Trends in childrens' ability to consent to a dental examination and the potential impact on reported caries indices

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New guidance on consent for England and Wales suggests that children aged over 11 should be asked to consent to the NHS child dental survey examinations. If they are "Gillick competent" then they can provide consent. Whether they are "Gillick competent" is a matter of clinical judgment of the examining dentist. This paper explores the level of understanding expressed after the examination by children apparently "Gillick competent". It considers issues how a dentist judges a child competent to make a decision to participate in a dental survey. Objective: The objective of this investigation was to examine the possible impact on reported DMFT indicators if children who have not fully understood an explanation of the nature and purpose of the survey could be identified by further questioning and excluded from the survey. This information will be helpful in making a decision on an appropriate threshold of competence used when obtaining consent from children participating in these NHS coordinated child dental surveys. Design and setting: Questionnaire data from the 2002/3 survey of 6,393 13-14 year-old children and the 2004/5 survey of 6,749 11-12 year olds were used. Questions were asked of participating children post-examination. The children were asked if they had actually understood the explanation provided before the examination of what was to be done and why. This information together with the NHS child dental DMFT data was analysed. Results: Approximately 15% of children in these age groups gave answers after the event which indicated that they had not understood either the nature or purpose of the survey. Deprived children were less likely to have understood an explanation and among 12 year olds the children who did not understand were more likely to have caries. There is potential for a small impact on DMFT indicators if higher thresholds of competence are used in future surveys. Conclusion: If different approaches to consent are used across England and Wales a small impact on DMFT indicators will result. Guidance on the judgment of capacity as part of the consent process will help to ensure comparability of data. A standard approach on consent method for use in NHS child dental surveys, in particular on how to judge competence, should be agreed.

Key words: Caries, consent, dental surveys, deprivation, DMFT, epidemiology,

Background

Children under 16 who in the opinion of a clinician are "Gillick competent" can consent to medical and dental care they can understand 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. The phrase "Gillick competent" was first used in the legal judgment on the ability of children under sixteen years of age to consent to medical treatment, specifically prescription of the contraceptive pill (Gillick v West Norfolk and Wisbech Area Health Authority, 1986).

To be valid consent must be voluntarily given (R v Rosinski, 1824). To give consent a person must be able to understand and retain information, and to weigh this information before making a decision and communicating it. The information which needs to be provided includes the nature and purpose of what is proposed (Chatterton v Gerson, 1981) and the risks of proceeding or not proceeding (Sidaway v Governors of Royal Bethlem Hospital, 1984). It is expected that explanations be given in broad terms and use simple language to facilitate understanding (Sidaway v Governors of Royal Bethlem Hospital, 1984). In judging "Gillick competence" it can be argued that the

clinician is to assess the mental capacity of the child to use the information provided, retain it so the child can weigh it in coming to a decision and then express a decision. Where risks are significant this is entirely appropriate. However as a visual examination of the teeth is a low risk decision it may be that the ability of a child to express a decision after being provided with an explanation is sufficient evidence of their retaining, weighing and using information to prove their competence. This presumption was built into the approach which the surveys in Wales in 2002/3 and 2004/5 utilised.

Childhood dental data is collected in the UK as part of the NHS dental epidemiological programme. This programme has targeted different age groups each year, focusing on 5, 12 and 14 year old children. The information culminating from the surveys facilitates comparisons between the constituent countries of the UK as well as comparison with data generated from international surveys. The consent arrangements for NHS child dental surveys in the four UK countries are discussed during annual UK dental epidemiology coordinators meetings. These meetings pull together the surveys which are locally coordinated within the constituent countries of the UK. The Dental Observatory within at the North West Public Health Observatory coordinates the programme

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within England. In Scotland the National Dental Inspection Programme is coordinated by a multi-agency Dental Epidemiological Committee. In Wales the Welsh Oral Health Information Unit and the National Public Health Service Wales jointly coordinate the local programme.

In advance of the issuing of guidance in England (Department of Health, 2006) and Wales (Welsh Health Circular, 2006) which required use of "Gillick competent" consent for NHS child dental surveys of older children, "Gillick competent" consent was piloted with children participating in surveys in Wales for school year 9 (approximately 14 year old children) in 2002/3 and for school year 7 (approximately 12 year old children) in 2004/5. Further detail on the method used to obtain consent for these surveys is fully described in a previously published paper (Monaghan and Morgan, 2009).

Understanding of the nature and purpose of an examination or treatment is a key element of consent. Additional questioning, after an explanation of the nature and purpose of the survey but before the survey examination commences, could identify children who think they have understood but have not in fact understood the explanations offered.

The previous paper noted that further analyses would be required to report on the relationship between the expressed level of understanding of the child and the impact on commonly reported caries indicators, if children with lower levels of understanding were excluded from future surveys. At this stage there is a lack of clarity on the method of judging competence of children for NHS child dental surveys. If a higher threshold is used than expression of a decision following an explanation, then there is potential impact on caries indices. This paper reports on analyses of these impacts.

Objective

The objective of this investigation was to examine the possible impact on reported DMFT indicators if children who have not fully understood an explanation of the nature and purpose of the survey could be identified by further questioning and excluded from the survey. This information will be helpful in making a decision on an appropriate threshold of competence to be used when seeking consent of older children for participation in NHS coordinated dental surveys.

Method

NHS child epidemiological surveys are conducted in Wales using a sampling frame based on the 22 Local Health Boards (LHBs). Dental health status of older children is assessed using the DMFT index, commonly referred to as dental caries, which is based on the number of decayed (D), missing (M) and filled (F) teeth. Dental decay (the D component of the DMFT) is diagnosed at the decay into dentine (D₃) threshold using a visual method without radiography, fibre-optic transillumination, or compressed air (Pine *et al*, 1997). This assessment constitutes a visual inspection of the permanent dentition and not a formal clinical diagnosis. It represents obvious decay experience. Questionnaire data from the 2002/3 survey of 6393 13-14 year-old children and the 2004/5 survey of 6749 11-12 year olds were used in this analysis.

The consent methodology used was designed to build on existing "negative consent" practice at the time the surveys were undertaken and supplement it with "Gillick competent" child consent. Full details are outlined in a previous paper (Monaghan and Morgan, 2009).

Because the Education Reform Act 1996 s 520 (2) still applies to health surveys undertaken in school settings the survey process used in Wales in 2002/3 and 2004/5 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 (Office of Public Sector Information, 2009). Children whose parents had indicated that their child should not participate were excluded from participating in the decision process. This approach parallels the existing "negative consent" arrangements where parents were sent a letter notifying them of a forthcoming survey and children were examined unless a parental refusal was notified.

Before each survey ethical advice was sought from a multi-centre research ethics committee. This included advice to ensure materials used were of lowest possible reading age. The annual training and calibration exercises which took place in preparation for the 2002/3 and 2004/5 surveys each included a training session in consent law.

On the day of the survey a standard script using simple language was read by the dentist providing children with an explanation in broad terms 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.

After the clinical examination was completed children were asked four questions 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. The questions were:

- Did you understand what the dentist was going to do today?
- 2. Do you understand why the dentist looked at your teeth today?
- 3. Were you happy with the way you were treated today?
- 4. 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. An analysis of the responses to these questions has been previously reported (Monaghan and Morgan, 2009). This paper reports on the relationship between level of understanding of the consent explanation, DMFT data and deprivation.

The survey data was analysed using SPSS (SPSS 12 for Windows; SPSS Inc., Chicago, Illinois). The relationship between ability to consent, caries and deprivation were analysed using four summary variables:

fullyunderstand – an amalgamation of questions 1 and 2 above. If children responded positively to both of these questions then fullyunderstand equaled "Yes". For all other combinations of responses to questions 1 and 2 (i.e. Yes, No, Did not answer) the summary variable equaled "No".

DMFT category 1 – where DMFT=0 equated to "no obvious dentine caries" and those children with one or more DMFT were classified as "with caries".

DMFT category 2 – where DMFT was categorised using five categories 0, 1-2, 3-4, 5-9 and 10 or more

Deprivation score – The postcode of residence was recorded for each child taking part in the surveys and geocoded.

A number of area based indices are available for use in this type of study; Townsend scores and the Index of Multiple Deprivation (IMD) are the most commonly used. Townsend is a composite of four elements (unemployment, no-car households, owner-occupation and over-crowding), whilst the Welsh IMD has had three incarnations. The 2000 version had six domains (income, employment, health, education, housing and geographic access to services). The 2005 Welsh IMD had seven domains (with an additional environment domain) and the latest 2008 version has eight domains (community safety has now been included) [Welsh Assembly Government 2009]. There are limitations to both Townsend and IMD; Townsend performs poorly in rural areas where people keep older cars in order to be able to access services (Jones, 2004). The weightings of each domain contributing to IMD, the rationale and methods used for the factor analysis and the data transformations have been criticised (Robson et al, 2002). In addition, the quality of data included in the domains has been questioned (Wales and Powell, 2003, Robson et al, 2002). Townsend scores are a widely used and it is valid measure of deprivation (Policy Action Team 18, 2000; Gordon, 2003). It correlates strongly with standardised illness and mortality ratios (Asthana et al, 2002) and has a well-defined conceptual and statistical basis. In light of criticism of IMD use in Wales. Townsend scores were felt to be most appropriate for use in analyzing data collected in Wales (Jones, 2004).

The geocode was assigned to a deprivation category based on the quintile distribution for the Townsend Index (Townsend *et al*, 1988) for the whole of Wales which was derived using 2001 census data. For example, if a child's record was assigned to the most affluent category, this meant that the child resided in an electoral division which was included in the most affluent fifth for the whole of Wales. In Wales the more affluent postcodes have fewer children than do deprived postcodes therefore the analyses in this paper do not have 1/5 of the sampled children in each quintile.

Each year when geocoding the postcode data collected in Wales a small percentage of postcodes are not recognized. The two main reasons for this are believed to be data inaccuracies and new buildings for which postcodes are not yet included in the postcode lookup files. A total of 6,305 out of 6,393 records from the survey of 13-14 year olds in 2002/3 (98.6%) and 6,552 out of 6,749 records from the survey of 11-12 year olds in 2004/5 (97.1%) were successfullygeocoded and then allocated a Townsend score." These data formed the basis of analysis by deprivation score. Cross tabulations of these categorical variables were performed and the Chi Square test was applied.

Results

The proportion of children with caries increased with increasing levels of deprivation. This was true for both survey cohorts. This is consistent with previous findings (Provart and Carmichael, 1995; Jones *et al* 1997). For example, the percentage of 12 year olds with caries in the in the most affluent quintile group was 35.7% in 2004/5 contrasting with 52.6% in the most deprived quintile ($\chi^2 = 84.7$, p < 0.001; Table 1).

The percentages of children stating that they understood both what the dentist was going to do and why the dentist looked at their teeth tended to decrease with increasing deprivation. Surprisingly this trend reversed for the most deprived quintile group, particularly among 14 year olds. For example, 87.5% of 14 year olds in the most affluent and next affluent quintiles appeared to fully understand, compared with decreasing percentages of 85.6% and 82.9% in the median and next deprived quintiles respectively, whilst the percentage understanding in most deprived group rose to 88.5% ($\chi^2 = 22.71$, p < 0.001; Table 2). Children participating in the survey of 14 year olds in 2002/3 showed slightly higher levels of understanding across all Townsend quintile groupings when compared with those taking part in the survey of 12 year olds undertaken in 2004/5 (Table 2).

The caries distributions of those children who fully understood (i.e. excluding those who said after the examination that they had not fully understood the process) and all children (i.e. not excluding any child who agreed to participate in the survey) were very similar. Consider those children taking part in the survey of 14 year olds in 2002/3 (Figure 2). 40.6% of children had no obvious dentine caries in both the fully understood and all groups. In addition 2.2% of children who fully understood and 2.3% of all participants had 10 or more carious teeth (Figure 2).

Table 3 illustrates the potential impact on mean DMFT indicator scores if children who said after the examination they had not understood had been selected out. The percentage with no obvious dentine caries, the average DMFT and the average DMFT of those with caries by survey year and level of understanding are presented in Table 3. The differences in caries indicators are present but small. The largest difference was exhibited for the mean DMFT of those with caries for 14 year olds, with those who understood having a mean of 3.46 compared with 3.51 for all those surveyed in 2002/3.

Discussion

Recently issued guidance has required changes in England and Wales to consent arrangements used for older children for NHS child dental surveys. The issues raised by these changes include lack of clarity on how to obtain "Gillick competent" consent to a low risk visual examination of the mouth, and losing comparability of data if different approaches are taken to obtain consent in future.

The methodology and data collected in Wales in 2002/3 and 2004/5 provide an opportunity to estimate what would happen to reported DMFT indices if such an alternative approach was used. This analysis suggests that for the majority of 12 and 14 year olds "Gillick

Table 1. Caries prevalence by deprivation

Quintile of Townsend	14 year olds 2002/3 (n=6305)				12 year olds 2004/5 (n=6552)			
	Caries		No obvious dentine caries		Caries		No obvious dentine caries	
	No.	%	No.	%	No.	%	No.	%
Most affluent	497	49.7	504	50.3	366	35.7	658	64.3
Next affluent	628	57.2	469	42.8	421	40.4	622	59.6
Median	790	58.8	554	41.2	655	46.2	764	53.8
Next deprived	862	62.7	512	37.3	689	47.0	777	53.0
Most deprived	969	65.1	520	34.9	842	52.6	758	47.4
Total	3746		2559		2973		3579	

 $[\]chi^2 = 68.1$, p < 0.001, $\chi^2 = 84.7$, p < 0.001

Table 2. Post-examination expression of complete understanding by deprivation

Quintile of Townsend	14 year olds 2002/3 (n=6305)				12 year olds 2004/5 (n=6552)			
	Fully understood		Did not understand		Fully understood		Did not understand	
	No.	%	No.	%	No.	%	No.	%
Most affluent	876	87.5	125	12.5	889	86.8	135	13.2
Next affluent	960	87.5	137	12.5	881	84.5	162	15.5
Median	1150	85.6	194	14.4	1173	82.7	246	17.3
Next deprived	1139	82.9	235	17.1	1191	81.2	275	18.8
Most deprived	1318	88.5	171	11.5	1309	81.8	291	18.2
Total	5443		862		5443		1109	

 $\chi^2 = 22.7$, p < 0.001, $\chi^2 = 17.1$, p < 0.01

Table 3. Possible impact on caries indices of a higher test of capacity

Caries indicator	14 year olds	2002/3	12 year olds 2004/5		
	Fully understood	All	Fully understood	All	
No obvious dentine caries %	40.6	40.6	56.0	54.6	
DMFT	2.05	2.08	1.05	1.09	
DMFT of those with caries	3.46	3.51	2.39	2.41	

competent" consent is a viable way forward in delivering NHS child dental surveys of older children without notably affecting the epidemiological outcome. Most children believe they understand the explanations provided and even if a higher test of understanding is used, for example by asking children to explain back what they have been told, then it is likely that the impact on DMFT indicators would be small and of little clinical or public health significance.

A previous paper showed 15% of children reporting after the examination that they had not fully understood both what was being done and why. This paper explores the relationships between caries indices, deprivation and levels of participating childrens' understanding of the consent process. This study also estimates the likely impact on DMFT indicators of excluding the 15% of children with lower capacity to understand a simple explanation.

Tickle and colleagues (2003) recommended that methods to detect and correct for non-response bias should be routinely used in surveys where consent reduces response rates. For a survey of this type they would propose use of socio-economic status as a means of identifying and

compensating for non-response. No attempt has been made in this paper to correct for non-response bias associated with parental exclusion of the child (which was just below 1% for these surveys in Wales) because the focus of this paper is to quantify the further impact of excluding children who have not fully understood an explanation.

The analyses here are based on the childrens' post-examination answers to questions as to whether they had understood what was done and why. They are intended to give an estimate of the impact should a more stringent test of child capacity be used. An example of this could be based on asking children to explain before the examination what had just been told to them. However, this may only be a test of their retention of information rather than their understanding and therefore their capacity to consent.

The known relationship between childhood caries levels and deprivation is demonstrated to be present in Wales with children living in deprived electoral divisions having greater likelihood of decay experience. The relationship between understanding expressed by participating children and deprivation is less linear than that for

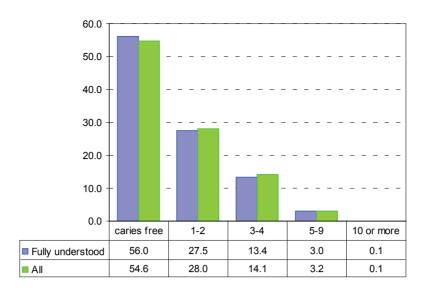


Figure 1. Mean DMFT distribution of those fully understanding versus all 12 year olds, 2004/5

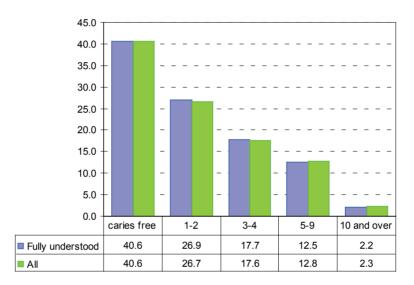


Figure 2. Mean DMFT distribution of those fully understanding versus all 14 year olds, 2002/3

caries. At 12 years of age there is a general tendency for deprived children to have lower understanding than their more affluent peers. Surprisingly however children living in the most deprived quintile of electoral divisions in Wales do not have the lowest levels of understanding. This trend is also present for 14 year olds where the most deprived quintile indicated the highest level of understanding of all quintiles. More research is needed to explore the reasons for this. Possible contributing factors include: additional support to school pupils in deprived areas, and greater exposure to dental examinations conducted in schools to identify those in need of treatment. Such examinations are still undertaken in Wales and are targeted at deprived areas.

It should be noted that on the advice of the ethical committee the script used to obtain consent for the 12 year olds was simplified from the script used to survey 14 year olds. Looking at the differences in levels of understanding expressed after the examination between 14 and 12 year olds, the 12 year olds, using a simpler

script, showed slightly lower levels of understanding than 14 year olds. It would be difficult to lower the reading age of the script used for 12 year olds much further and have it still comply with the requirements of a legal consent process. Other approaches intended to cope with low capacity would require considerably more training of the dental staff and more time to be used communicating with the children. It is suggested therefore that further research should be undertaken before the approach utilised in this study be relied upon to obtain consent of children younger than 11.

Spending more time and effort with each child testing what they have retained, what they have understood, what factors they included in coming to a decision and what their decision is, is a valid approach for a serious medical care decision. However the authors would argue that a decision to participate in a survey to have teeth visually examined has no serious consequences or risks. It is questionable whether there are good reasons to challenge further the level of understanding of a child

who believes that they have understood an explanation, have been given an opportunity to ask questions and has said they are happy to participate. Ethical issues related to developing consensus on an appropriate method of communicating with the child which allows the dentist examining to come to a judgment about capacity to consent include:

- What is the level of understanding a child needs for a low risk decision such as a simple visual examination of the teeth?
- Do we help childrens' ability to make decisions when we allow them to make simple decisions?
- Do we expect children to show a greater level of understanding than we expect of adults?

In legal terms the judgment of capacity is a matter of the clinical judgment of the examining dentist. Under English and Welsh law health professionals are expected to act in accord with a "responsible body of opinion." The opportunity is there for those coordinating the NHS dental survey programme across the UK to express a responsible opinion on an appropriate approach to consent for children aged 11-15 to support the survey programme.

This study was undertaken within the legal system of England and Wales and shows that excluding children with a lower level of understanding could have a small impact on DMFT indices. Similar approaches to consent in other countries with different legal structures but which result in similar participation rates for child dental surveys are likely to generate comparable data.

Conclusions

This paper has explored possible impact on reported survey findings if more rigorous testing of child understanding is expected. The analyses in this paper suggest that exclusion of children who have not fully understood an explanation of the nature and purpose of the examination would have a small impact on the results and the utility of the data produced. The relationship with deprivation scores highlighted in these analyses is complex and would benefit from further research.

There remains the ethical issue of whether all children who believe they have understood an explanation are "Gillick competent" or whether this should be routinely challenged by further questioning. It would be helpful if guidance was developed on the level of understanding expected for participation in NHS dental surveys by older children.

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