Summary of: Do parents of children with caries choose to opt out of positive consent dental surveys in Wales?

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FULL PAPER DETAILS

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Background Recently, positive consent has been required for dental surveys in some parts of the UK. Concerns have been raised that when positive consent is used participation is reduced in deprived areas and reported caries levels are biased as a consequence. This paper analyses caries data collected under positive and negative consent arrangements to explore this issue further. **Method** Retrospective analysis of response rates by deprivation fifth and by caries experience of participating children in NHS coordinated dental surveys in Wales undertaken from 2001/2 until 2005/6 using negative consent and in 2007/8 using positive consent. **Results** Across Wales, the change from negative to positive consent was associated with greatly decreased participation. In comparison with previous surveys there was a large increase in children sampled but not examined. The decrease in the proportion of children sampled, who were examined and found to have no decay was similar across all deprivation fifths, with no obvious deprivation-related trend. There was a much larger reduction in the number of children with decay who participated across all quintiles of deprivation. **Conclusion** Caries status could be a more important factor than deprivation regarding opting out of the survey. It appears that children with caries are more likely to be opted out of the survey than similarly deprived peers without caries. Parents appear to be more likely to opt children with caries out of dental surveys when positive consent is used. These findings have significant implications for targets aimed at improving oral health which were set before the change in consent procedures, but reported upon after.

EDITOR'S SUMMARY

In an age when so many people are anxious, some to the point of paranoia, about privacy, identity theft and the giving of fully formed consent it is hardly surprising that the matter of opting out of school dental inspections has come under scrutiny. It does remind me of my own first such inspection as a primary schoolboy when a fellow pupil standing next to me in the line asked if I thought my Mother knew about this? Frankly it hadn't occurred to me at that point why she might even be interested, let alone any more concerned than with other activities at school. Perhaps I was always destined to become a dentist.

Whether or not parents are concerned, the law in most of the UK is now that positive (that is opt-in) consent is required before dental inspections can be undertaken. The consequence, as this paper outlines, is that as far as the oral health of individuals is concerned,

as well as the accuracy of data collection, it is something of a loss. For the children with caries for whom consent is not given and whose parents are probably aware of this but inactive on seeking care for whatever reason, there is the missed opportunity to have a way found for them into dental care. For the epidemiology, the inevitably skewed data means lesser accuracy with a consequent greater variance in the ability to plan services successfully.

The authors are very accommodating in the recommendations they make by suggesting tagging of data and statistical manipulation and that the reasons for non-participation of non-responders be further researched. Surely a more robust approach would be to seek political backing to change the law, albeit accompanied by an educational campaign to explain why modification of this particular 'right' might be in the interests of us all but especially the oral health of

young children. Society confers certain rights and insists on certain safeguards but each has to be balanced by the greater good. Maybe this has slipped too far in one direction.

The full paper can be accessed from the *BDJ* website (www.bdj.co.uk), under 'Research' in the table of contents for Volume 210 issue 2.

Stephen Hancocks

Editor-in-Chief

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IN BRIEF

- Consent changes have reduced participation in school-based dental surveys.
- The reduction in participation is not fully understood but may be associated with presence of decay.
- Until reduced participation is understood, data collected using different consent methods should not be compared.

COMMENTARY

One of the cornerstones of dental public health in the UK is the rich child dental health data set provided by the regular delivery of standardised cross-sectional dental epidemiological surveys delivered under the auspices of BASCD. Using these data, we have, for many years, been able to describe, with some confidence, the changes that have taken place in the dental health of age-specific year groups of children over time and this information has proved both a simple and powerful device for dental planners when communicating with key decision makers in the NHS and elsewhere. Unfortunately in 2006 things changed. The way that study participants were recruited into the BASCD dental surveys moved from negative to positive consent and this raised two separate issues. Firstly, a 'fault line' has appeared in the child dental health data stream. Data collected prior to the change can no longer be directly compared with those collected after it. Secondly, little is known about the impact this change in recruitment protocol has had on the type of individual prepared to participate in such surveys.

The study considers this latter problem. It examines dental epidemiological data, as it applies to five-year-olds, collected prior to and after the change in consent arrangements. In particular, it reports levels of participation in the dental surveys and the proportion of participating children with no caries experience. The authors note that following the consent changes, there was

a reduced level of child participation and proportionally, children with no decay were more likely to be entered into studies by their parents than their peers with decay experience, in all quintiles of deprivation.

The authors speculate that the key driver for these findings may be active opt-out by parents based on embarrassment associated with their child having decay, although no supporting research evidence was provided and more research is called for.

This study provides a timely reminder of the dangers attendant on the careless comparisons of dental epidemiological data sets, particularly when different methodologies are used to collect those data. The authors underline the need for those using such data to have a clear understanding of the type of consent used and the reported participation rates.

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AUTHOR QUESTIONS AND ANSWERS**1. Why did you undertake this research?**

When positive consent had been used in the UK previous to 2006 in response to local problems, reported caries levels fell for the period over which positive consent was used, particularly in deprived areas. It had been suggested that positive consent resulted in a lower response rate in deprived areas. As caries is commoner in deprived areas an alternative hypothesis is that response rate could be linked to caries status.

If deprivation did explain participation then the reduction in participation within a deprivation quintile should be similar for children with and without caries. Such a simple relationship would allow data to be reweighted for non-participation.

2. What would you like to do next in this area to follow on from this work?

This paper has suggested that non-participation (when compared with previous surveys) may be related to caries status more than to deprivation.

While comparisons of data collected in Wales before and after 2006 are not appropriate, there is a continuing need to monitor oral health. The NHS epidemiology programme will have to continue with the new consent arrangements. Caries trends will be assessed using 2007/8 as a new baseline. Qualitative research engaging parents who have not provided consent could explore whether awareness of caries status does influence parental response to the letter inviting participation in the survey. Consideration will also be given to asking parents to provide information on their child's caries status if they decline participation of their child.