: Developing a Child-Centred Satisfaction Survey

3.1 Introduction

3.1.1 Involvement of children in the measurement of patient satisfaction

Clinical Audit is defined as “a quality improvement cycle that involves measurement of the effectiveness of healthcare against agreed and proven standards for high quality, and taking action to bring practice in line with these standards so as to improve the quality of care and health outcomes” (Burgess R., 2011). Promoting quality in health care is the aim of The Healthcare Quality Improvement Partnership (HQIP), which is led by members of the Academy of Medical Royal Colleges, National Voices and the Royal College of Nursing (Dixon N., 2013).

The data collection setting for those working in the National Health Services has changed over the last few years, due to an increasing number of policies (Mabbott I. et al. 2011). Best Research for Best Health was published as part of the National Health Research Strategy by the Department of Health (Department of Health, 2006). Following that, the National Institute of Health Research (NIHR) was created to “facilitate the goal of improving the both health and wealth of the population by using research as a tool” (Tooke J., 2008). As part of this review, it was recommended that measured outcomes should also include those evaluated by patients themselves, and is considered a key strategy for the improvement of care quality in the NHS.

Patient-centred care is defined as “care that is respectful of and responsive to individual patient’s needs, preferences and values while ensuring that patient’s values guide clinical decisions” (Espinel AG. et al, 2014). The American Academy of Paediatrics (AAP) recently recommended that family and patient centered care should be applied to all aspects of paediatric surgical operations (Coyne I., 2008; American Academy of Pediatrics Committee on Bioethics, 1995).

Health care that makes patients achieve the benefits they want and meet their need individually by using services and decisions based on best research evidence has shown to provide effective outcome clinically (Department of Health, 2006). Patient feedback is needed to apply these standards and in order for it to be met. It is clear that the NHS has gradually given patients more control over their own health care. Choosing when they want to receive the treatment and better information about the treatment will lead to better treatment outcomes. Patients empowered in such a way are more likely to take greater concern and responsibility over their own health and these patients are more prone to dedicate time, effort and energy to solve their health issues (Darzi A., 2008).

3.1.2 Children and Shared Decision Making (SDM)

Shared decision-making is defined as “the way in which children can contribute to the decision making”. Therefore, the importance of children involvement in shared decision making process (SDM) depends on their abilities, age, and previous experience (Cavet and Sloper , 2004). Although there is strong support from policy makers, the evidence on children’s participation in SDM is weak as this area of research is fairly new and under-developed (Coyne et al, 2014).

While there is debate about children’s competence to give valid information, researchers have suggested that if children provide invalid information, this is the fault of the researcher by not using the suitable technique and language (Alderson 1995). In the past data obtained from young people were viewed as invalid or unreliable because children lacked verbal and conceptual abilities (Vogl, 2015; Docherty and Sandelowski, 1999). Another reason is the ethical concern over their involvement in research (Kirk, 2007) which has been summarised here already. However, not all children will be keen to take an active part in research or audit projects. Balancing between children rights to be part of decision making and their right for protection and their needs is be the key in a health care situation (Coyne, et al 2014).

Current UK policies have made it a priority for service providers to listen to children opinions. These include their experience about treatment provided to them and services related to them directly (Department of Health, 2013). As a result, they will be able to make decisions about their care using age appropriate information and suitable methods. Previously, researchers in paediatric dentistry has used the view of adults, mostly the parents, as proxy for children (Marshman et al, 2007). Therefore, there is a need to develop and use methods that facilitate the involvement of children by dental professionals nowadays (Gilchrist et al, 2014).

Regarding children satisfaction as service users, there have been no validated questionnaires to measure this group’s perspective of dental services and preventive interventions (Morgan et al, 2014). Children as health care service users receive one third of all services around the UK, therefore they should have an opportunity to give their opinion about services (UCLH, 2013).

Previous surveys developed have explored parent satisfaction about service and treatment in paediatric dental departments (Bhatia et al, 2012). These surveys can cover multiple aspects: reception area, waiting time, paediatric dental unit, the dentist, the dental assistance, Information and explanations provided parental involvement and overall care. But they look at the parent's perspective, not the child.

Casas et al reported that children's age can affect their acceptance of a research method (questionnaire) after he did a case control study considering children aged 8, 10 and 12 years of age (Casas et al, 2012). Feeney CN. 2014 involved children in his sample to measure patient and parent satisfaction in Newcastle in the paediatric dental department. They adapted the Young Patient's Survey (2004) and University of Cambridge's General Practice Assessment Questionnaire (2013) to develop the questionnaire, which included the following:

- Anxiety levels prior to the visit (before you saw the dentist today were you-happy/ok)
- How was your visit today?
- How do you feel about seeing our dentist again?
- What do you think of the toys and games in the waiting room?

This questionnaire was also used by McDonnell in 2012. The survey includes 38 questions, 32 of them about events throughout the patient journey. However, only four per cent of the questionnaires (3 out of 77) were completed by children themselves.

The acceptance of fissure sealants by children was examined in 2014 (Morgan et al, 2014). The research team used faces scale to record children's responses, using three different faces representing positive, neutral and negative feedback. This technique was used as it had been used before as a non-validated instrument for service evaluation of preformed metal crown and application of fluoride varnish because no validated questionnaire published yet to asses this matter (Morgan et al, 2014).

3.1.3 Examples of measuring children satisfaction and method used in health care:

A summary of examples of children involvement in the medical field is described below.

A. The Development of a Patient Reported Experience Measure (PREM) for Paediatrics

Patients (0-16 years) in Urgent and Emergency Care October 2012 (Royal College of Paediatrics and Child Health, 2012).

I. Background:

The Department of Health (England) commissioned the Royal College of Paediatrics and Child Health to develop and pilot a tool to measure the paediatric U&EC (Urgent and Emergency Care) experience in order to broaden the setting to incorporate multiple providers, following a report which demonstrated unsatisfactory patient experience for children under the age of five years with a fever accessing U&EC. Children make twenty five per cent of all urgent and emergency care and it is usually not a pleasant experience. The project was led by the Royal College of Paediatrics and Child health with participation of the College of Emergency Medicine. The board included:

- Ambulance service
- Royal college of nursing
- NHS direct
- Picker institute
- Royal college of general practitioners
- Patient advice Liaison service

II. Aim:

- To develop a PREM (Patient Reported Experience Measure) to be used by 0-16 years old paediatric patients by using children advice to be completed by them.
- To test a paper-based survey in U and EC settings
- To ensure the ability of using the survey at national level by NHS
- To ensure the adaptation of the survey by using it either electronically or by telephone
- To ensure that it is working if used outside England and the method can be applicable to be used in other paediatric health care settings

III. Sample:

Only 229 surveys were returned from a total of 1430 distributed across the eight different sites (St Mary’s Hospital London, Grove hill Medical Centre Hemel Hempstead, Leicester Royal Infirmary Leicester, London Ambulance Service, Wycombe General Hospital Buckinghamshire, Primary Care Trust Middlesbrough, Leicester ambulance service and Urgent Care 24 Liverpool). Two versions of the survey are available:

- 0-7 years (to be completed by parents and to engage the child as possible)
- 8-16 years to be compared by young people and children directly

IV. Survey development:

A full literature review was carried out to know the current evidence available. This was followed by using a focus group to cover the potential areas of interest when children visit the department of U and EC. Third, the survey was designed and tested cognitively by face to face interview with children from different ages. The piloting was the end stage before survey distribution.

IV. Methodology:

Three qualitative research methodologies were used; focus group, interviewing and questionnaire. This was supported by continuous feedback throughout the project.

V. Conclusion:

Using the developed tool to measure the paediatric patient attending Urgent and Emergency care experience, the project incorporated the views of children. The survey can be used for immediate feedback using the paper format or can be tested for use in electronic formats, or mailed out (electronically or paper). A telephone version of the survey is currently being piloted by the Picker Institute, Europe.

B. Young Outpatients Survey – autumn 2013 SHEFFIELD CHILDREN'S NHS FOUNDATION TRUST 01/2014 (Attwood et al, 2014):

I. Background:

The survey was carried out by Picker Institute Europe on behalf of children NHS Foundation Trust.

II. Aim:

To understand what young outpatients think of provided services by the Trust.

III. Sample:

Parents/carers and children to give their feedback by invitation.

IV. Survey development:

The survey developed was based on an adult national outpatient survey as well as previous research by the Picker institute. Two versions were developed by the Picker Institute Europe in collaboration with Sheffield Children's Hospital. Children patients aged 8 and above were the target for one version while the parents or carer will take care of the questionnaire for younger children and themselves in the other version. The parents were encouraged to include their children where possible. Motivation and child friendly design and language were used in the survey development. This was followed by testing the questionnaire cognitively on both paediatric patients and parents. In 2009 the survey was piloted in the children's department at Sheffield Children's Hospital and then it was conducted annually until today since 2010.

V. Methodology:

850 patients who attended outpatient's appointments were selected randomly. 425 were aged 7 years or under at the sampling time. The children surveys were sent to the remaining same numbered sample of 8 and above children.

VI. Conclusion:

The outpatient children survey was conducted to identify the key issues for improvement from children patients prospective and results were reported in multiple ways to ensure answering the key questions.

C. Children and young people's inpatient and day case survey, Care Quality Commission 2014-2015 (Care Quality Commission, 2015).

I. Background:

The document developed by Care Quality Commission in order to score and analyses the trust level results for the children's survey 2014. This is the first national children's survey conducted by Care Quality Commission. Despite the fact it is the first survey, it represents the experience of about 19000 children and young people. Those patients could be inpatients or experienced a day case care in 137 National Health Services acute trusts at the time of August 2014. Every NHS trust treating children were rated independently.

II. Aim:

The survey was designed to take direct feedback from children and young people alongside their parents' or carer to analyze the trust service level provided to this age group. The voices of young people, children and their parents/carers and about their experience of using medical services is essential in order to enable CQC to identify good care and highlighting probable risks to service quality.

III. Sample:

Parents/carers and children to give their feedback by invitation. Questionnaires were sent to 850 children and young people (in each trust that took part in the project), or their parents and carers in each of the trusts that took part in the survey. More than one half of the total patients included had an emergency appointment. And the majority (about 73%) had their first experience in a hospital paediatric ward. Patients who need long term care were only 28% from the total sample.

IV. Survey development:

Survey data available for the three groups: - Children and young people aged between 8 and 15 years - Parents or carers of 0 to 15 year olds - Parents or carers of 0 to 7 year olds.

V. Methodology:

Questionnaires were sent to children aged 8-15 years. Every single one included a section about children views in addition to the parents or career section for the children to complete. The survey was built on a voluntary survey by Picker institute Europe.

VI. Conclusion:

The findings were reported in two categories. There were some findings of good care e.g. a child aged between 8 and 15 reported that they were told about the operation by the staff and what to expect. Another child from the same age group said that when he experienced pain, the staff did everything they can to control it. On the other hand, the result reported some poor outcomes. For example, forty-one percent of parents reported that the medical staff were not always aware of the child previous medical issues.

These three reported examples highlighted the importance of service evaluation directly from the service users. Children in this case, showed the ability and desire to feedback about their experience. However, none of these scales were dental related and only one of them was developed by children. In paediatric dentistry, until today, there is no well reported tool to seek children's opinion throughout their dental journey. It is still relatively rare for children (especially youngsters) to be part of developing a satisfaction tool to be filled by their age peers. This reflects the demand for a paediatric dentistry satisfaction questionnaire in order to get reliable feedback from children patients. This will lead to reliable feedback as well as better service evaluation and improvement.

Therefore, the aim of the second part of this project was to develop a satisfaction tool for paediatric dentistry with children and compare the outcomes to the standard survey already in use.

At present, there is no validated instrument to measure the satisfaction of children about the service and treatment they have received in the paediatric dental setting. In the medical field, there are three recent reliable examples in outpatient services, urgent and emergency care and trust inpatient services. All used questionnaires as a method to measure children views and feedback. Two of these questionnaires were developed by modifying the adult version (Attwood et al, 2014; Care Quality Commission, 2015).

The survey developed by the Royal College of Paediatric and Child Health in 2012; 'Patients Reported Experience Measure for Paediatric Patients in Urgent and Emergency Care' was designed in collaboration with children at all stages. A summary of the three studies that involved children in evaluating services is shown in table 3.1:

	PREM, Urgent and Emergency Care 2012	Young Outpatients Survey 2013	Children and young people's inpatient 2014
Aim	To develop a PREM (Patient Reported Experience Measure) to be used by aged 0-16	to understand what young outpatient think of provided services by the Trust	the survey was designed to take direct feedback from children and young people alongside their parents
Number of Participants	229	850	19000
Method	Three qualitative research methodologies were used; focus group, interviewing and questionnaire	Questionnaire	Questionnaire
Questionnaire Design	5 stage development	was based on adult national outpatient survey as well as previous research by picker institutes	survey was built on a voluntary survey by Picker institute Europe
Children Involved	yes	No	No
Age group	0-7 and 8-16	Parents and children aged 8 and above	Parents and children aged 8 and above

Table 3.1 Reported examples of involving children in research

In the dental field, children views about paediatric dental services were explored in Newcastle in 2014 (PEANUT project: Patient experience at Newcastle upon Tyne Paediatric Dental Department, Feeney, 2014). The children questionnaire Based on the child questionnaire used in the FICTION Trial. This questionnaire previously used as a part of outcome measures used to assess three different restoration options of carious primary teeth for children aged 3-7 in 2013 (Innes 2013). During piloting, this got a 48% completion rate. However, the final version had a higher rate of 80% and 65% for

parents and children questionnaire respectively (n= 314 and n= 256). Moreover, in the Newcastle project, they didn't collect the child's age as a part of the demographic information and the results focused more on parents prospective. As this survey was based on an adult questionnaire, it did not fully capture the children's views or concerns.
In the last few years all aspects of health care have emphasised the importance of the input of the patient themselves. Therefore, there is a need to develop a valid tool for paediatric patients involving children themselves.

Currently, in the Paediatric Dentistry Department at the Eastman Dental Hospital, we are using the parents views to evaluate services provided in our department, by asking them to complete a quick questionnaire following their child's visit which is designed for parents and provided by the NHS for service evaluation in order to identify patient satisfaction and areas that need improvement The ideal situation to evaluate any service is to ask the treatment receiver, children in our case, as well as their parents. There may be a difference between parents and children's views due to differences in needs and expectations. Therefore, there is a need to develop patient satisfaction surveys specifically designed for children. This can only be achieved by involving children to develop a suitable tool for them.

3.2 Aims and objectives

To develop a satisfaction tool for paediatric dentistry with children and compare the outcomes to the standard survey already in use which is for adults which is provided by the NHS and we use to measure parents/carer satisfaction.

3.3 Methodology

The survey was produced through collaboration between the research team at Eastman Dental Hospital and children and young people that visited the paediatric department in the period from February to April 2016.

Governance:

The Audit was approved by the clinical governance and audit committee at the Eastman Dental Hospital. Written and verbal information was provided and verbal consent was obtained from parents and verbal assent from children. Ethical approval was not required.

3.4 Participants

Participants in the study were children aged 4-16 years, recruited from the paediatric dentistry department at the Eastman Dental Hospital. A member of the research team (AA) was present in the waiting room area to recruit children after they had finished their dental appointment, by asking both the child and his/her care giver to participate while they are waiting for their new appointment to be scheduled. As a result, the sample depended on the parent's agreement, child willingness to participate and time availability. This formed a convenient sample. We divided the children into three age groups (below 8, 8-10 and above 10 years). This was to reflect the developmental differences reported between age groups (Hetherington et. al. 1996; Bee 1998). A total of 29 child patients were interviewed for the purpose of developing relevant themes for the questionnaire. Ten children were aged below 8 (group one), 11 and 8 were in group two and three respectively (Table 3.2).

	Group 1 (n=10)	Group 2 (n=11)	Group 3 (n=8)
Boys	6	6	4
Girls	4	5	4

Table 3.2 Children interview sample

3.5 Materials and Methods

The research team used the method developed by the Royal College of Paediatric and Child Health PREM survey, as it was designed by children for children, and gave promising results as a children participation tool.

I. *Stage One:*
    A. *Qualitative stage interview and identifying key themes:*

Method:

Interviewing as a qualitative research method to involve children in the research process was reported to be the most effective way to gain valid information (Marshman et al., 2012). Following a guidance and training from an expert in school of education about children interviewing, A member of the research team (AA, Paediatric Dentist) interviewed children using open ended questions in the waiting room area, after their appointment to identify key themes. A topic guide was developed in order to facilitate the interviews and ensure patients were asked similar questions (Figure 3.1):

Patient Number:
Age:
Gender
Number of previous visits:
Parent's verbal agreement …
Hello
We would like to find out how children feel about coming to the dentist and what they like / don't like.
We would like to speak to your child about their experience of visiting our department – would you be happy for us to talk to them? (It should only take a few minutes)
Could you please help us, by answering a few questions?? …..
There is no right or wrong answers; we are just interested in what you think
What is the most important thing for you when you come to visit us?
What things make you happy when you visit us? What do you like?
What things don't you like? Why?

Figure 3.1. Interviewer parent and child information guide

Interviewing of very young children (aged 4-7) was done in cooperation with the department play specialist. The department play specialist facilitated the interview and she were playing with them and directing their attention to the interviewer. In addition, she was giving them a suitable explanation if needed to understand the question. Children quotes were directly written on papers. This was followed by a simple framework analysis was undertaken for each group, and quotes were transcribed into an excel spreadsheet, for each main theme, with each line representing a child and each column representing an identified subtheme.

<u>Results:</u>

Five key themes were identified from the interviews: waiting area, the dentist, appointment, treatment provided and staff. The waiting area and waiting time before they were called to see the dentist were the most interest of the children from the first group (below 8 years), while all themes were of interest to the two older age groups. Quotes for the main themes for each of the age groups is shown in tables 3.3, 3.4, 3.5:

Group One: Children under 8 years old (Total Number = 10)

Waiting Area	**Dentist and Dental Clinic**	**Common themes for this age group**	**Questions**
• I Like everything • More games and toys • I Like everything • I don't know all is okay	• I like everything • I like everything • give me more stickers	• Waiting area • Games and toys	• What do you think of the toys in the waiting area? Good ok bad • Do you find space to play in the waiting area? Yes sometimes no • What do you like most in the waiting area: Video games coloring books toys • Can we make you happier when you visit us again, please tell us how: ________________________

Table 3.3 Data collected and analyzed from group one children interview

Group Two: Children between 8-10 years old (Total Number = 11)

Waiting Area	Dentist and Dental Clinic	Common themes for this age group	Questions
• More space to play • Can you bring one more Wii? • I need more games, toys, color and children books • Get more games • More books • More games • Get Ipad • more channels • More coloring books are needed • I like being here because I make a lot of friends and I meet new people • more toys than video games • more stuff to keep kids	• Awesome dentist • A lot of people talk to me • I like my way to here • I like my dentist, but last time when I went home my tooth hurts • My dentist is good • I like the headphones • I don't understand what my dentist say but she is nice to me • Today's appointment is too long • A lot of people come to see my teeth	• Waiting area • The Dentist • Appointment • Treatment • Staff	• How do you feel seeing the dentist again: Happy ok unhappy • What do you think of the toys in the waiting area: Good ok bad • Do you find space to play in the waiting area: Yes sometimes no • Do you enjoy the waiting time before you see the dentist today: Yes a lot yes a little no • The time you spent with the dentist today: Too short normal too long • Did you wait a long time before you saw the dentist today Yes No • Can we make you happier when you visit us again, please tell us how: ______________________

busy while waiting • I like everything, but I want some fruits	• When I come here I miss school • Dentist should make us laugh • Dentist is good • My dentist is good		

Table 3.4 Data collected and analyzed from group two children interview

Group three: Children above 10 years old (Total Number = 8)

Waiting Area	**Dentist and Dental Clinic**	**Common themes for this age group**	**Potential questions**
• TV is boring • no suitable stuff for my age, but when I was younger I liked the coloring pages • I hate waiting time, I want more magazines. Stuff are not for my age • please get Lego, all place is good • Long waiting time	• I like my dentist to tell me everything. Last time I came to make my teeth whiter and the dentist took one of my baby teeth out • Dental nurse She talks and confuse me	• Waiting area • The Dentist • Appointment • Treatment • Staff	• How was your visit today? Good Ok Bad • How do you feel seeing the dentist again? Happy ok unhappy • Did you waited a lot before you see the dentist today? Yes No • Did you enjoy your trip to the dentist today? Yes sometimes no • Do you enjoy the waiting time before you see the dentist today? Yes a lot yes a little no

• I like the staff, I want free coffee • everything is good • I like the staff, I want free coffee	• Why should I stay too long at the dentist? • more private cubics needed • sometimes it is hard to get an appointment • more regular treatment • everyone is really polite • x-ray machine is really annoying • I want to get my teeth fixed • my dentist is good, telling me what is wrong and that is very helpful		• The time you spent with the dentist today (depends on the procedure) Too short normal too long • Do you find waiting area, bathrooms, clinics clean Yes no • Do you find a lot of Things suitable for you in the waiting area? Yes No if no what do you like to have more? • Are the people who work here friendly? Yes No • Do you feel comfortable and private in our clinic? Yes No • Can we make you happier when you visit us again, please tell us how: ________________________

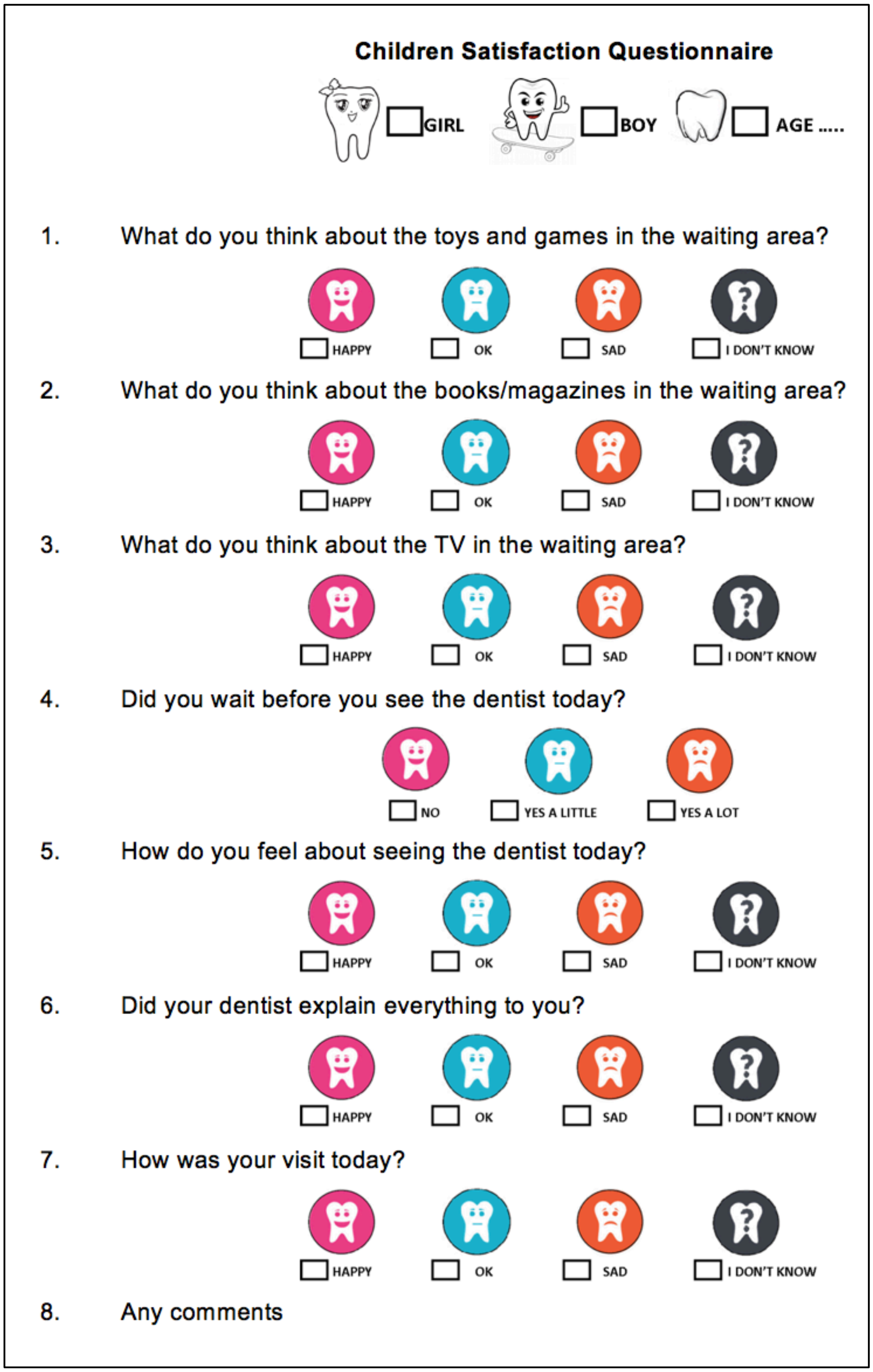
Table 3.5 Data collected and analyzed from group three children interview

B. *Questionnaire development and design:*

It was felt that the survey should be quick and easy to complete, to encourage participation, therefore it was limited to one side of A4 paper, using tick boxes and pictures, as well as a free text box using age appropriate language.

Initially, it was planned to design a separate questionnaire for each age group, but due to similarities between the 3 groups, and logistics of ensuring that the appropriate questionnaire could be given to the correct child by reception staff, it was decided to produce only one version of the survey that would be suitable for all ages. Three different versions of the questionnaire were produced, with different layouts, and piloted amongst children in the department to see which one was preferred. The three different questionnaire designs were designed; with and without horizontal lines and as two columns, as shown in figures 3.2, 3.3, 3.4:

1st design:



Children Satisfaction Questionnaire

☐ GIRL ☐ BOY ☐ AGE .....

1. What do you think about the toys and games in the waiting area?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

2. What do you think about the books/magazines in the waiting area?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

3. What do you think about the TV in the waiting area?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

4. Did you wait before you see the dentist today?

☐ NO ☐ YES A LITTLE ☐ YES A LOT

5. How do you feel about seeing the dentist today?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

6. Did your dentist explain everything to you?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

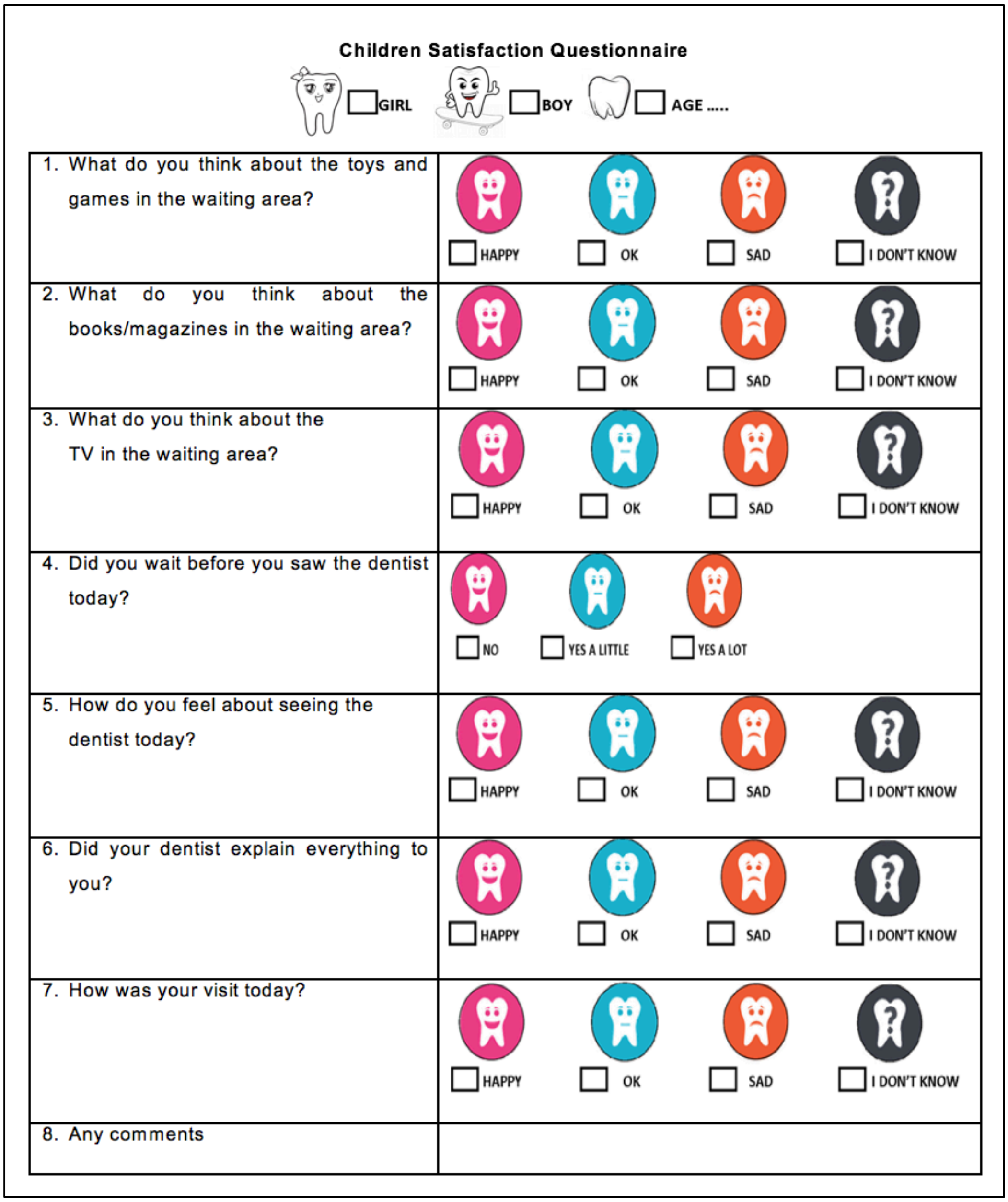
7. How was your visit today?

☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW

8. Any comments

Figure 3.2. Children's questionnaire design number 1

2nd design:



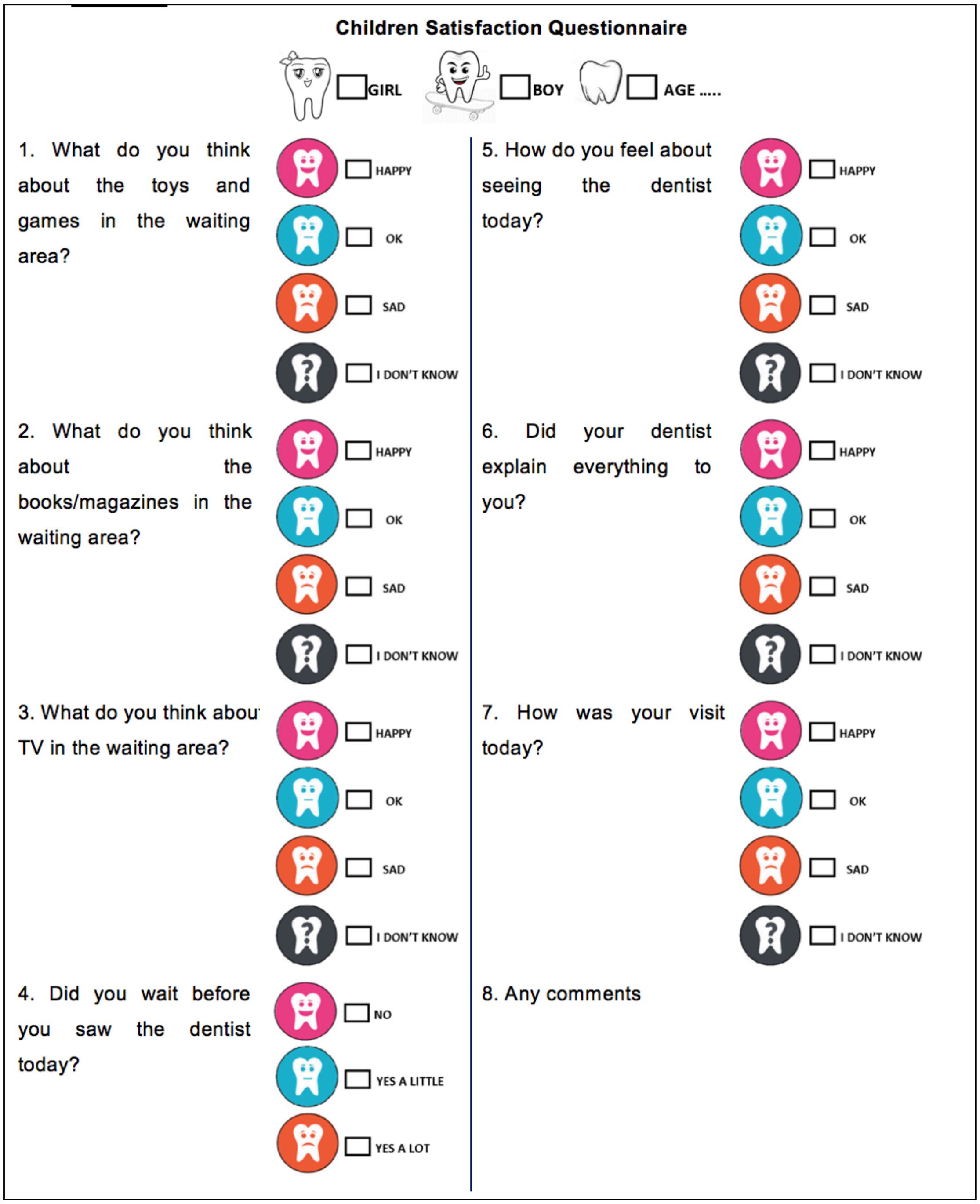
Children Satisfaction Questionnaire

☐ GIRL ☐ BOY ☐ AGE .....

1. What do you think about the toys and games in the waiting area?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
2. What do you think about the books/magazines in the waiting area?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
3. What do you think about the TV in the waiting area?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
4. Did you wait before you saw the dentist today?	☐ NO ☐ YES A LITTLE ☐ YES A LOT
5. How do you feel about seeing the dentist today?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
6. Did your dentist explain everything to you?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
7. How was your visit today?	☐ HAPPY ☐ OK ☐ SAD ☐ I DON'T KNOW
8. Any comments	

Figure 3.3. Children's questionnaire design number 2

3rd design:



Children Satisfaction Questionnaire

☐ GIRL ☐ BOY ☐ AGE .....

1. What do you think about the toys and games in the waiting area?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

2. What do you think about the books/magazines in the waiting area?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

3. What do you think abou TV in the waiting area?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

4. Did you wait before you saw the dentist today?
   - ☐ NO
   - ☐ YES A LITTLE
   - ☐ YES A LOT

5. How do you feel about seeing the dentist today?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

6. Did your dentist explain everything to you?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

7. How was your visit today?
   - ☐ HAPPY
   - ☐ OK
   - ☐ SAD
   - ☐ I DON'T KNOW

8. Any comments

Figure 3.4. Children's questionnaire design number 3

C. Piloting and Cognitive testing

Method:

To pilot the design of the questionnaire, 15 children aged between 4 and 16 years, were approached in the waiting room and asked to choose which design they preferred. In addition, the children were asked if the questions were easy to read and understand. Testing of the general layout and questions sequence was also assessed by offering three different layout versions, columns, table and normal page layout.

Results:

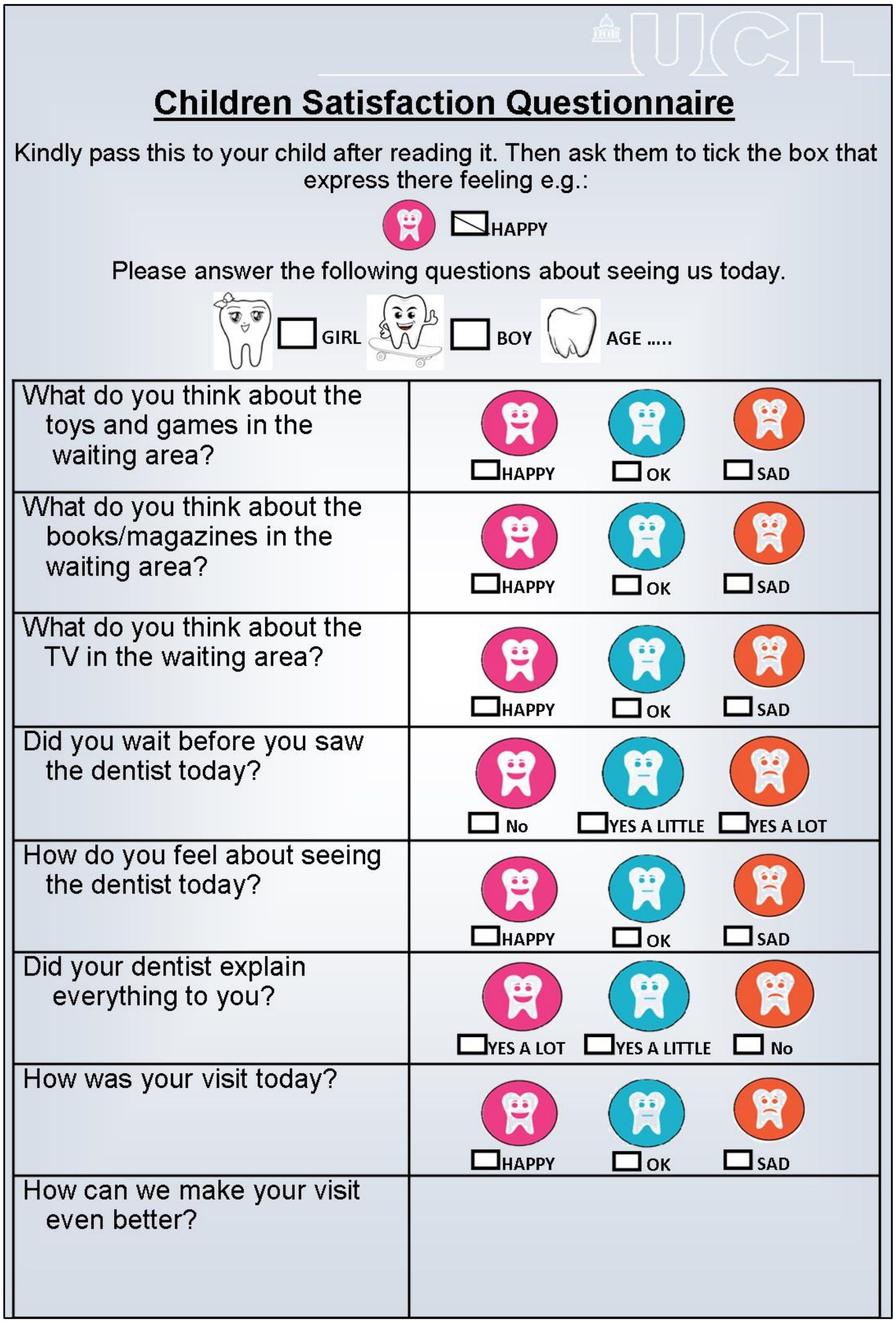
The pilot was conducted between February to March 2016 and 55 children aged between 5 -16 years participated.

Most children preferred questionnaire second design, table (figure 3.3), because it was easier to follow, more organised, clearer and caused less confusion.

The minor changes which were made to modify the questionnaire were:

- A line was also added requesting parents give the questionnaire to their child to complete, as there had been some confusion initially regarding who was to complete the questionnaire.
- The personal information (age and gender) were moved from the top of the questionnaire to just below the instructions,
- Some children's hand writing is large, so the comments section box was expanded to accommodate this

The final version of the child satisfaction questionnaire is shown in figure 3.5.



Children Satisfaction Questionnaire

Kindly pass this to your child after reading it. Then ask them to tick the box that express there feeling e.g.:

☒ HAPPY

Please answer the following questions about seeing us today.

☐ GIRL ☐ BOY AGE .....

What do you think about the toys and games in the waiting area?	☐ HAPPY ☐ OK ☐ SAD
What do you think about the books/magazines in the waiting area?	☐ HAPPY ☐ OK ☐ SAD
What do you think about the TV in the waiting area?	☐ HAPPY ☐ OK ☐ SAD
Did you wait before you saw the dentist today?	☐ No ☐ YES A LITTLE ☐ YES A LOT
How do you feel about seeing the dentist today?	☐ HAPPY ☐ OK ☐ SAD
Did your dentist explain everything to you?	☐ YES A LOT ☐ YES A LITTLE ☐ No
How was your visit today?	☐ HAPPY ☐ OK ☐ SAD
How can we make your visit even better?	

Figure 3.5 Final children satisfaction questionnaire

II. Stage Two: Questionnaire validation

To ensure that the newly developed children's satisfaction survey measured children's true feelings and views about the paediatric dental department at the Eastman Dental Hospital, it was necessary to test the questionnaire on a separate sample of children. Therefore, the questionnaire was handed out to all children attending the department in the one-week period from 11/04/2016-15/04/2016.

The data from the questionnaires were transferred to Excel spread sheet after coding the responses. Qualitative analysis was used to determine the percentages for each response.

3.6 Results

A total of 106 questionnaires were distributed between 11/04/2016-15/04/2016. There were 3 incomplete questionnaires, that were excluded from the analysis. The total number of questionnaires distributed was almost equal for boys and girls, (54 vs. 49 respectively) and the age ranged between 4-15 years.

The overall feedback of the questionnaire was that it was highly accepted by children and easy to complete. Although it was decided to have one questionnaire for all age group, the results were analysed by the three age groups, dependent on the cognitive ability was used (group 1= under 8 years, group two between 8-10 years and group 3 above 10 years).

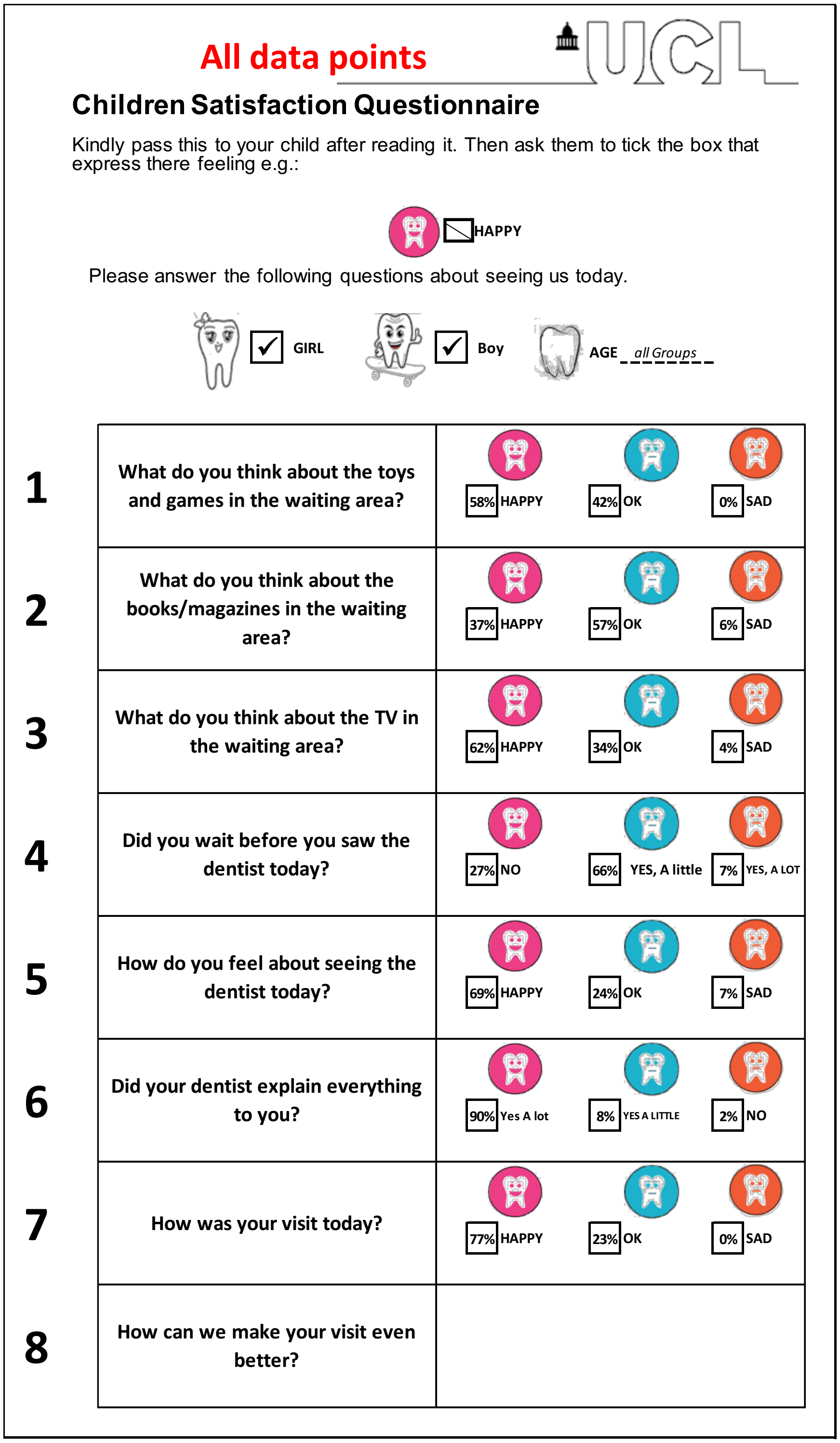
The demographics of the respondents is shown in table 3.6.

Gender	Age group	# of test subjects	%	Total #	%
Boy	1	21	20.4%	**54**	52.4%
Boy	2	16	15.5%		
Boy	3	17	16.5%		
Girl	1	16	15.5%	**49**	47.6%
Girl	2	14	13.6%		
Girl	3	19	18.4%		

Table 3.6 Illustration of questionnaire results - gender spread results

Overall responses:

About 60 percent of the sample reported a happy response about how waiting area is and no sad response reported about this matter. Books and magazine in the waiting rated to be okay by most of the children, one third were happy and only 6% are sad about books and magazine provided. This question was followed with asking opinion about spending time watching TV provided in the waiting are, 62% and 34% were given respectively for happy and okay responses. However, only 4% of children were sad about TV in the waiting area. Moving to waiting time theme, two third exactly of the children reporting waiting for a little period, about one quarter did not wait and long waiting reported by 7%. About 70% of children were expressing a happy feeling about seeing the dentist. 24% and 7% for okay and sad were given respectively for seeing the dentist. The highest points participant agreed on is that dentists are involving them in the situation by explaining everything they need. This was expresses by given 90% yes a lot answers for question 6. The rest 10% were shared by yes a little and no (8% and 2%). The last question (before the comment section) asked about the visit in general. It is good for service that in general, none of the children reported sad in this question. More than three quarters were happy (77%). An okay answer was provided by 23%. This result shows in figure 3.6.



All data points

UCL

Children Satisfaction Questionnaire

Kindly pass this to your child after reading it. Then ask them to tick the box that express there feeling e.g.:

☒ HAPPY

Please answer the following questions about seeing us today.

☑ GIRL ☑ Boy AGE _ *all Groups* _

1	What do you think about the toys and games in the waiting area?	58% HAPPY	42% OK	0% SAD
2	What do you think about the books/magazines in the waiting area?	37% HAPPY	57% OK	6% SAD
3	What do you think about the TV in the waiting area?	62% HAPPY	34% OK	4% SAD
4	Did you wait before you saw the dentist today?	27% NO	66% YES, A little	7% YES, A LOT
5	How do you feel about seeing the dentist today?	69% HAPPY	24% OK	7% SAD
6	Did your dentist explain everything to you?	90% Yes A lot	8% YES A LITTLE	2% NO
7	How was your visit today?	77% HAPPY	23% OK	0% SAD
8	How can we make your visit even better?			

Figure 3.6 Satisfaction questionnaire overall results

Overall, boys were happy (>50%) in 5 out of 7 questions. In question 1, asking about the waiting room area, none of the boys were unhappy with the environment. For the second question regarding books and magazines provided in the waiting area, most of the responses (56%) were okay. Boys who responded as unhappy were less than 10% of respondents. 9% of boys feedback negatively about dentist explaining everything they needed to know. 4% of the boys were giving a negative response to both question 3 and 4. Almost three quarters happy response was given for question 5. Highest positive response from boys was given for the last two questions. The overall responses by boys are shown in figure 3.7.

The overall girls responses displayed a majority of positive responses in all questions except question two and four. 10% reported waiting a lot after their appointment time. The percentage of unhappy responses were 4% for questions two, three and five, and it was 2% less for question 6. A highest happy response was given to question 6 by 92% followed by 71% for the last question about the visit overall. More in figure 3.8.

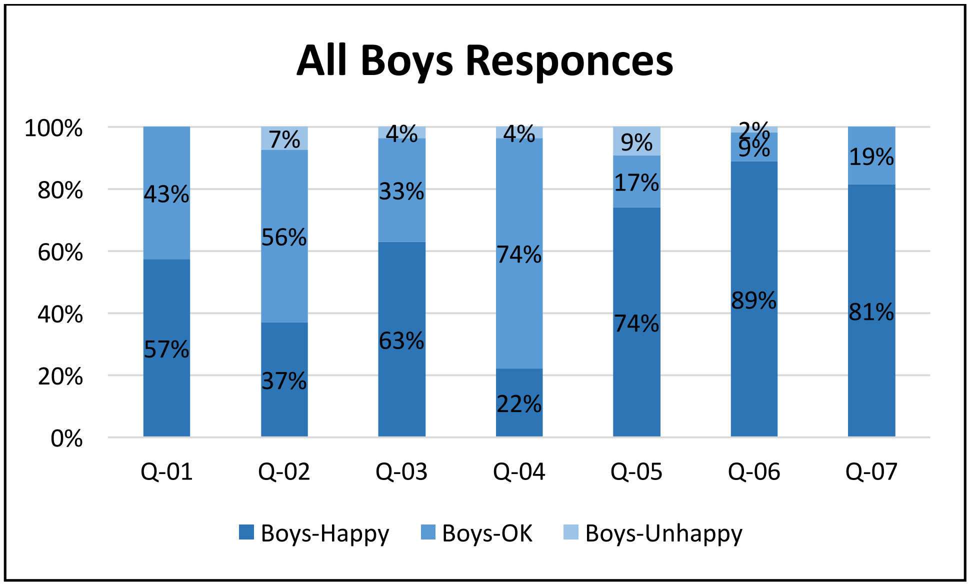


Figure 3.7 Over all boys response to questionnaire

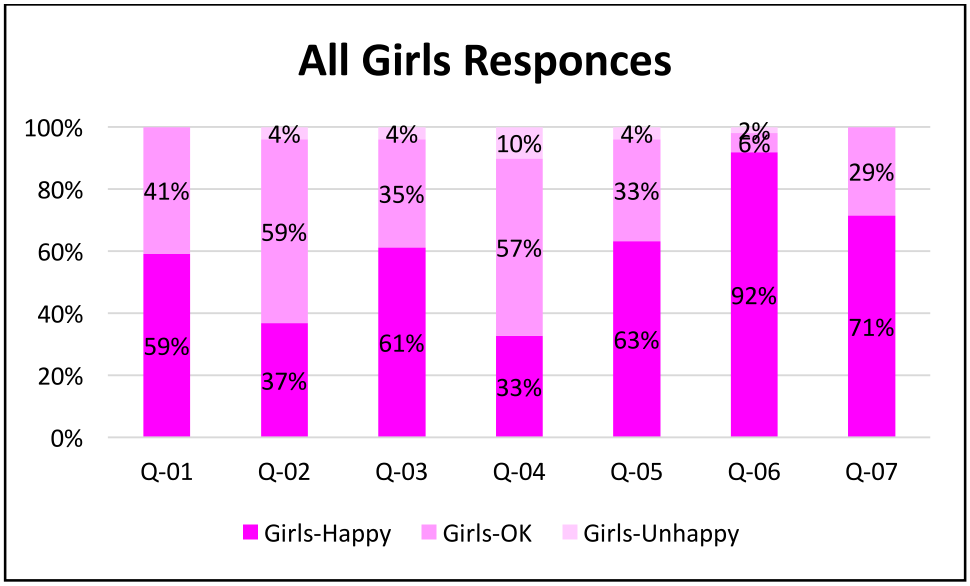


Figure 3.8 Over all girls response to questionnaire

Comparing between girls and boys, data are similar to some extent as shown in figures. All responses are within 5 percentages different more or less between the two groups. An exception for that is question 4, 5 and 7 generally which asking about waiting time before dentist and feeling about seeing the dentist and the visit generally. The difference in response to question 5 and 7 are within the 10% limit (except for unhappy response for question 5). A significant different between the two groups is question 4 is noticed. That might reflect that girls and boys have different perspective on this matter.

To see if there were any differences by age group, the data was analysed by age group.

Group 1 (below 8 years):

Boys aged below 8 years, the key point for this group is the waiting time as 71% reported to wait for a short time before being seen by the dentist. More about this group in figure 3.9. this group is expressing different opinion about first three questions about waiting area. We mentioned previously that it is the most important for this age group. The response shows that the waiting are a is suitable for this group as in first and third questions the happy percentage is 86% compared to 57% and 63% for overall boys.

Girls aged less than 8 years old (age group 1), 56% were neither happy nor sad about the book and magazine in the waiting area. Point worth mentioning that one quarter of the girls in this group reported long waiting time. More in figure 3.10. girls in this group appear to be systematic with their overall response. However, for question 5 about feeling about seeing the dentist, unhappy response is 15% more than the whole group reflecting that younger girls exhibit more anxiety than their older peers.

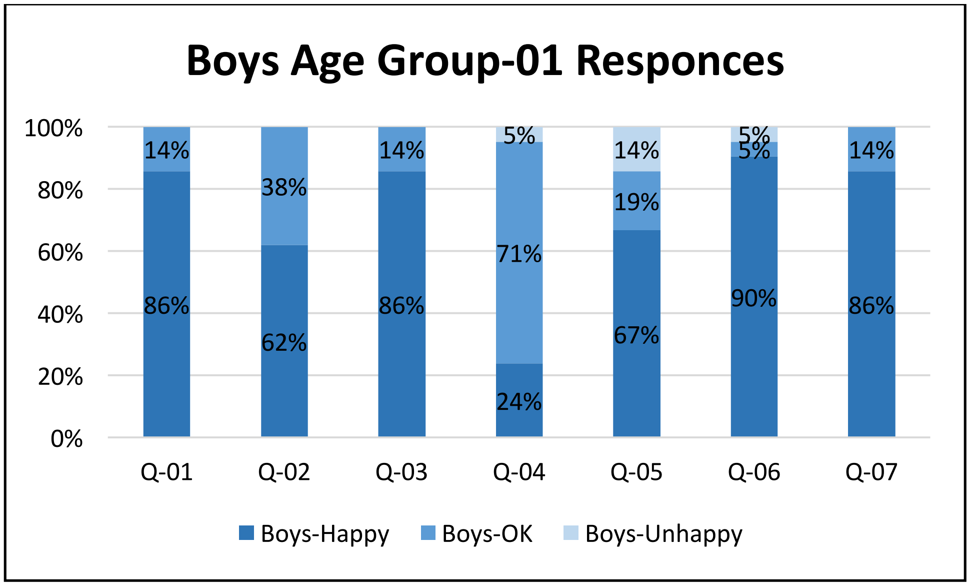


Figure 3.9 Boys aged below 8 years (group 1) responses

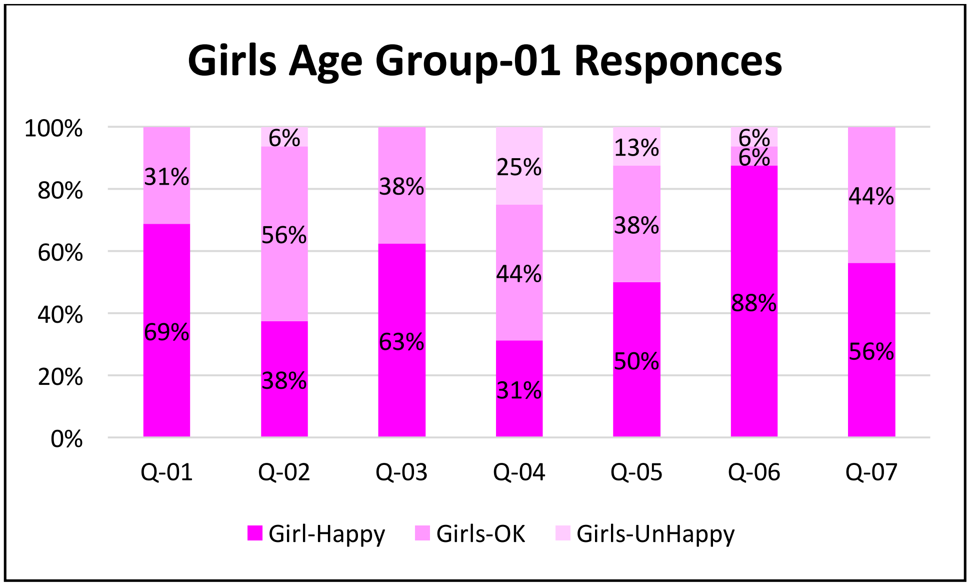


Figure 3.10 Girls aged below 8 years (group 1) responses.

Group 2:

Boys aged between 8-10 years, equal happy and okay response were given for question one about toys and games in the waiting area. Only 31% from total boys in this age group reported no waiting after the appointment time while the rest (69%) waited for a short time. More about this group in figure 3.11. in this group as they are older, more children are okay about TV, 56% comparing to 63% that were happy overall. As this group expected to ask for more, 31% filed okay about the visit generally compared to 19 reflected by overall boys

Girls aged between 8-10 years, only 21% from this age group were happy about books and magazine in the waiting area, the rest were okay. Negative response reported in one question only as 7% of the girls reported waiting for a long time. More in figure 3.12. girls in this age seemed more interested in spending time reading books and magazines. But they are not happy about it as only 21% of them respond happy compared to around 40% overall.

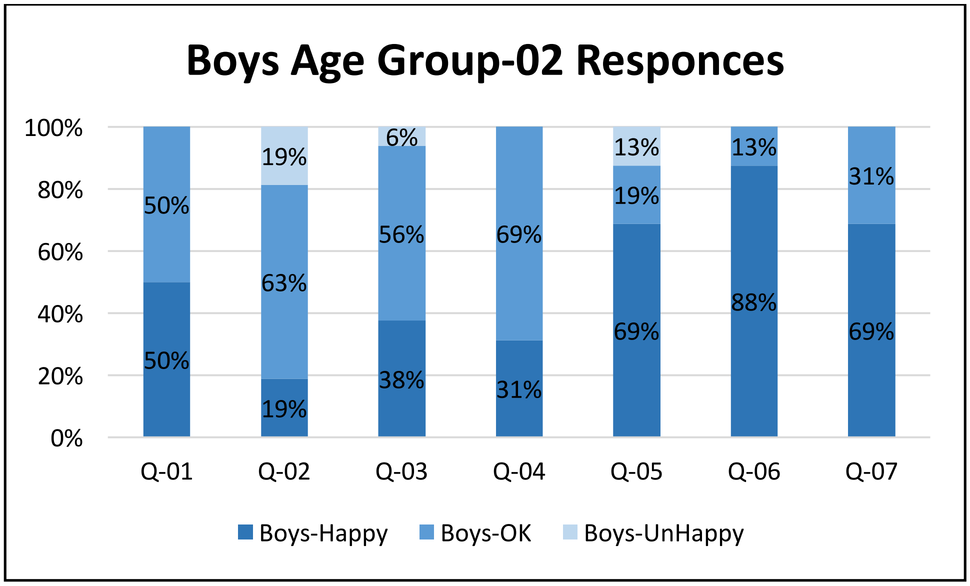


Figure 3.11 Boys between 8-10 years (group 2) responses

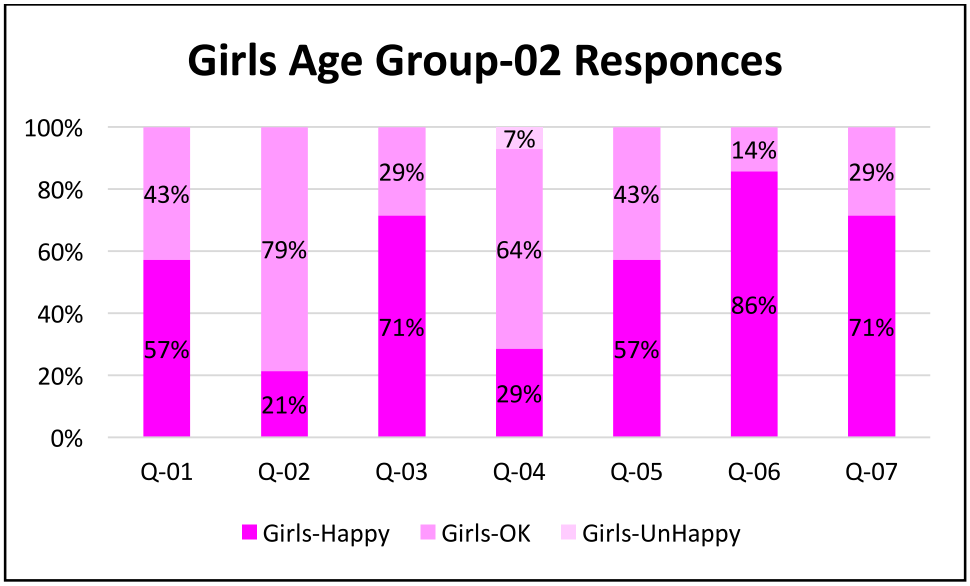


Figure 3.12 Girls aged between 8-10 years (group 2) responses.

<u>Group 3:</u>

In boys aged above 10 years, the last group were happy about the experience with dentist giving 88% happy response for the last three questions. On the other hand, regarding the waiting area, happy response was only 29% and 24% for questions one and two respectively. More in figure 3.13, teenagers boys in this group like the group before, expressing unhappier responses about waiting area as no suitable stuff available for them. In first two questions, 71% of this group boys responded okay about toys, games, books and magazine compared to only 43% in first and 56% in the second question of all responses.

Girls aged above 10 years, all the girls in this group reported a lot of explanation by the dentist about their visit. However, less than half of them reported positive feedback for books in the waiting area and waiting time. More in figure 3.14. the only 100% response was given by girls in this group for question 6 proving that girls felt involved in their treatment as a result of dentist explaining everything to them. Other question were in the range with overall responses.

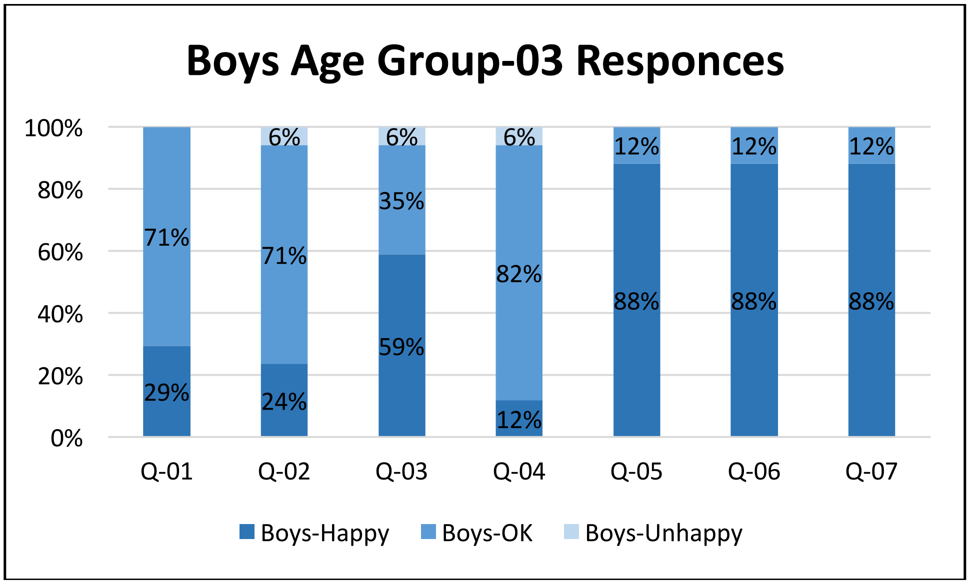


Figure 3.13 Boys aged above 10 years (group 3) responses.

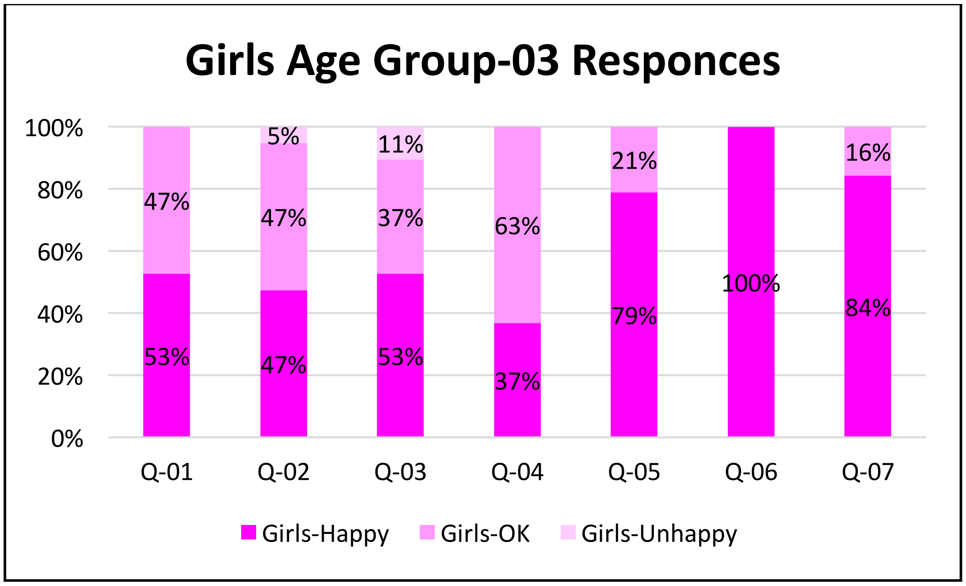


Figure 3.14 Girls aged above 10 years (group 3) responses.

Comments:

A variety of comments were obtained, and provided additional useful information.

From the questionnaire results, it was clear that the waiting area facilities and items were not appropriate for older children. Many children asked for items suitable for their age pointing at the fact that waiting area currently is designed to accommodate those aged below 8 years old. Therefore, items like colouring books, video games and chapter books for older children as well as TV shows suitable for them are in huge need. More about comments in table 3.7.

Child Age	Gender	Comment
11	Girl	Put chapter books in waiting area
13	Boy	Nothing good for me to play
8	Boy	By upgrading the Wii in to Wii U so I can Play
12	Boy	By having books for older kids
12	Girl	Add in books for children of an older age range
13	Girl	By doing more things for teenage children
15	Girl	Include activities/television that interests older children and teenagers
11	Girl	Everything is great! Can you make sure that the waiting area is tidy though and have something for me to read.
11	Boy	Add bigger varieties for older children
10	Girl	By putting grown up drawings
11	Boy	TV for older children

Table 3.7 Children's' comments

Group 1:
Different comments provided, arranged from great service to asking for more games, toys. More in table 3.8

Child Age	Gender	Comment
7	Boy	More gentle and child friendly in X- Ray
7	Girl	By saying I am brave
4	Girl	good
5	Boy	I want a toy
6	Boy	I am happy thank you
7	Girl	By more games in waiting area
7	Girl	Great
6	Boy	I don't know
7	Girl	Get more picture to color
5	Boy	Good
6	Boy	Not paint my teeth

Table 3.8 Group 1 children's comments

Group 2:

Many children in group two express their good experience by saying nothing else needed. However, many children in this group pointed about waiting time. More in table 3.9.

Child Age	Gender	Comment
8	Boy	I am happy the same way it is
10	Girl	To not be waiting too long
10	Boy	You can not
10	Girl	It was absolutely perfect
10	Boy	You can not
8	Boy	Not sure
8	Boy	By upgrading the Wii in to Wii U
10	Girl	Maybe less waiting
10	Boy	You can not
10	Girl	By putting grown up drawings
10	Girl	Great because I wanted two teeth to come and they did
8	Girl	By calling us and telling us to go
8	Girl	Nothing really

Table 3.7 Group 2 children's comments

Group 3:

The last group asked for more things toward adult side like Wifi internet, TV for teenagers and books. Many of them stressed on the good work as well. More in table 3.10.

Child Age	Gender	Comment
12	Girl	Drinks/ water, tea and coffee
11	Boy	Less waiting in the x-ray room. But in this room it is good I did not wait a lot but I did wait a little
14	Girl	Very happy keep up the good work
13	Girl	No it was really good
11	Girl	Put chapter books in waiting area
14	Boy	Wifi working

13	Boy	Nothing
12	Boy	By having books for older kids
11	Boy	I do not know
13	Girl	Well looked after
12	Girl	Add in books for children of an older age range
11	Boy	You can not
13	Girl	By doing more things for teenage children
15	Girl	Include activities/television that interests older children and teenagers
11	Girl	Everything is great! Can you make sure that the waiting area is tidy though and have something for me to read
11	Boy	Add bigger varieties for older children
11	Boy	TV for older children
15	Girl	Very good service
12	Boy	TV in the dentist chair to keep still during a long appointment

Table 3.8 Group 3 children's comments

3.6.1 Comparing between child satisfaction survey and the adult satisfaction survey we use in our trust:

Two themes in the child satisfaction questionnaire, the waiting area and the dentist, were consistent with the adult survey. Other questions in the adult version related to: recommending the paediatric department to others, self-check in, welcoming upon arrival, staff kindness, waiting time and personal information. But these themes if it is not exactly the same in the child version, it is considered to have some similarity. For example, the question about staff you came in contact to is a sub question of the child version (feeling about visit generally, question 7). General differences between the two scales in table 3.11.

General information (Table 3.11):

Questionnaire	Total Questions	Response guide	Personal information questions	Type of personal information	Comment section provided
Adult	7	written	4	Gender, age, ethnicity and disability	yes
Child	7	Written and faces	2	Age and gender	yes

Table 3.9 Comparison between adult and child questionnaire

As the idea of the satisfaction survey came after an adult satisfaction audit in the department, it is expected to find similarities between the two scales used. Out of the eight questions we developed, two appears to be quite similar to two questions from the adult version which contain 8 questions. Question one is about waiting time and the other about staff and how friendly they are. In regard to demographic data, it is more detailed in the adult scale as they asked about ethnicity and disability in addition to gender and age. The comments section was nearly the same between the two versions. One last difference in the adult questionnaire is a description of how we use this information and the explanation about the not to participate option. On the top of the children scale we clearly stated that it should be filled by children only. It is not clear on the adult version which we give to parents only who it is for or a direction on how to fill it or if a child wants to provide feedback using it, knowing that an option to choose the age between 0-15 is available on the scale. Language seemed to be simple in both versions. This supports the research team decision to use one version only. However, questions on the adults scale are a bit longer. Short formulating questions on the children's scale aimed to ease the experience and reduce time needed for participation.

Adult satisfaction questionnaire questions guide (Table 3.12):

Area of investigation (number of questions)	Question asked	Response options
Recommendation of paediatric department to others (2)	How likely are you to recommend our clinic to friends and family if they needed similar care or treatment?	6 responses range from extremely likely to I don't know
	What is the main reason for this?	4 options and others
Arriving at the department (2)	Did you use a self-check in kiosk today	Yes/no
	Were you welcomed and acknowledged upon arrival today at the clinic?	4 options from yes definitely to not at all
Staff (1)	Were the staff you came into contact with today friendly and helpful?	4 options from yes definitely to not at all
Waiting time (2)	How many minutes after your appointment time were you seen?	4 options from seen on time to more than 60 minutes
	If your appointment was delayed, did you feel you were kept updated?	4 options from yes definitely to not at all

Table 3.10 Guide questions for adult satisfaction questionnaire

Child satisfaction questionnaire questions guide (Table 3.13):

Area of investigation (number of questions)	Question asked	Response options
Waiting area (3)	What do you think about the toys and games in the waiting area?	3 written and faces images options, happy, ok and sad
	What do you think about the books/magazines in the waiting area?	3 written and faces images options, happy, ok and sad
	What do you think about the TV in the waiting area?	3 written and faces images options, happy, ok and sad
Waiting time (1)	Did you wait before you saw the dentist today?	3 written and faces images options, no, yes a little and yes a lot
The Dentist (3)	Did your dentist explain every-thing to you?	3 written and faces images options, no, yes a little and yes a lot
	How do you feel about seeing the dentist today?	3 written and faces images options, happy, ok and sad
	How was your visit today?	3 written and faces images options, happy, ok and sad

Table 3.11 Guide questions for children satisfaction questionnaire

The children satisfaction review agreed on what the adults satisfaction review showed. Children reported overall positive response as well as adults. 66.67% of adults responded extremely likely to recommend the department to others while children provided a 77% happy response generally about their visit. However, we have to keep in mind that adults can choose between 6 options from extremely likely to I don’t know and children have happy, okay and sad only. A waiting time theme is available in both scale as previously mentioned. About half of adults felt that they were seen on time. However, only 27% of children reported no waiting at all, others felt they waited a little bit. This shows again that adult and children takes things from different perspective. Comparing between waiting time response showed in the figures (3.15 and 3.16) below between two scales.

In the comments section where anyone can express their feeling. Adults showed a totally different interest compared to children. for example, many adults express the need an air conditioning and parking (almost half of the comments responses). In fact, no child even mentioned anything about these two issues. Comments were concentrated about providing a suitable age appropriate materials to use while waiting.

As a result, that 60% of adults did not fill their age in brackets, it was not possible to compare age and demographic data between the two scales. However, 35% of adults who filled the satisfaction scale were aged between 25-34.

It is hard to compare between other aspects of the two scales because of different scope. The recommendation of the adult satisfaction scale was mainly below one of the following:

- Ability to book appointments more and in advance
- More information and leaf lets about treatment modalities especially general anaesthesia
- To make the waiting area suitable for older children

The third recommendation is in common between the two versions.

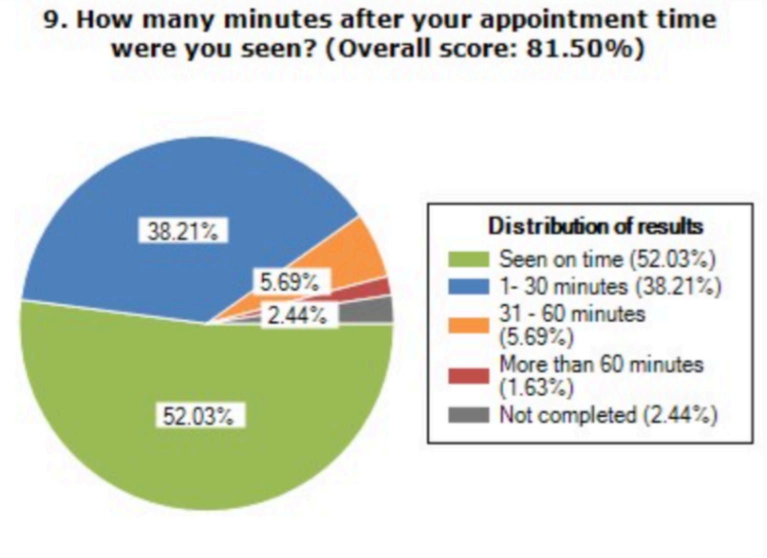
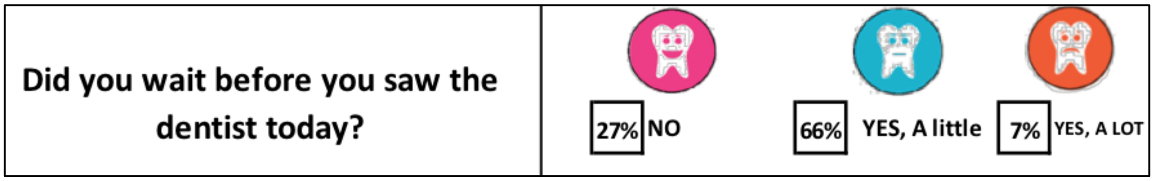


Figure 3.15 Waiting time, adult questionnaire



Did you wait before you saw the dentist today?	27% NO	66% YES, A little	7% YES, A LOT

Figure 3.16 Waiting time, children questionnaire

Clear differences between two satisfaction surveys exist. Children are not concerned about regarding recommending the department to others, while adult's feedback on that is mandatory to maintain a good overall repetition. When arriving at the department, children have no roll in check in or communication with reception staff, whereas adults care about ease of this process and an availability of friendly staff if assistance is needed. Although both children and adult's visitors do care about waiting time, it seems that children care more about quality of that time not like adults who seems to care more about quantity. Enjoyment during waiting is what all children ask for. Therefore, multiple sources of fun are required like video games, TV, toys and books and magazine. The adult should be informed about delays in their child care so they will feel not ignored during waiting and the staff are trying to see their child as soon as possible.

3.7 Discussion

This report describes the development of a validated tool for measuring the paediatric experience whilst visiting the paediatric dentistry department. Capturing patient experience has become a significant part of service evaluation. As dental caries is one of the most common infectious diseases in children, Paediatric dentists could be one of the first healthcare providers to have frequent contact with child patients. As a result, it is essential to develop an easy tool for them to evaluate dental services. The age range of 0 – 16 years was chosen to differentiate between young and adult services. While parent's opinion about dental services in very important, the methodology concentrated on children's view in design, development and results.

Children's cognitive ability were taken in consideration in the results and analysis as well as development. Children from different age groups, and gender showed different interests and responses, highlighting the need to distinguish between different age groups when considering a child satisfaction tool. Communication between the child and dentist before delivering the treatment, appears to be essential for children when receiving treatment. Involving the child in the process of treatment adds to building trust between the child and the dental team.

Child questionnaires should be simple and easy to read and complete. The adult versions contains 4-6 responses to most questions. Enhancing clarity by using facial images as well as text was helpful, in addition to limiting the options to three for all questions. Adults accompanying a child are able to identify exactly how long they have been kept waiting (from 1-30 minutes), whereas children prefer a general expression about waiting (e.g. ‘Yes a little’).

Children have different cognitive abilities depending on their age, therefore they were divided into three subgroups in result and analysis, even though only one questionnaire was used. Having one version is easier to use by any of the staff members and avoids confusion and errors by increasing the chance of giving the wrong version. Even though having one questionnaire for all children is more practical, some children above 10 years found the scale too easy to fill and some of the children less than 8 years needed help from the researcher or the play specialist to complete the questionnaire.

The approach followed to develop the children satisfaction survey was similar to the one used by the PREM Survey for Children 0-16 Years in Urgent and Emergency Care. In that study, a focus group was used followed by interview to test the cognitive ability. For the child satisfaction questionnaire in paediatric dental department, we used direct interview for both stages. The choice of questionnaire and interviews as qualitative method was as a result of the systematic review.

Children’s age and their response to the questionnaire is an important issue. Having only one version for all age group, could make it too hard for younger children to understand or boring for older children. The final version of the questionnaire was most accepted by older children aged above 6 years. Therefore, it is recommended to instruct parents to assist their child for younger children who may need further assistance, but remind them to not lead their child as this will compromise the purpose of the survey.

Time is an important factor to consider when developing a questionnaire. Appointment times range between 9am to 4:30 pm, with some children having to return back to school, so every minute counts.

We are pleased to report that the overall experience was enjoyable for both children and the research team. When children were involved in questionnaire development, their motivation to help, confidence while answering and smiling when giving the questionnaire back to researcher, was evident. There were benefits in involving children for both researcher and participant. As paediatric dentists, dealing with children in situations other than dental chair resulted in more engagement with children. For the child participant, they are likely to be more confident that their opinion matters.

The sample in this study was limited, especially when children were divided into subgroups for results and analysis. A larger sample size is recommended and considered for future research involving multiple paediatric dentistry centres is advisable. When larger sample is to be considered, it is recommended to keep in mind the language of the child. In the paediatric dental department at the Eastman dental hospital, nearly all the children speak and read English fluently even if their parents do not. However, it is possible that the language of the child attending is not English in our department or in any other parts of United Kingdom. Thus, considering different language versions is of high importance in our future work.

This study was successful overall. The final analysis showed that the scale is fit for purpose. This is shown in the response rate we received. We believed that we achieved our aims of creating a survey that can be used in paediatric dentistry departments.

Chapter Four: Future Work and Summary

4.1 Future Work

Research is moving towards more child involvement. Our systematic review displayed the shift in the field. Older children (mostly above 14 years old) are most likely to be represented as co-researchers, as demonstrated by this systematic review.

As a result, more participation of younger age groups is needed until we can determine which are the best methods and/or approaches for child involvement. This is applied specially to dentistry, as other fields like medicine and education appear to have a step ahead in child related research.

To address this, a satisfaction scale to measure child patient's views was developed, using children as co-researchers. When we want to involve children in research design of research, we must ensure children understand what is research, why they should take part? So the first step is to ensure every child and parents have a full understanding of what research means and what the research topic is.

When children are the researchers or the participant, you have to keep in mind two important elements, time and age. The next step is the actual participation process. Children are different in their cognitive abilities depending on their age. As a result, multiple factors are in consideration before deciding what is the best method to use at this stage between questionnaire, interview and diaries. researcher skills and ability to extract information from the child is an indicator to use interview.

Finally, for children to feel this is real and useful, they must know what the results are and how their contribution helped. It is the adult researcher's responsibility to feedback the result, so children will agree to take part again and give positive feedback to their peers, which leads to more involvement of children in research.

From this review, a combination of two methods; focus group or interview, followed by questionnaire was found to be the most successful way to engage children in research.

The paediatric dental department at the Eastman Dental Hospital is moving location as a part of the whole hospital move in 2017-2018. The department is still in the planning stage and modifications are still possible. Waiting areas matter to the children patients and for young children (age below 8 years of age), more toys and games should be available. More importantly, these should be current, such as iPad and playstation with games for boys and girls. Very young children like toddlers need more areas to play and suitable safe toys. These resources need to be available at times when the department is crowded.

For older children between 8-10 years old, video games and age appropriate toys (e.g. Lego) need to be available, as well as suitable books and magazines. For teenagers, they feel the department is too childish for them, Not only because of the children themes and wall pictures, but being surrounded by younger children playing. Ideally their waiting area should be slightly separate from young children, with free Wi-Fi internet.

In summary for paediatric dentistry department:

1. More toys and games in the waiting area
2. To include more books in the waiting area especially those suitable for older children
3. To inform children about the expected waiting time
4. More current technology, such as iPads
5. To involve children in more explanation and demonstration of dental procedure

4.2 Summary

Very few published studies discuss the involvement of children in research. Furthermore, research studies related directly to children should be done by or with children rather than on them. The children satisfaction questionnaire is a reliable tool, developed with the help of children to evaluate the service and care provided in the paediatric dentistry department. Overall, children reported positively to the study but further research is needed to validate the questionnaire.

Chapter Five:
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Chapter Six:
Appendices

Project registration form

Received by Clinical Governance: ☐

1 Eastman Dental Hospital Clinical Audit - Project Registration Form

Project Title: Children Satisfaction Survey		
Start Date: June 2015	**Expected End Date: September 2015**	**Department: Paediatric Dentistry**
Project Lead: Abdulfatah Alazmah Urshla Devalia Paul Ashley Susan Parekh	**E-mail: rmhvlaz@ucl.ac.uk** urshla.devalia@uclh.nhs.uk P.ashley@ucl.ac.uk S.parekh@ucl.ac.uk	**Phone: 07938682357**
✓ **Approved by Departmental Audit Lead (__Isabelle Holroyd_____)**	✓ **Approved by Departmental Clinical Lead (_Amanda O'Donnell____)**	

Other Personnel Involved (please include contact details)**:**

Abdulfatah Alazmah (rmhvlaz@ucl.ac.uk)

Reasons for audit:
(*e.g.* It is thought that practise can be improved; Response to feedback/complaint; validation against recently published guidlelines; Recent changes in law, etc.)

To determine the level of satisfaction amongst paediatric patients in the Department of Paediatric Dentistry.

To identify areas for improvement in service provision and positive aspects of care provided by the Paediatric Dental team.

Aims and objectives with an overview of the project:

To determine the current levels of satisfaction amongst paediatric patients in the Department of Paediatric Dentistry– by - asking children to complete a questionnaire with questions covering multiple aspects of the Paediatric Dental Service.

Standards:
This is what your audit will measure your current activity against (e.g. 90% of patients are seen within 10 minutes of their appointment time; Failure of an implant is defined as…etc.)

100% satisfaction in all areas.

Materials and method for measuring against standards (include sample size & timescale):
(*e.g.* A questionnaire to be completed prospectively by the clinician/patient; Patient interview)

Sample – Initially - All paediatric patients attending the department over a one month time period will be asked to complete the questionnaire.

After designing a preform considering important aspect for children using face to face interview method to involve them in designing stage. A pilot study of ten questionnaires will be completed prior to commencing the survey. Aim for 100 forms.

Then Children will be asked to complete the questionnaire before the appointment and to place the questionnaire in a designated box to ensure anonymity.

Results will be transferred to a data base and then analysed and presented at the departmental monthly governance meeting & actioned as per averages of the audit.

Interdepartmental audit:	☐ **X No**	☐ **Yes,** specify departments**:**	
Multi-professional audit:	☐ **X No**	☐ **Yes,** specify professions**:**	
Type of audit project:	☐ **Structure**	☐ **Process**	☐ **X Outcome**
Scope of audit project: (tick one or more)	☐ **National**	☐ **Regional**	☐ **X Local**
Does this project link with research?	☐ **X No**	☐ **Yes,** give details**:**	
Does this project link with the clinical audit priorities in the annual report?	☐ **No** If No, please give good reason for audit:	☐ **X Yes**, please specify: **Patient satisfaction**	
Audit Office support required: (*e.g.* project design, database creation, Formic)	☐ **No**	☐ **X Yes,** please specify**:** Data analysis	

2 Guidance Notes

The audit project you undertake can be part of the local audit, hospital wide or national audit programmes.

3 Types of Audit Project

Structure (What you need): Structure standards refer to the resources required. They may include the numbers of staff and skill mix, organisational arrangements, and the provision of equipment and physical space.

Process (What you do): Process standards refer to the actions and decisions taken by practitioners together with users. These actions may include communication, assessment, education, investigations, prescribing, surgical and other therapeutic interventions, evaluation and documentation.

Outcome (What you expect): Outcome standards are typically measures of the physical or behavioural response to an intervention, reported health status, and level of knowledge and satisfaction.

4 Clinical Governance Office Support

The Clinical Governance Office offers a wide range of support. For more information, or if you are unsure about any aspect of your audit, please do not hesitate to contact Will Van der Byl who will be happy to assist. Please also see the audit information guide: *'Clinical Audit Protocols,'* and the audit pages on Insight: http://insight/departments/SpecialistHospitalsBoard/EDH/QualityAssuranceandSafetyEDH/ClinicalAuditEDH/Pages/default.aspx

Registration Process

Once you have completed this form, you should submit it along with a typed proposal to the Clinical Governance office. If you have already designed any data collection forms you should submit these at the same time (do not worry if you haven't). You should not start your audit at this point.
Your audit proposal should be reviewed by the Clinical Audit Lead in your department and the approved form submitted to the Clinical Governance Office, after which point you may start the audit.

Completion of Audit Project

Once you have completed your audit your Clinical Audit Lead should be informed. A completed audit outcomes form should be submitted to the Clinical Governance office, **along with your audit report and presentation (if present).** The easiest way is to send them electronically via e-mail (.doc, .xls, .pdf, .rtf, .ppt file types preferred) though if this is not possible hardcopies will suffice. There is also an audit outcome form that you **must** complete, including the recommendations. An audit can not be considered complete until all documentation has been submitted to the Clinical Governance office.

Terminating an Audit

If for some reason you are unable to complete an audit, or an audit is placed on hold, please inform the Clinical Governance Office as soon as possible along with the reasons why you are unable to complete the audit.

Implementation of Recommendations

The Clinical Governance Office should be kept informed of any recommendations made as a result of an audit, and the progress (or otherwise) in implementing these recommendations. A record is kept of all recommendations and progress toward their implementation is monitored regularly. An implementation tracking form is included as part of the Audit Outcomes form.

Checklist

To ensure approval of your audit as quickly as possible please ensure you have done the following:

- Completed the registration form and set the standards.
- Defined any terms where necessary.
- Ensured you are collecting appropriate data to allow measurement of activity and comparison against the standard.
- Completed a typed proposal which must include sample population criteria, the time period of the audit, and a schedule for re-audit.
- Included your contact information.
- Got approval from your Clinical Audit Lead.

Please ensure you do not start your audit before an approved registration form is submitted to the Clinical Governance office.

Data extraction forms of eligible and relative studies:

Study #1

Date: 8 November 2012	*Publication (year/ Vol/ Pages):* Vol 6, issue 2, Nov 2012, pp 193-212
Title: Children as Advisers of Their Researchers: Assuming a Different Status for Children	
Authors: Ferran Casas, Mònica González, Dolors Navarro and Mireia Aligué	
Source / Journal: Children Indicators Research	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* 8,10 and 12 years, the children were all pupils at a semiprivate school. ☐ *Other measure of age:* The choice of ages was made as per the discoveries of the universal international venture ISCWEB (the International Survey of Children's Well-Being); is a worldwide research survey on children's subjective well-being. ☐ *Males vs females:* Both were included
Location/ Setting	Catalonia-Spain, study was situated in the Alt Empordà region of Girona area (Catalonia-Spain) which consented to team up in this examination.
Conflict of interest statement:	☐ **Yes** ☐ No

Funding	☐ *Non-governmental* ☐ Governmental ☐ **The specific institute and source for funding is not clear**
Type of Study	☐ Research with children ☐ **Research by children**
Aim	The specific aims were to explore the preferences of each age group with regard to four aspects relating to the format: • Visual ways of presenting the questions. • The scale used to respond to each question. • The labels used for each response option on the scale. • The direction and degree of the options on the scale for responding to each question. Demonstrate a way of involving children in improving the questionnaire that other children will be asked to respond to in the future.
Inclusion criteria	Children age between 8 -12 years old
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	Agreement with the schools was done prior the beginning of the study.
Data collection	☐ **Prospective** …………………………………………………… ☐ Retrospective ………………………………………………………
Study duration	☐ Days ☐ Weeks ☐ Months ☐ Years ☐ **Not Mentioned**

Sampling technique *(How selected)*	• The study participants comprised 24 children. • The sample selection method was not mentioned.
Research Method	☐ Interview ☐ **Written questionnaire** ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ **Research question development** ☐ Literature Review ☐ **Methodology** ☐ Select research subjects ☐ Data Collection, process and analysis ☐ Questionnaire ☐ No involvement in the study ☐ Others…

How the method selected was used:

<u>First stage: Pilot study (pre-questionnaire)</u>

- Explain that the aim is to improve everything about it.
- Ask for help and advice.

<u>Second Stage: Focus group</u>

in which the children discussed and made alternative suggestions to improve the design of the research instrument. They were presented with a folder with 14 different models in the form of short questionnaires, all with exactly the same questions.

In the questionnaires models, children were made choice between:

A. Visual ways of items:
  - capital letters VS. small case letters
  - one line VS. two lines
  - block VS. box format
  - shade VS. with no shade

B. Scale used to respond to questions • 0-10 • 1-7 • 1-10 • six-options scales without numbers • scales with emotions C. Direction and degree of scale • bipolar • positive unipolar • negative umipolar D. Label of each response • only at the end • on the end and middle value • on all values Scale format: number inside the box or outside, with numbers at the beginning of the block of questions or in each question, with number above or below the response.	
Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ Degree of guardian acceptance and cooperation. ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) …………………………..…………………………….

Results of the study	• When children were asked to help the researchers, they all became impressively cooperative and highly motivated to do both the individual work and the group discussion. They actively tried to find alternative wording and solutions to any difficulty raised. • Adult researchers must be as open as possible to dialogue with children of these ages in order to facilitate their understanding of the questionnaire format and the aims of the research. • It is better to have grouped items than repeat the same question for every item. • Alternative shading of the items makes them easier to follow. • Faces/emoticons are considered to be both attractive and easy to understand. • A few children from each age group reported that it is easier to have each question on only one line.
Future recommendation	• More understanding of unipolar and bipolar at these ages. • Explore what makes questions "easy", "difficult" and "serious"

Study #2

Date: 08 June 2010 (online), Sept 2010	*Publication (year/ Vol/ Pages):* Vol. 46, No. 1-2, Sept 2010, pp 215-227
Title: Children as Research Collaborators: Issues and Reflections from a Mobility Study in Sub-Saharan Africa	
Authors: Gina Porter, Kate Hampshire, Michael Bourdillon, Elsbeth Robson, Alister Munthali, Albert Abane and Mac Mashiri.	
Source / Journal: American Journal of Community Psychology	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* Children up to 18 years old. But the paper concern children under 14. ☐ *Other measure of age:* 70 children, 20 under 14 years ☐ *Males vs females:* 33 girls and 37 boys were included
Location/ Setting	Local school in 3 sub-Saharan African countries: Ghana, Malawi and South Africa, in 2 regions in each country.
Conflict of interest statement:	☐ Yes ☐ **No**
Funding	☐ *Non-governmental* ☐ **Governmental (UK's Economic and Social Research Council and Department for International Development.)**

	☐ The specific institute and source for funding is not clear
Type of Study	☐ Research with children ☐ **Research by children**
Aim	• To provide a base of evidence strong enough to substantially improve transport and mobility related policies and programs for children and young people, with important developmental implications in terms of improved educational and health status. • To explore the significant ethical issues associated with working with young child researchers in sub-Saharan Africa
Inclusion criteria	• In-school children aging up to 18. • 2 Local schools in each region of Ghana, Malawi and South Africa.
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	Not mentioned
Data collection	☐ **Prospective** two-strand kid focused strategy, including both grown-up and tyke scientists ☐ Retrospective …………………………………………………………
Data Analysis	• Simple data analytic techniques done by children researchers, based around observation, interview analysis, counting and ranking. • Writing up their findings as the field work progressed.
Study duration	☐ Days ☐ Weeks ☐ Months ☐ **Years (3 years)** ☐ Not Mentioned

Sampling technique (How selected)	• Recruitment and Training • Selecting and Employing Research Methods Where schools approved the project concept, the collaborators usually visited to present the project to the pupils, who were asked to volunteer to participate. An essay mobility was sometimes set to help select children; which had a clear interest in the research. Parental and school approval for the training and subsequent research period was sought in all cases.
Research Method	☐ **Interview** ☐ Written questionnaire ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ **Diaries** ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ **Research question development** ☐ Literature Review ☐ **Methodology** ☐ Select research subjects ☐ **Data Collection, process and analysis** ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used: Six individual child researcher preparing workshops were held. All strategies were engaged at enhancing understanding of the spots offspring of changing age, sexual orientation and educating status go, how they travel there, and the vehicle issues they face.	

Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ **Degree of guardian acceptance and cooperation.** ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) …………………………..……………………………..
Results of the study	• Child researcher groups findings have fed into and helped shape the wider ongoing adult research program. • the child researchers (of all ages) in all 3 countries were encouragingly positive about their interactions with their adult partners, especially where regular face-to-face contact was feasible. • the younger ones clearly felt they had made significant friendships. • Being on first-name terms from the training workshops onwards helped set the tone of communication. • Boy found it hardest to communicate with young girls • In all 3 countries it was generally observed that children from rural areas were shyer than the urban children in interaction with both their (urban) peers and the adults.
Outcome for the children involved	• Building working relationships across the ages: both children and adults seem to have grown more appreciative of the contributions of the other. • Younger people found interactions with their own age and gender most easy to accomplish. • Children of all ages coped remarkably well with refusals.

Future recommendation	Not mentioned clearly, but it can be withdrawn of the context that: ➢ making payments to all child researchers, irrespective of age, seems to have been widely perceived by the children and their families as an important recognition of the value of the children's contribution. ➢ encourage child researchers to work primarily with those of around their age or younger.
Points from discussion	Nothing to add
Conclusion	Participatory action research with children is an exciting yet potentially perilous adventure for both the adults and the children who take part; for all parties it requires patience, trust and a willingness to take risks.

Study #3

Date: 4 June 2010	*Publication (year/ Vol/ Pages):* Vol 46, issue 1-2, June 2010, pp 195-203
Title: Small Shoes, Big Steps! Empowering Children as Active Researchers	
Authors: Mary Kellett	
Source / Journal: American Journal of Community Psychology	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* ☐ *Other measure of age:* 11-year girl ☐ *Males vs females:* Only girls were included
Location/ Setting	Not mentioned
Conflict of interest statement:	☐ Yes ☐ **No**
Funding	☐ *Non-governmental* ☐ Governmental ☐ **The specific institute and source for funding is not clear**
Type of Study	☐ Research with children ☐ **Research by children**
Aim	To celebrate and value children's own research and includes the full text of an original research study by an 11 year old girl.
Inclusion criteria	Not mentioned
Exclusion criteria	Not mentioned

Ethical measures included	☐ Yes ☐ **No**
Describe ethics	Non done nor needed
Data collection	☐ **Prospective** Stating her life as an experience ☐ Retrospective …………………………………………………………
Data Analysis	Not mentioned
Study duration	☐ Days ☐ Weeks ☐ Months ☐ Years ☐ **Not Mentioned**
Sampling technique (How selected)	Not mentioned
Research Method	☐ Interview ☐ Written questionnaire ☐ Focus Group ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ **Diaries** ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ Literature Review ☐ Methodology ☐ Select research subjects ☐ Data Collection, process and analysis ☐ Questionnaire ☐ No involvement in the study ☐ **Others (The study was done by an 11 year old girl)**
How the method selected was used	Not mentioned

Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ **Degree of guardian acceptance and cooperation.** ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ No ☐ **Yes**. If yes by who? (specify: parent, teacher, etc...) **by university staff**
Results of the study	• With proper training of children in research, this will shift power dynamics toward children driving their own research agendas with support-not management-from adult. • Developing children's sceptical, critical and analytical thinking makes them less vulnerable to media and advertising spin. • Training in research ethics encourages a heightened ethical awareness in other aspects of their lives and an ability to understand others' perspectives and respond to them sensitively. • Enhanced communication skills flow from dissemination of research in oral and written forms. • Including children in research will promote and increase participation in other issues affecting their childhoods which intensifies their own sense of agency and the exercising of their right.
Outcome for the children involved	• the impact that engagement in research has on children's self- development, confidence and agency. • Increase their confidence and self-esteem. • Increase sense of personal worth.
Future recommendation	No future recommendations were stated.

Points from discussion	• There are limitations that have to be acknowledged such as the subjective nature of Manasa's life narrative data and the small scale of her study • The positive embracing of her research in the adult world and the influence it had in bringing about change gives other children confidence to engage in their own research about issues that concern them
Conclusion	This type of child drove research creates profitable information about their lived experiences otherwise inaccessible to adults, knowledge that those who advocate for children's meaningful participation cannot be ignored.

Study #4

Date: 06 January 2010	*Publication (year/ Vol/ Pages):* Val. 16, No. 1, January 2010, pp 55-82
Title: Involving Children in the Design and Development of Research Instruments and Data Collection Procedures: A Case Study in Primary Schools In Northern Ireland.	
Authors: Kellie Turtle, Aisling Mc Elearney and Joanne Scott.	
Source / Journal: Child Care in Practice	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* • 11 children (drawn from Years 5, 6 and 7) • 8 children (drawn from Years 8 and 10) from the school council within a special school • 10 of the participants were female and nine were male. ☐ *Other measure of age:* Age group decision was made following consultation with teachers and school staff in relation to the content and format of the standardised questionnaire instrument. ☐ *Males vs females:* Both were included
Location/ Setting	Primary School in Northern Ireland
Conflict of interest statement:	☐ Yes ☐ **No**

Funding	☐ *Non-governmental* ☐ Governmental ☐ **The specific institute and source for funding is not clear**
Type of Study	☐ **Research with children** ☐ Research by children
Aim	• To provide a detailed description of the process by which children involved in the design and development of a research study. • To identify and explore the key outcomes for the research process and for the children and young people involved.
Inclusion criteria	• School participation in the overall research project and also by school management type. • Children attending schools across the maintained, controlled and integrated management types.
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	Ethical approval for the overall research project was granted by the NSPCC Research Ethics Committee. The methodology was informed by best-practice evidence and standards (NSPCC, 2008) with regard to involving children and young people. Written permission was sought from parents to approach their child with regard to participation. written consent was sought from all participating children. The sessions were carried out within a safeguarding framework.
Data collection	☐ **Prospective** Two stages, the first one to take views about research tools and the second is a feedback stage ☐ Retrospective …………………………………………………………

Data Analysis	• Qualitative content analysis was carried out on the data collected. • Stage One consultation sessions. The analysis was carried out by the NSPCC participation worker who conducted the sessions, first by reading and re-reading the data collected and then by naming the key themes emerging from these data. • A list of recommendations/suggestions representing all of the themes identified was formulated • Qualitative content analysis was also used to analyse the questionnaire data collected from participants at the end of both the Stage One and Stage Two.
Study duration	☐ Days ☐ **Weeks (2 weeks)** ☐ **Months (1 month)** ☐ Years ☐ Not Mentioned
Sampling technique (How selected)	• Purposive sampling strategy was used • 23 schools participating in the overall research project were invited to nominate their school council to be considered for involvement only two replayed, one of them is a special school. • A total of19 children participated.
Research Method	☐ Interview ☐ **Written questionnaire** ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….

At which stage did children get involved in the actual study or where they only subjects in it	☐ **Research question development** ☐ Literature Review ☐ **Methodology** ☐ Select research subjects ☐ Data Collection, process and analysis ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used: First stage: Children (19 in total, across two separate school council groups) sat around a large table, and an informal conversational tone conducive to group work activities was created. Children were engaged in a range of activities in line with the objective of the sessions. Verbal data were recorded on flipcharts by the NSPCC worker, and the children used words and drawings to record data on worksheets and sample questionnaires. Include: Introduction (welcome the groups, stickers name, what is research, agreement and thank them), ice-breaker (by using picture cards) introduce the question (by using flip chart, ‘‘What do children think about keeping safe?’’), questionnaire (Questionnaires are a good way of finding out what people know... I’m going to show you the Keeping Safe questionnaire and ask for your ideas about how we can improve it…Collect at end), photography instruction (thank for helping, by taking photograph we want children …), storing and matching data and evaluation. Stage Two: feedback session The feedback sessions took place approximately six weeks after the consultation sessions. They lasted approximately 20 minutes and took place during the school day with the support of a teaching assistant. They were informed how the information was collated and recommendations were produced. They were then provided with the revised questionnaire and a copy of the photography guidelines, and were supported through the process of tracking changes that had been made in light of their comments and suggestions during the Stage One(introduction, tracking changes, discussion, evaluation and close).	

Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ **Degree of guardian acceptance and cooperation.** ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) …………………………..……………………………..
Results of the study	Presentation of questionnaire • Length is the key issue • recommended the use of color, pictures, graphics • different fonts and symbols should be used • section font was to small and close together. • Structure of the questionnaire: ➢ Participants reported that the questions were generally well-structured. ➢ Some answer format considered more difficult ➢ Some suggested that the order/sections should be in different sequence. ➢ Participants in both school councils welcomed the statement ‘‘you do not need to write your name’’ in the introductory paragraph". ➢ participants identified a number of issues that were important if children were to be safe while participating in this project.

Outcome for the children involved	<u>Stage one:</u> ➢ The majority of children reported having enjoyed the consultation session, 16 out of 19 gives score 5 out 5. ➢ The majority of the children reported feeling listened to during the sessions, 18 gives 5. <u>Stage two:</u> ➢ Being listened to: Twelve out of the 15 participants gave this a rating of 10, the highest possible score. ➢ How I benefited: All of the children provided a rating of 10for how good they felt about being involved in the project.
Future recommendation	The level of participation could have been improved by inviting children into the decision making process at an earlier stage
Points from discussion	• This research study contributes new practice examples of how children can be involved at the design stage of a research project while the majority of studies published to date focus on participation at the stage of data collection (Fleming et al.,2009; Murray, 2006; Tyler et al., 2006) and data analysis (NicGabhainn& Sixsmith,2006). • The research reported here confirms what is proposed by Tisdall and Davis*that children can be ‘‘possessors of indispensable information’’ (2004, p. 136). • This study demonstrated a high standard of participation practice in this regard: the Stage Two feedback sessions to provide feedback to the participants were carried out in line with the NSPCC’s Charter of Participation requiring that adults always feedback what has happened and

	why.
Conclusion	• This study makes a novel contribution to the research literature in this area; in terms of the high standard of participation practice documented and described, which yielded clear outcomes for the design stage of the research process. • This research has implications for the development of practice and policy, particularly at this time when there is a concerted strategic drive to improve practice.

Study #5

Date: 26 March 2008	*Publication (year/ Vol/ Pages):* 11:112
Title: Survey Design From the Ground Up Collaboratively Creating the Toronto Teen Survey	
Authors: Sarah Flicker	
Source / Journal: Health Promot Pract	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* 13-17 first stage (n=12). 4 of them continued to second stage with an additional 16 more (20 in total). ☐ *Other measure of age:* Recruitment from partner agencies within the city of Toronto ☐ *Males vs females:* both were included (2 M and 10 F)
Location/ Setting	• Toronto, Canada • Community youth group settings • The setting for sessions was informal, youth friendly, and located near a major subway line.
Conflict of interest statement:	☐ **Yes** ☐ No
Funding	☐ *Non-governmental* ☐ **Governmental** ☐ The specific institute and source for funding is not clear

Type of Study	☐ Research with children ☐ **Research by children**
Aim	• To gather information on the accessibility and relevance of sexual health services for diverse groups of urban youth. • The goal of the YAC was to take the lead in developing a youth-friendly survey and study protocol. I AND partner closely with young people in the development of our survey tools and research protocols.
Inclusion criteria	Comprehensive and open enlistment systems were utilized
Exclusion criteria	People above age of 17 was allow to fill the application but they were not included in the analysis.
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	• Agency management and an academic partner were present at each interview. • Consent procedure.
Data collection	☐ **Prospective** ………………………………………………………… ☐ Retrospective …………………………………………………………
Data Analysis	Not mentioned
Study duration	☐ Days ☐ Weeks ☐ Months ☐ Years ☐ **Not Mentioned**
Sampling technique (How selected)	**By Youth Advisory Committees:** Using the partners' respective experience with standard survey design methods and previous work with youth, the team merged their understanding toward a participatory youth-driven survey design

<table>
<tr><td></td><td>model.</td></tr>
<tr><td>*Research Method*</td><td>☐ Interview
☐ **Written questionnaire**
☐ **Focus Group**
☐ Pictures, cards and drawing
☐ YES or NO questions
☐ Diaries
☐ Treatment (specify)…
☐ Others….</td></tr>
<tr><td>*At which stage did children get involved in the actual study or where they only subjects in it*</td><td>☐ **Research question development**
☐ Literature Review
☐ **Methodology**
☐ Select research subjects
☐ Data Collection, process and analysis
☐ Questionnaire
☐ No involvement in the study
☐ Others…</td></tr>
<tr><td colspan="2">*How the method selected was used:*
Interventions are more likely to succeed if they involve youth in a manner that stimulates learning.
Pilot study was done first include two youth group.

First stage: the youth might individually complete a series of draft survey questions developed in the previous
session and then discuss how respondents might interpret them as a group.
break into smaller groups to discuss a case study on a relevant scenario involving a young person attempting to access sexual health services.
The youth were provided with general topic areas of interest to the hosting organization and investigator team but were also asked to supplement these general concepts with their own areas of interest

Stage Two: Copies of the survey were sent to 12 key stakeholders at a variety of community organizations serving particular youth subpopulations.</td></tr>
</table>

Service providers were asked to comment on the survey and provide feedback on issues of diversity, inclusion, and equity. Simultaneously, the survey was piloted with youth groups in a variety of community settings.	
Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ Degree of guardian acceptance and cooperation. ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) …………………………..……………………………..
Results of the study	• The question "To which ethnic or cultural group(s) do you belong, if any? (Please check all that apply)" incited much discussion about inclusion/exclusion criteria. • Youth are not always familiar with terms that professionals take for granted. • Question that proved problematic was one that involved disability and mental illness. • Researchers felt that the survey would be better received if it were administered by a youth peer researcher.
Outcome for the children involved	• Collaborating with youth improved and challenged the research team's understanding of youth sexual health issues. • The research team was surprised by concerns around commonly asked demographic questions. • Researchers have changed some sensitive words that might be misunderstood by young people.
Future recommendation	• Youth work is vital for fruitful youth engagement. • Having a researcher who ability in gathering process. • The research group likewise battled with pressures

	identified with the amount of preparing the adolescent ought to be given. - Importance of ethical consideration. - Importance of youth reflection of the session.
Points from discussion	- Benefits to both youth and society when young people are provided with opportunities to contribute to policy development. - Including youth as core searchers demands a higher investment of human and financial resources.
Conclusion	No conclusion mentioned

Study #6

Date: 22 August 2012	*Publication (year/ Vol/ Pages):* 12/143
Title: The management of dental caries in primary teeth - involving service providers and users in the design of a trial.	
Authors: Zoe marshman, Nicola Innes, Chris Deery, Melanie Hall, Chris Speed, Gail Douglas, Jan Clarkson and Helen Rodd	
Source / Journal: Trials Journal	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ *Age range:* • 17 dental team member (adults) • Children 4-8 years old. • 4 parents (face interview) • 5 parents (telephone interview) ☐ *Other measure of age:* ☐ *Males vs females:* Both were included
Location/ Setting	• United Kingdom • Children were interviewed at their home • Interviews with dental specialists and dental colleagues were completed in gatherings or independently at once and venue helpful to them, either in their dental practices, in the neighborhood dental school or at the dental specialists' homes.
Conflict of interest statement:	☐ **Yes** ☐ No

Funding	☐ *Non-governmental* ☐ **Governmental** ☐ The specific institute and source for funding is not clear
Type of Study	☐ **Research with children** ☐ **Research by children**
Aim	To describe service providers' and users' perspectives on the FiCTION pilot trial to improve the design and conduct of the FiCTION main trial
Inclusion criteria	Not mentioned
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	• Written consent was gotten. • Pseudonyms were utilized to guarantee classification. • Ethical approval was gotten from NHS Forth Valley Research Ethics Committee (NRES reference 10/S1402/8) and research governance approval was obtained.
Data collection	☐ **Prospective** …………………………………………………… ☐ Retrospective ………………………………………………………
Data Analysis	• All interviews were audio-recorded and transcribed verbatim with transcription carried out as soon as possible after the interviews to allow the data to be analyzed as it was collected. • Accounts, framework analysis was conducted to improve external validity, three researchers were involved in the analysis and interpretation of the data.
Study duration	☐ Days ☐ Weeks ☐ **Months** (the allocation Tx was provided and reviewed after 3-6 month)

	☐ Years ☐ Not Mentioned
Sampling technique (How selected)	Randomization was directed through an web-based office keep running by the clinical trials unit. The distributed treatment was given and surveyed following three to six months
Research Method	☐ **Interview** ☐ Written questionnaire ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ Literature Review ☐ **Methodology** ☐ Select research subjects ☐ Data Collection, process and analysis ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used: Individual interviews were held with four dentists and a group interview was held with 17 dental team members. Face-to-face interviews were held with four parents and children (four- to eight-years old) representing the three arms of the trial and five telephone interviews were conducted with parents. All interviews were transcribed verbatim. Framework analysis was used. *Pilot:* The pilot trial was conducted in three areas in the UK involving 11 practices (20 dentists) working in purposively selected primary care dental practices. Dentists were asked to send project information sheets to potential participants, within the correct age range (three to seven years). at the time of their recall appointment.	

At this appointment, children assessed as eligible were invited to participate and consent was obtained. *Study:* Data saturation was achieved after individual interviews were held with four dentists (from three different practices) and a group interview was conducted with an additional 17dental team members (ten dentists, two nurses and two practice managers) representing a further six practices. A flexible approach was taken to ensure participants were encouraged to introduce their own topics about the design and conduct of the trial and any contradictory views probed.	
Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ **Degree of guardian acceptance and cooperation.** ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) …………………………..………………………………..
Results of the study	• The results are presented as the themes that emerged from the data rather than preconceived ideas. Quotes are used to support and illustrate points. • Results was divided in five group and our concern is the children involvement.
Outcome for the children involved	• Children were able to describe their perspectives on being involved in the study. While some of the older children understood what a study was, • Others did not understand and were not aware, or did not remember, that they were enrolled. Those who were aware of their involvement enjoyed being asked to sign their names on the consent form and were familiar with the smiley face response format used in questionnaires

Future recommendation	• A factor not previously reported in the dental literature was the recommendation for recruitment of whole practices with participation of all members of the practice team rather than individual practitioners. • The main recommendation regarding training and support was the format of the practice trial documentation. • Findings of this study suggest that improvements should be made to the explanations given to children about the trial and also to parents on the effectiveness of the treatments in the trial.
Points from discussion	Overall service providers, children and parents found the pilot trial to be well conducted and an interesting experience and they were able to provide valuable recommendations.
Conclusion	• Overall, more research is needed into existing barriers to involving patients and the public in dental research and exploration of approaches to improve their involvement. • limited number of children involved in this study did not allow full exploration of children's experiences of the different interventions • The findings have provided valuable recommendations and are being used to refine the main trial and improve the recruitment of dental practices and patients, training and support for dentists and engagement of children and parents

Article #7

Date: 2012	Publication (year/ Vol/ Pages): 2012, 20(2), pp. 169–184
Title: Towards a creative synthesis of participant observation and participatory research: Reflections on doing research with and on young Bhutanese refugees in Nepal	
Authors: Rosalind Evans	
Source / Journal: Childhood	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ Age range: 14-17 years old. ☐ Other measure of age: not mentioned ☐ Males vs females: 7 girls and 6 boys were included
Location/ Setting	In a refugee camp managed by United Nations High Commissioner for Refugees and Nepal government Nepal
Conflict of interest statement:	☐ Yes ☐ **No**
Funding	☐ Non-governmental ☐ **Governmental** ☐ The specific institute and source for funding is not clear
Type of Study	☐ **Research with children** ☐ **Research by children**

Aim	This article reflects on Wright and Nelson's (1995) assertion that a 'creative synthesis' of participant observation and participatory research may lead to a more theoretically dynamic and active social science. This is accomplished by examining the influence of using this approach in research *on and with* young Bhutanese refugees in Nepal.
Inclusion criteria	Not mentioned
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	Ethics was done and monitor by the adult research assistant and local authority.
Data collection	☐ **Prospective**: ……………………………………………………… ☐ Retrospective: ………………………………………………………
Data Analysis	The data were analyzed directly by the adult researcher and the research assistant.
Study duration	☐ Days ☐ Weeks ☐ **Months 11 month** ☐ Years ☐ Not Mentioned
Sampling technique (How selected)	• First stage:13 children aged 14-17 • Second stage: 29 children aged 12-17 • All are refugees children live in a seven different refugee camp in Nepal.
Research Method	☐ **Interview** ☐ Written questionnaire ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries

	☐ Treatment (specify)… ☐ **Others….** ➢ Group discussion ➢ Drawing, essay writing, observation and photography
At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ Literature Review ☐ **Methodology** ☐ Select research subjects ☐ **Data Collection, process and analysis** ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used: It was accomplished through two field trips, he used participation observation on his first trip one using a day-to-day activity. During both fieldtrips the researcher organised training and support to permit young refugees to conduct their own research by building long-term relations with a small group of young people through an combined approach of ethnographic and young person-led research methods, which allowed the collection of qualitative data on young people's political learning and decision-making. The participants discussed issues affecting children and selected four topics: school drop-outs, domestic violence, the impact of the BRCF and early marriage.	
Outcome measure	☐ Degree of involvement. ☐ Degree of child's acceptance and cooperation. ☐ Degree of guardian acceptance and cooperation. ☐ **Other, children were subjects in the research where no involvement occurred**
Was any help given to children when designing or conducting the research	☐ No ☐ **Yes. If yes by who? (specify: parent, teacher, etc...)**

	Adult research assistants
Results of the study	As is common in participatory research, the results were used to provide break interventions for refugee children, including material aid for certain families and social activities aiming marginalized young people, engaging ethnographic methods that allows a better understanding of refugee children's daily lives, activities and hopes beyond their arrangement in agency-sponsored social activism
Outcome for the children involved	• Some advantages were gained by the young refugee's feedback; some like making new friends, building confidence and public-speaking skills, improved knowledge of children's rights, more admiration from community members and enhanced communication skills. • The young people were recognised by having particular skills to be requested to be involved in more research project. Following their research, some young refugees engaged in activities to help disadvantaged children
Future recommendation	The young refugees proposed further research by children on a wider range of issues in all seven camps, where this will be beneficial.
Points from discussion	Nothing to add

Conclusion	Providing opportunities for young refugees to collaborate in this research allowed individuals to progress new skills and allowed examination of issues relevant to the BRCF’s activities. Although the combination of participant observation and participatory research had some positive impacts on the research process and outcomes, it is doubtful whether this fusion adequately addressed either the issue of participants

Article #8

Date: 2011	Publication (year/ Vol/ Pages): 2011, 19(1), pp. 129–144
Title: Children's rights and research processes: Assisting children to (in) formed views	
Authors: Laura Lundy and Lesley McEvoy	
Source / Journal: Childhood	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ Age range: 10-11 years old. ☐ Other measure of age: not mentioned ☐ Males vs females: Both
Location/ Setting	Primary schools in England and Wales
Conflict of interest statement:	☐ Yes ☐ **No**
Funding	☐ Non-governmental ☐ **Governmental** ☐ The specific institute and source for funding is not clear
Type of Study	☐ Research with children ☐ **Research by children**

Aim	• To discover children's and teachers' perspectives on the use of a range of e-consultation tools. The e-consultation tools explored encompassed: an online survey; chat rooms; interactive storyboard • The founding of Children's Research Advisory Groups (CRAGs) who worked alongside the adult researchers as co-researchers. • To discover children's and parents' perspectives on science assessment in primary schools in England and Wales
Inclusion criteria	Not mentioned
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	Done by university committee. The key ethical principles of informed consent and voluntary participation, emphasized in ethical protocol.
Data collection	☐ **Prospective**: Surveys were sent electronically ☐ Retrospective: …………………………………………………………
Data Analysis	Not mentioned
Study duration	☐ Days ☐ Weeks ☐ Months ☐ Years ☐ **Not Mentioned**
Sampling technique (How selected)	Not mentioned

Research Method	☐ Interview ☐ Written questionnaire ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….
At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ **Literature Review** ☐ **Methodology** ☐ Select research subjects ☐ **Data Collection, process and analysis** ☐ Questionnaire ☐ No involvement in the study ☐ Others…

How the method selected was used:
A rights-based approach adopted in these projects.

The 'bespoke' capacity building strategies was established for each of the projects (arts-based activities, individual reflection, paired and small group discussions, sorting and ranking activities).

Stage One: children's advice on the research process including the best way to engage with other children on the topics; contribution with the analysis and interpretation of the findings; giving insight on the main issues underneath investigation; and recognizing potential solutions which might address some of the issues identified by the research.

Stage Two: evaluating participant response. Each CRAG was supplied with a large number of cards containing answers from the participants and asked to group these into groups based on any similarities they noticed between the responses of children involved in interpretation of data.

Outcome measure	☐ **Degree of involvement.** ☐ Degree of child's acceptance and cooperation. ☐ Degree of guardian acceptance and cooperation. ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) ……………………………………
Results of the study	• This has given the children's confidence to engage with the research. Most of comments from CRAG children made direct reference to 'increased confidence' as a result of the bulk building sessions. • The children showed that this approach maintained them in engaging with other aspects of the research • The additional vision resulting from capacity building also assists CRAGs in the interpretation of data
Outcome for the children involved	• Participants indicated that they had profited from assistance in forming views. • They were amused by reading other children's views on the issues, this helped them in creating their own opinions. • Assisting children in forming views had increased their confidence in answering research questions.
Future recommendation	Non
Points from discussion	Focus groups carried out with children who had contributed in the 'E-consultation' study, children identified that first, they enjoyed reading other children's views on the issues and that this assisted them in forming their personal views.

Conclusion	• The conceptualization of the approach which combines CRC provisions into a framework for confirming that children being part in research studies are assisted in developing their views • Children are not only allowed to have their views given due weight in research studies but that the adults working with them ensure that their participation is compliant. • From a children’s rights perspective, a key benefit of this approach is that it does not exclude children from being involved in research projects outside their immediate experience as prearranged by adult gatekeepers.

Article #9

Date: 2010	Publication (year/ Vol/ Pages): 2010, 17(3), pp. 360–375
Title: Power, agency and participatory agendas: A critical exploration of young people's engagement in participative qualitative research	
Authors: Sally Holland, Emma Renold, Nicola J. Ross and Alexandra Hillman	
Source / Journal: Childhood	
Eligibility	
Is it Health Related	☐**Yes** ☐ No
Is the aim of all (or part) the study to involve children in the design/conduct of research or the development of research ideas (i.e. research with children or research by children?)	☐**Yes** ☐ No
Study Eligible	☐**Yes** ☐ No
General	
Demographics	☐ Age range: 10-20 years old. ☐ Other measure of age: all referred by their social workers ☐ Males vs females: 6 girls and 2 boys.
Location/ Setting	Cardiff University
Conflict of interest statement:	☐ Yes ☐ **No**
Funding	☐ Non-governmental ☐ **Governmental** ☐ The specific institute and source for funding is not clear
Type of Study	☐ Research with children ☐ **Research by children**
	• Main substantive research inquiry was intentionally expansive to empower the youngsters to take a lead in selecting which parts of their lives they wished to

Aim	investigate. • They wished to find the ethical and expository issues raised and tested by permitting youthful members to pick and characterize their own particular method for representation.
Inclusion criteria	Not mentioned
Exclusion criteria	Not mentioned
Ethical measures included	☐ **Yes** ☐ No
Describe ethics	All were referred by their social workers, a situation requested by the relevant local authority, and consent for participation was given by an adult with parental responsibility.
Data collection	☐ **Prospective**: …………………………………………………………… ☐ Retrospective: ……………………………………………………………
Data Analysis	Cross-‘case’ analysis was carried out with the use of Atlas ti (qualitative analysis software)
Study duration	☐ Days ☐ Weeks ☐ Months ☐ **Years (2 years)** ☐ Not Mentioned
Sampling technique (How selected)	Not mentioned
Research Method	☐ Interview ☐ Written questionnaire ☐ **Focus Group** ☐ Pictures, cards and drawing ☐ YES or NO questions ☐ Diaries ☐ Treatment (specify)… ☐ Others….

At which stage did children get involved in the actual study or where they only subjects in it	☐ Research question development ☐ Literature Review ☐ Methodology ☐ Select research subjects ☐ **Data Collection, process and analysis** ☐ Questionnaire ☐ No involvement in the study ☐ Others…
How the method selected was used: Multi-media data generation methods at main fieldwork stage Free flowing and unplanned generation technique. The project was clarified to potential participants over a set of accessible information leaflets and a DVD, which elucidated both the purpose of the project and the possible data generation methods. Themes associated to each young person’s everyday life were made and shared and then developed with the young person. Data were then coded according to these themes. Data generation evolved through young people’s patterns of talking and recording. This was often on the move, in short bursts, and in fast-moving conversations Each of the young people were revealed with the key themes that were drawn out from our initial analysis of their separate data, following the main stage of fieldwork. This was completed using diagrams and photographs, verbally or in a written form depending on the participant.	
Outcome measure	☐ **Degree of involvement.** ☐ **Degree of child's acceptance and cooperation.** ☐ Degree of guardian acceptance and cooperation. ☐ Other, children were subjects in the research where no involvement occurred
Was any help given to children when designing or conducting the research	☐ **No** ☐ Yes. If yes by who? (specify: parent, teacher, etc...) ……………………………………

Results of the study	• Involving children in analysis proposes that it is an undeniable a 'good thing' • There are many rewards to such involvement, including a potential enhancement of our understanding of children's lives, and an ethical-political motivation to engage children throughout the research process rather than just as providers of data.
Outcome for the children involved	• Visual data, such as scores of photographs and videos, mainly produced by the young people independently, gave rich insights into their everyday routines. • A key obstacle in engaging young people in analysis was confidentiality. • They brought together participants who would not normally meet together, and it changes from focus groups in that there was little formal direction by researchers.
Future recommendation	• The lack of privacy over personal data also suggest that the analysis of the entire data set by participants was ethically impracticable. • It is very resource intensive for a small number of participants and therefore might be hard or unwanted to replicate in its entirety.
Points from discussion	Once in a while, attempts to perform some formal participatory 'techniques' (such as a group discussion evaluating the research towards the end of the project), these were less successful at generating data than more free-flowing, unintended data generation techniques that mimicked more closely the young people's everyday means of communication. It is clear that just spending time together enabled relationship building between the participants.

Conclusion	• The concern remains in the attempt to deliver participatory aims and objectives that leaves a bad ethical taste. • While working in groups as well as individually best imitated the young people’s preferred modes of communication, and was possibly more authorizing for young people who were able to have fun together it is more vital to pay close attention to how participation is passed than to focus in on how much participation was achieved.