# Consent of older children participating in BASCD coordinated dental epidemiology surveys in Wales.

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New guidance on consent for England and Wales, which has positive consent at its core, has implications for the UK-wide BASCD coordinated dental epidemiology programme. This paper describes a method used in Wales for obtaining consent from older children which is believed to comply with the new guidance. *Objective* The objective was to establish a more robust approach to gaining consent from 12 and 14 year olds taking part in the surveys, by building on existing "negative consent" practice and supplementing it with Gillick competent child consent. *Design and setting* Questionnaire data from the 2002-03 survey of 6,393 13-14 year-old children and the 2004-05 survey of 6,749 11-12 year olds were used in this analysis. Questions specifically designed to establish competency to consent were asked of participating children. These ascertained whether children were happy to proceed and if so, whether they understood the nature and the purpose of the survey and whether they were happy with the outcome. *Results* Ninety-nine percent of those taking part in both survey years were happy to proceed with the examination and questionnaire. Whilst the majority of children, agreeing to take part, indicated that they had understood what was proposed and were happy with the outcome, approximately 15% of these age groups gave answers after the event which indicated that they had not understood either the nature or purpose of the survey. *Conclusion* Use of "Gillick competent" consent in Wales did not affect participation rates adversely. The authors would suggest that indication of assent as used in Wales in these two surveys is appropriate and would only exclude 1% of children. The alternative, of examining only those children who answered questions on whether they understood the nature and purpose of what is proposed prior to assenting, would exclude 15% of children.

Key words: Consent, dental surveys, epidemiology

# **Background**

The law on consent in relation to medical and dental inspections and treatment in the school setting is particularly complex. The phrase used in the legal documents is dental inspection. This inspection normally consists of a visual inspection of the oral cavity and teeth. Within the meaning of the legal phrase "dental inspection" children's teeth have been visually examined for both collection of epidemiological data and for early identification of disease. Within this paper reference to examination refers to the visual examination only of teeth and mouths as part of data collection for epidemiological purposes.

Recent guidance in England (Department of Health, 2006) and Wales (Welsh Health Circular, 2006) requires changes to existing custom and practice regarding consent issues. Experience in Scotland has shown that parental consent by letter at the time of the survey produced unreliable survey results compared with previous surveys (Merrett, personal communication).

In the past, because the dental epidemiology takes place in schools, the programme in England and Wales has been guided by the Education Reform Act 1996 and the preceding 1944 Education Act. The 1996 Act requires local education authorities to:

"make arrangements for encouraging and assisting pupils to take advantage of the provision for medical and dental inspection and treatment" provided that "if the parent of a pupil gives notice to the authority that he objects to the pupil availing himself of any of the provision so made, the pupil shall not be encouraged or assisted to do so." (Education Reform Act 1996 s 520 (2) – Office of Public Sector Information, 2009).

Custom and practice has been for a letter to be sent home in advance of a planned survey and then for the children to have their teeth examined provided a parental refusal had not been received. The phrase "negative consent" was commonly used for these arrangements. The new guidance on consent states that this practice is insufficient and should cease in England and in Wales, and that for children aged 10 or over individual child consent should be sought.

To be valid a consent must be voluntarily given (R v Rosinski, 1824), by a person who can understand and retain information and use and weigh this information on the nature and purpose of what is proposed (Chatterton v Gerson, 1981) including risks of proceeding or not proceeding (Sidaway v Governors of Royal Bethlem Hospital, 1984), before deciding and communicating their decision. It is expected that explanations be given in broad terms and simple language to facilitate understanding (Sidaway v Governors of Royal Bethlem Hospital, 1984). Under the common law parents and guardians may consent to or refuse on behalf of their

children aged under 18. The legal concept of Gillick competence allows children under 16 who have sufficient capacity to consent to medical and dental care they can understand (Gillick v West Norfolk and Wisbech Area Health Authority, 1986). It also allows under 18s the possibility of consenting to matters other than medical and dental treatment including dental surveys. The courts have left to clinical judgment the decision whether or not a young person is competent to make a decision for his or herself (Gillick v West Norfolk and Wisbech Area Health Authority, 1986).

When planning the 2002-03 survey of Welsh 14 year olds during the spring of 2002, four years before the guidance on consent was issued, it was decided that Gillick competent child consent would be used to supplement the existing "negative consent" approach because of two main concerns. Firstly, there had been occasional UK reports of parents complaining that their children were examined without parental consent. Secondly, the existing process did not engage children in the decision process as fully as they could be, and therefore was in conflict with the UN Convention on the Rights of the Child (United Nations, 1989). Furthermore, there was a window of opportunity to test an alternative to "negative consent" before any legal or operational impediment prevented its use.

This paper describes a method used in Wales for the BASCD coordinated surveys in 2002-03 for 13-14 year olds and in 2004-05 for 11-12 year olds using child consent which is believed to comply with the new guidance for seeking child consent.

### Method

Each year childhood epidemiological surveys, coordinated by the British Association for the Study of Community Dentistry are carried out in the UK. The survey in Wales conforms with the BASCD standards for calibration and training (Pine *et al*, 1997). Questionnaire data from the 2002-03 survey of 6,393 13-14 year-old children and the 2004-05 survey of 6,749 11-12 year olds were used in this analysis.

The consent methodology used was designed to build on existing "negative consent" practice and supplement it with Gillick competent child consent. Additionally, it aimed to engage children as fully as possible in the decision process so as to comply with Article 12 of the UN Convention on the Rights of the Child. The approach taken also sought to address all relevant points of consent law in communications with parents and with children. Ethical advice was sought and provided from the All-Wales Multi-centre Research Ethics Committee in planning for both the 2002-03 and 2004-05 surveys.

Because the Education Reform Act 1996 s 520 (2) still applied the new survey process needed to notify parents of an impending survey, giving them an opportunity to withdraw their child and inform them that their child's consent would be sought. Children whose parents had indicated that their child should be excluded were excluded from participating in the decision process.

Standard letters to parents and scripts for use with the children were designed to use simple language on the nature and purpose of the planned survey. Both documents emphasized that participation was voluntary. No mention was made of risks in the documentation, as it was believed that there were no material risks associated with a visual examination of the oral cavity. The letter to parents indicated that their child would be asked to consent to the examination, and asked the parents to notify the school if they believed that their child should not be included. Contact details to deal with queries were also provided.

Before each survey the All Wales Multi-centre Research Ethics Committee were asked to comment. For the 2002-03 survey they recommended that all communications to the parents be sent through the postal system rather than be carried home from school by the children. The Ethics Committee were keen that all parents should be informed so that they could respond on behalf of their child when necessary, for example in relation to decisions about participation by children with learning difficulties. In 2004-05 the Ethics Committee considered similar scripts and letters to parents as had been used in 2002-03. They recommended changes to these to lower the reading age still further including removal of some of the content.

The annual training and calibration exercises which took place in preparation for the 2002-03 and 2004-05 surveys included a session on training in consent law. This was to ensure that the dentists and recorders conducting the survey understood the importance of using the standard scripts and processes. The session covered features of consent law and highlighted the need to respect any notification of parental refusal received in any format, including verbal statements made by a child such as "My mum says you're not to look in my mouth".

On the day of the survey the standard script was read by the dentist providing children with an explanation in broad terms and simple language of the nature and purpose of the survey, indicating that there would be an opportunity to ask questions and telling them that they did not have to co-operate if they did not want to. The dentist would ask each child in turn if they had any questions, after answering any question from the child he or she would ask if the child now understood what had been explained before asking the child if they were happy for the dentist to proceed with the examination. The recorders ensured that the script was read accurately, and that these questions were asked, answered appropriately and the results recorded before the dentist proceeded with the clinical examination.

After the clinical examination was completed children were asked four questions which related to their experience on the day with a request for a yes or no answer to the first three questions and open answer for the fourth:

- Did you understand what the dentist was going to do today?
- Do you understand why the dentist looked at your teeth today?
- Were you happy with the way you were treated today?
- If not why not?

It was intended that the answers to these questions would assist in evaluating the approach intended to generate "Gillick competent" consent, and planning of future surveys.

## Results

Ninety-nine percent of those taking part in both survey years were happy to proceed with the examination and questionnaire; this consisted of 6,388 out of the 6,393 14 year olds taking part in 2002-03 and 6,732 out of 6,749 for the survey of 12 year olds in 2004-05. Of those who were happy to proceed, the majority understood what was going to happen to them and why the dentist was going to look at their teeth. Practically all the children (99.9%) were happy with the way they had been treated (Table 1). During both surveys approximately 10% of children did not appear to understand the nature of the survey, since they responded negatively to the question Did you understand what the dentist was going to do today? Similarly 11.7% and 13.8% of 14 and 12 year old children respectively did not appear to understand the purpose of the survey. They gave a negative response to the question Do you understand why the dentist looked at your teeth today? (Table 1).

A total of 14 children said that they were unhappy with the way they had been treated (Table 1). During the 2002-03 survey of 14 year olds three out of the four children who were unhappy gave a reason for this; one child did not like the safety glasses, another had missed their favourite lesson and the remaining child indicated that no one had explained what was being recorded. Ten 12 year olds said that there were unhappy, three gave reasons for this, two said they "did not like dentists" and another indicated that "the gloves were smelly".

86.1% (5,498/6,388) and 83.2% (5,598/6,732) of 14 and 12 year olds surveyed in 2002-03 and 2004-05 respectively answered "Yes" to the two questions which focused on the nature and the purpose of the process, i.e., the children understood both what was going to happen to them and why. A further, 7.5% (479/6,388) and 6.8% (461/6,732) of 14 and 12 year olds answered "No" to both questions, whilst a noteworthy percentage of children responded positively to one question and negatively to the other, i.e. 5.7% (363) of 14 year olds and 9.9% (664) of 12 year olds (Tables 2 and 3).

On the basis of the information provided it would appear that the great majority of children indicated that they had understood what was proposed and were happy with the outcome. However approximately 15% of these age groups gave answers after the event which indicated that they had not understood either the nature or purpose of the survey.

#### Discussion

Testing of capacity is part of clinical practice but to date there has been little guidance upon this aspect of care. Clearly somewhere between being a newborn child and adulthood capacity is something we acquire. The law has long recognized that ability to consent to different things is acquired with increasing maturity, but not for all things at the same time.

For adults in England and Wales the law assumes capacity and the Mental Capacity Act 2005 (Department of Constitutional Affairs, 2005) which came into force on 1<sup>st</sup> April 2007 defines a functional test of capacity. An adult lacks capacity if he or she is unable to:

- Understand information relevant to decision
- Retain that information
- Use and weigh that information in making a decision
- Communicate their decision.

Adults have the right to make unwise decisions. Under English and Welsh law children are presumed to lack capacity. Ideally the test should use the same criteria as are used for adults. The problem for the clinician is there is little guidance on how to test using these criteria.

The clinicians undertaking the BASCD co-ordinated surveys in future will need to use their clinical judgement to assess the mental competence of children they seek consent from. The law gives little guidance on how to do this. The law does recognise that the level of mental competence to make a simple decision with no associated risks is less than that required to make a more complex decision, especially where important consequences can result from one or more of the available choices. Arguably the decision to participate in a dental survey involving visual examination of the teeth is a simple choice without serious consequences from participating or not participating. Thus it can be argued that if a child aged 10 or older expresses a decision there is little reason to

Table 1. Percentage response to questions used to ascertain consent

Survey	Total (n)	Happy to proceed (n)*	Did not understand what the dentist was going to do		Did not understand <b>why</b> the dentist looked at teeth		Unhappy with the way they were treated	
		-	%	n	%	n	%	n
14 year olds 2002-03	6393	6388	9.0	574	11.7	747	0.1	4
12 year olds 2004-05	6749	6732	10.0	676	13.8	925	0.1	10

<sup>\*</sup>The numbers of 14 and 12 year old children "Happy to proceed" were used as the denominators for the percentages included in this table.

Table 2. A comparison of responses to questions concerning the nature and purpose of the survey - 14 year olds 2002-03

		Do you understand <i>why</i> the dentist looked at your teeth today? (PURPOSE)				
		Yes	No	Did not answer	Total	
Dil a subsect of a feet	Yes	5498	268	1	5767	
Did you understand <i>what</i> the dentist was going to do	No	95	479	0	574	
today? (NATURE)	Did not answer	45	0	2	47	
	Total	5638	747	3	6388	

**Table 3.** Comparison of responses to questions concerning the nature and purpose of the survey - 12 year olds 2004-05

		Do you u	Do you understand <i>why</i> the dentist looked at your teeth today? (PURPOSE)				
		Yes	No	Did not answer	Total		
Did a subsect of other	Yes	5598	457	1	6056		
Did you understand <i>what</i> the dentist was going to do	No	207	461	0	668		
today? (NATURE)	Did not answer	2	2	4	8		
	Total	5807	920	5	6732		

challenge that decision by further questioning to check understanding, retention of information or how they weighed that information.

The alternative approach would be to ask each child detailed questions on whether they have understood what is proposed and why it is being done and receiving affirmative answers to these questions before asking permission to proceed with the examination. Examining only those children who answered questions on whether they understood the nature and purpose of what is proposed prior to assenting, would exclude 15% of children from the survey process. Further analysis of the Welsh data will be required to quantify what impact, if any, this would have on DMFT scores, however it is possible this could significantly impact on mean DMFT scores if there is a relationship between lack of understanding and social class.

For the purpose of this survey any decision made by a child was respected. This does not mean that all of the children who made a decision were "Gillick competent", but that in expressing a decision it appeared that they had understood, retained, weighed and used information. In coming to a decision they did not demonstrate that they were not "Gillick competent".

Only 15% of the children examined in Wales gave answers after they had been examined which suggested that they may not have understood either the nature or purpose of what had been explained to them despite an opportunity to ask questions. While this may indicate that they did not have a high level of understanding of what they then agreed to, it does not mean they were

automatically lacking sufficient capacity to consent to a simple visual examination of their teeth. In the absence of alternative legal or professional guidance to the contrary it may be that for a simple visual dental examination the ability of a child to listen to an explanation, and to express a preference to being or not being examined may be sufficient expression of capacity to judge the child competent to consent to or refuse that examination.

The examining dentist who provides an explanation, offers an opportunity for questions and asks whether a child aged 10 or more whether they are happy for the examination to proceed should use that exchange as the basis of their assessment of capacity. If the child expresses a view they should respect that view. If the child cannot express a view then they may be demonstrating an inability to make a decision and therefore be regarded as lacking the capacity to consent. In the absence for formal consent from another such as a parent they should not examine that child.

#### **Conclusions**

The use of "Gillick competent" consent in Wales as described in this paper did not affect participation rates adversely. There are uncertainties over how examining dentists should judge competence of children who are asked to consent to participating in epidemiological studies such as BASCD coordinated surveys. The law presumes that children are not competent and leaves it to the examining dentist to judge competence. In England

and Wales the Mental Capacity Act covers adult mental capacity, but it does offer a potential framework for judging competence in children. The fact that decision on participation in a BASCD survey offers no great risk or benefit to the individual means a low level of competence is appropriate.

The evidence collected in Wales suggests that the great majority of 13-14 and 11-12 year old children examined in 2002-03 and 2004-05 respectively, showed little evidence that they were not "Gillick competent" to consent to participate in a BASCD co-ordinated survey. The authors would suggest that indication of assent as used in Wales in these two surveys is appropriate and would only exclude 1% of children. The alternative of only including children who indicated that they understood the nature and purpose of what is proposed prior to assenting would exclude 15% of children and the impact of this on DMFT scores is yet to be established.

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