Community Dental Health (2018) **35,** 201–203
Received 24 March 2017; Accepted 21 January 2018

doi:10.1922/CDH_4162Day03

Dental Public Health in Action

A feasibility study to explore the governance processes required for linkage between dental epidemiological, and birth cohort, data in the U.K.

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Birth cohort initiatives, such as 'Born in Bradford', provide a unique opportunity to study the influence of socio-economic and environmental factors acting in pregnancy, birth and infancy on the development of dental caries in later life. This paper describes a feasibility study which established the processes required, and outcomes of, successful linkage of oral health data collected by the 2013 three-year-old national dental epidemiology survey with the Born in Bradford birth cohort database. The necessary processes included achieving research permissions and ethical approval; creation of a data sharing agreement; ensuring data security and encrypted data transfer. With regard to the outcomes, a robust *a priori* statistical plan was developed. 152 three-year-old children were examined for the 2013 dental epidemiology survey in Bradford, and of those, 69 parents consented to data linkage believing that their child was part of the Born in Bradford cohort. However, only 36 of these 69 children were participating in the cohort. Of these, six children had obvious dentinal caries experience (dmft >0). There was insufficient power with such small numbers, to examine the association between birthweight and dental caries at the age of three-years-old. Key learning points from this feasibility study have informed the design of a larger study to link the 2014/5 five-year-old dental epidemiology surveys with the Born in Bradford cohort. This paper reveals the important methodological considerations for future data linkages between routine health data and research data.

Keywords: Dental caries, Birth cohort, Dental data linkage, Lifecourse epidemiology, Feasibility study

Initial impetus for action

Dental caries is the most prevalent preventable condition in children and is a significant public health priority in England (Department of Health, 2012). The Public Health England (PHE) Dental Public Health Epidemiology Programme (DPH EP) maintains a programme of internally and externally valid dental surveys to estimate the prevalence and severity of dental conditions in specific population groups. Biennially, the surveys endeavour to collect data on caries in a representative random sample of children within each local authority area. These cross-sectional age specific surveys provide robust and comparable data to monitor changes in the prevalence and severity of dental caries. However, they are not primarily designed to explore or identify which components of local oral health improvement plans are effective and cost effective. Data linkage provides an opportunity to answer such research questions by linking robust dental outcomes collected by DPH EP with wider datasets such as those collected by the Born in Bradford birth cohort.

National guidance for the design of local oral health improvement plans advocates the delivery of multifaceted programmes delivered by different members of the early years workforce (PHE, 2014). With the welcome reduction in the prevalence of dental caries, as shown in the last two five-year-old dental epidemiology surveys (PHE, 2013), and tightening financial landscape, the effectiveness of different components of these oral health improvement plans are important to establish.

Solution(s) suggested

Birth cohorts, such as Born in Bradford (BiB), provide a unique opportunity to study the influence of socio-economic and environmental factors acting in pregnancy, birth and infancy on the development of dental caries in later life. A lifecourse approach suggests that adverse exposures and insults are accumulated throughout life. It applies the dynamic concept of a chain of circumstances, where the exposure to one factor is likely to be connected with exposure to other factors and these exposures are likely to accumulate over the lifecourse (Kuh & Ben-Shlomo, 1997). This approach has the potential to explain disparities in oral health by identifying risk factors occurring in early life that result in poor oral health. Few longitudinal birth cohorts have included measures of oral health. Those cohort studies are often small in size, have not always collected detailed dental data through childhood and may not be directly relevant to UK population (Peres et al., 2005; Thomson, et al., 2004). They describe how conditions during pregnancy and at birth are associated with oral health in later life (Broadbent et al., 2011). Importantly, birth cohorts have the potential to describe comprehensively the lifecourse of children who do and do not develop dental caries, describe the early-life interventions they receive and potentially examine the effectiveness of different combinations of oral and general health preventive interventions.

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Bradford district, located in West Yorkshire in the North of England, is the 6th largest district in England and is the 19th most deprived local authority of 326 in England (Dickerson et al., 2016). In 2007, the Born in Bradford birth cohort (BiB) commenced recruitment. All mothers giving birth at the Bradford Royal Infirmary maternity unit were invited to enrol from 2007 to 2011. Over 13,500 diads were recruited, representing over 60% of all births in the hospital (Wright et al., 2012). These children come from a Pakistani origin (45%) and 39% come from a white British origin. A unique opportunity in Bradford existed to link the extensive socio-economic and environmental data already being collected by BiB (Day et al., 2015; Wright et al., 2012) with validated dental data collected for the PHE National Dental Epidemiology programme (PHE, 2013). The 2012/13 dental epidemiology survey was the first in England to examine a representative sample of three-year-olds in each local authority area (PHE, 2013).

Actual outcome and challenges overcome

Detailed findings of the feasibility study are published in the White Rose Depository (Day et al., 2015), however, this publication focuses on the methodological process and outcomes. The findings can be summarised in two broad headings and provide a number of key learning points which influenced the design of a further dental data linkage study using the data arising from the dental epidemiology survey of five-year-olds (PHE, 2013).

Feasibility

The study (Day et al., 2015) successfully answered a number of key feasibility challenges. These included:

1. Ethical approval and research permissions were achieved. A data sharing agreement was signed between three different publicly funded bodies (University of Leeds, Bradford Teaching Hospitals Foundation Trust and Public Health England).
2. With agreement of the ethics committee, two modifications were made to the parent information sheet and consent form for those children living in Bradford. A small paragraph was added to the Dental Epidemiology information sheet. This explained what this dental data linkage study involved, how it would be undertaken and the potential benefits of participating. An additional box was then added to the Dental Epidemiology consent form that allowed parents to opt in for their child's dental data to be linked with BiB cohort data.
3. Following ethical approval and parental consent, the child's demographics (NHS number, full name, date of birth and address) and dental data collected during the dental epidemiology survey were securely transferred using encrypted email to Bradford Teaching Hospitals Foundation NHS Trust, which houses the BiB cohort data. The data sharing agreement clarified how this process would be undertaken and outlined the data sharing policies that were to be followed.
4. Bradford Community Dental Service undertook the dental epidemiology survey in Bradford, looked up the NHS number of each child who participated in the dental survey and gained parental consent for data linkage.

Research findings

The study (Day et al., 2015) aimed to examine the association between birthweight and dental caries at the age of three. The dental epidemiology survey of three-year-old children in Bradford consisted of dental examinations of 152 children. From this sample, 69 parents consented for data linkage (45.4%). When these 69 children were compared to the BiB records, only 36 children were part of both BiB and dental epidemiology survey (23.6% of the initial three-year-old sample). Six out of the 36 children included had obvious dentinal caries experience. Consequently, only simple descriptive statistical analysis was possible.

Learning points

1. The main ethical considerations included: the use of patient identifiable data to facilitate data linkage with the BiB dataset, secure data transfer following BiB and NHS data protection protocols, and ensuring that an anonymous dataset was used for by researchers for data analysis.
2. Navigating the ethical and research permissions was time consuming, with 13 months between the submission of the ethics application and the start of data linkage. The main reason for the long delay was the establishment of a data sharing agreement and identifying who owned the data. The latter was complicated by wider structural changes in the NHS. The survey of three-year-old children's was commissioned by the Primary Care Trust which was subsequently disbanded and dental public health staff transferred to Public Health England. The final data sharing agreement was signed between the University of Leeds, Public Health England and Bradford Teaching Hospitals NHS Foundation Trust.
3. The study received a small research grant (approximately £6,500) to enable BiB research staff to undertake data linkage and statistical analysis.
4. The method used in this study led to many false positives (33/69) with parents thinking that their child was part of BiB when they were not.
5. With a larger sample, describing the lifecourse of children with and without dental caries is eminently achievable. Such analysis requires close collaboration with statistical colleagues to ensure a robust *a priori* plan is drawn up prior to statistical data exploration.

Future implications

The findings from this study have informed the design of a new study to link the 2014/5 dental epidemiology survey of five-year-olds with the BiB cohort. This new study has navigated ethical approval, research permissions, a data sharing agreement and is currently undertaking data linkage. The key learning outcomes include:

1. To address the high number of false positives, the new study has identified children participating in both the 2015 five-year-old dental epidemiology survey and BiB before writing to their parents for permission to link their child's dental data with BiB. This was permissible as BiB parents provided consent at recruitment to be contacted by the BiB research team about additional research studies. Unlike the earlier study, this method required no changes to the dental epidemiology survey information sheet or consent form.

2. This new design uses only the NHS numbers to link children participating in the five-year-old dental epidemiology survey and BiB. The method, however, brought concerns that children participating in the dental epidemiology survey of five-year-olds, but who are not part of BiB would have their NHS numbers shared between two different NHS organisations (Bradford Community Dental Service who undertake the dental epidemiology survey and Bradford Teaching Hospitals Foundation NHS Trust who run BiB) when they have not consented for this to happen. To address this concern pseudoanonymisation software (OpenPseudonymiser from the University of Nottingham) was used to independently encrypt the NHS numbers of children participating in the dental epidemiology survey and BiB. The software randomly encrypted each NHS number within a text line of 256 characters. The software then identified which NHS numbers link without sharing with either organisation the original NHS numbers from either dataset.
3. Based on the earlier study, where 36 of the original sample of 152 (23%) agreed and were eligible to participate, an opt out consent process was used. The justification for this approach was three-fold: (i) When parents initially consented (opted in) to participate in the BiB cohort they expressly consented for data linkage to medical records. This consent process has been used extensively for data linkage with primary care and hospital medical records for the cohort to date; (ii) Opt out consent has been used by BiB for data linkage with other datasets such as school based anthropological measures collected for the National Child Measurement Programme and finally, (iii) parents have already consented (opt in) to participate in both dental epidemiology survey and BiB independently and had a further opportunity to opt out if they did not want their child's dental data to be linked.
4. These approaches have resulted in a larger dataset available for statistical analysis. In summary, 1011 children participated in the 2014/15 dental epidemiology survey of five-year-olds in Bradford. For 983 children, the Community Dental Service was able to access their NHS number, and 324 participated in both the dental epidemiology survey and BiB. Eight parents opted out of data linkage, leaving a sample of 316 children.

Conclusions

This feasibility study has demonstrated the feasibility of linkage between dental data collected at the age of three with the extensive lifecourse data available from BiB. The findings have influenced the design of a subsequent study using the five-year-old data. Both studies rely on the robust oral health data collected by the PHE National Dental Epidemiology Programme and demonstrate further utility of this national programme.

Acknowledgements

These studies have been supported by funding from the Oral and Dental Research Trust. The research team acknowledges the support of the National Institute of Health Research Clinical Research Network (NIHR CRN). One of the authors of this paper (PD) was supported by the NIHR Collaboration for Leadership in Applied Health Research and Care Yorkshire and Humber (NIHR CLAHRC YH). www.clahrc-yh.nihr.ac.uk. The views and opinions expressed are those of the author, and not necessarily those of the NHS, the NIHR or the Department of Health.

We are grateful to all the Born in Bradford participants, practitioners and researchers and to Bradford District Care NHS Foundation Trust Community Dental Service who undertook the epidemiological survey in Bradford, in particular Mrs Shahid, Clinical Director, and Mrs Debra Clavin.

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