



# Challenges encountered when conducting a dental health needs assessment of older people resident in care homes: experience from England

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This paper describes the process of undertaking a dental health needs assessment of older people resident in care homes in the North East of England and the challenges involved. It illustrates many competency areas of interest to dental public health practitioners: oral health surveillance, dental public health intelligence and collaborative working.

**Key words:** needs assessment, residential facilities, dental health surveys

## Initial Impetus

In England, there is a national rolling NHS Dental Epidemiology Programme. In recent years, Primary Care Trusts (PCTs), whose purpose is to develop health services for the community, have been able to extend beyond traditional child caries surveys as the national programme has allocated time specifically for this purpose. In the North East region, the Strategic Health Authority (the organisation responsible for defining and managing the overall health strategy in an area) dental commissioning group agreed that during the academic year 2010/11, the population group for scrutiny would be older people resident in care homes. The 2009 adult dental health survey (ADHS, NHS Information Centre, dental and eye care team, 2010) had collected data on the oral health needs of older people living in their own homes, but not in residential care homes. Therefore, it was agreed that a needs assessment would be required to assess whether the oral health needs of older people resident in care homes were different from their counterparts living in households, and whether these needs were being met. It was intended that this survey would: improve knowledge about the condition of the natural dentition and supporting tissues; investigate dental experiences, knowledge and attitudes towards dental care and self-care and assess the extent to which the oral health needs of this vulnerable group living in care homes were being met. The findings would be used to inform commissioning of services, particularly domiciliary care in the North East.

NHS commissioners and local authorities (LAs, local government organisations) are keen to base their commissioning decisions on data relating to smaller geographic units than those sampled in the ADHS. The NHS North East survey, was therefore commissioned to ensure a sample size that would provide reliable and robust data on which to commission dental services at PCT / LA level.

## Process described

As there was no national protocol for the conduct of an oral health needs assessment in older adults, the NHS North East survey used the existing guidance to develop a reduced and simplified local protocol. That guidance was drawn from the following sources:

- the protocol for the 2009 Adult Dental Health Survey (O'Sullivan, 2011)
- the protocol for Dental Health Survey of care home residents in Wales 2012/11 (Karki *et al.*, 2010) which had received ethical approval for Wales only.
- the sampling procedures described in the BASCD guidance on sampling for surveys of child dental health. A BASCD co-ordinated dental epidemiology programme quality standard (Pine *et al.*, 1997).

The Welsh protocol had not been piloted at the time of its use in the North East, but was adopted as a matter of expediency, with the intention that in due course the protocol could be amended after testing in the field. Every effort was also made to follow the ADHS data fields and questions to ensure comparability of results.

## Preparation

### *Considering the need for approval/ethical approval*

As there was no nationally agreed protocol that had received ethical approval, and the proposal was to examine a vulnerable group of older adults, the Regional Director of Public Health (RDPH) was contacted to seek advice whether approval or ethical approval was required for this needs assessment. The RDPH advised that approval and support needed to be sought from each LA Director of Public Health (DPH). The DsPH and governance leads in each PCT were contacted by the relevant consultant in dental public health or regional epidemiology co-ordinator

to seek their views. Diametrically opposite views were received. While the majority of DsPH expressed the view that an NHS needs assessment to determine the treatment needs for an identified vulnerable group did not need ethical approval as this was not a research project, one DPH did feel that ethical approval was required. Therefore, the Chair of the Newcastle & North Tyneside Research 2 Ethics Committee was contacted for an opinion.

### *Sampling procedure*

The sampling frame was the list of care homes registered with the LA that provided care for older people. The survey aimed to provide a minimum sample of 200 residents examined in each PCT, from ten care homes. A staged sampling technique was applied and the principles adapted from the NHS dental epidemiology programme (Pine *et al.*, 1997). The care homes were categorised as small ( $n \leq 20$  residents), medium ( $n = 21$  to 40 residents) or large ( $n \geq 41$  residents). In the small homes ( $n = 2$ ) all residents were selected, in medium sized homes ( $n = 4$ ) 1 in 2 residents, and in large homes ( $n = 4$ ) 1 in 4 residents were sampled.

If any sampled care home did not wish to participate, it was substituted by another. The list of residents sampled at each care home was then reviewed by the care home manager who was asked if any of the residents on the list needed to be substituted as they would not have the ability to give consent. The residents sampled who did not have the ability to consent were substituted. It was anticipated that 10 sampled sites would provide sufficient consenting and willing older people until a sample of at least 200 residents per PCT had been seen in the proportions calculated.

### *Consent*

The procedure for obtaining positive consent from residents followed the guidance from the Department of Health (2009) Reference Guide to Consent for examination or treatment. Residents who did not consent were replaced by substitute residents up to a maximum of 12 residents per home. The number of residents refusing to participate was recorded.

The procedure for positive consent involved:

- Provision of a letter informing residents of the needs assessment.
- Giving an information sheet for care home residents.
- Requesting informed consent from those who volunteered to take part. Capacity to consent was determined by dental examiners on the basis of the Mental Capacity Act Code of Practice (Department for Constitutional Affairs, 2005). Residents were given at least 24 hours to consider the information and whether or not they wished to take part.
- Exclusion of adults deemed unable to give consent because of mental incapacity.

### *Training and standardisation*

Dental examiners were required to fulfil the following criteria:

- Experience of providing dental treatment to care home residents.
- Experience of undertaking dental epidemiology surveys, ideally having examined in the ADHS.

- Standardisation against a standard examiner.
- Attendance at a training session about the protocol.
- An understanding of the Mental Capacity Act 2005.

The North East 2010/11 NHS Dental Epidemiology Programme training and standardisation exercise for older people was undertaken on one day. Seven examiners were trained and standardised against one standard examiner. The first session provided training in all elements of the protocol including: sampling, consent, personnel, general conduct of the survey, field work, collection of data and reporting of data. The dental epidemiology teams also completed sampling for their PCTs during this session. The second session allowed examiners to simulate the clinical procedure using PCT staff volunteers as a pilot sample. Each examiner saw an average of six adults who had been previously examined and scored by the regional standard examiner. All examiners were given feedback on their level of agreement with the standard and given the opportunity to discuss and re-examine any differences in scoring. All examiners successfully completed the exercise.

Support workers practised asking interview questions and recording data accurately.

### **Fieldwork**

Clinical examinations took place in residential and nursing care homes for older people with participants seated in their most comfortable chair ensuring neck support. The standard sequence of data collection was as follows:

- Collection of personal information and demographic details
- Examination of the mouth and dentures using ADHS criteria
- Assessment of treatment need data
- Collection of questionnaire data on a subsequent visit to the home.

### **Actual Outcome**

Table 1 shows the participation levels in the survey. The total number of residents that were examined (568) was considerably lower than the protocol required (2000). Lack of capacity of residents to give informed consent (69%) was a significant issue in this survey and contributed to low participation rates: North of Tyne 24%; South of Tyne 18% and Tees 10%.

### **Challenges**

Gaining approval from individual PCTs to undertake this needs assessment for a vulnerable group of adults met with different responses. Most PCTs (9/10) considered that there was no need to take this to the ethics committee as it was recognised that a needs assessment did not need ethical approval, and all necessary safeguards had been built into the protocol. The chair of the ethics committee agreed that this survey should be progressed not as research and stated "*I would consider this a service evaluation. It is part of a comprehensive system of surveys to evaluate the healthcare needs and the service provision in specific populations.....if a service is to be*

**Table 1.** Participation in NHS North East care home needs assessment for older adults

Participation	North of Tyne cluster		South of Tyne cluster		Tees cluster	
	n	%	n	%	n	%
Total care homes in cluster	173	100	236	100	200	100
Care homes sampled	46	27	37	16	48	24
Care homes participating	30	n/a	30	n/a	40	n/a
Total number of residents in participating homes	768	100	1,017	100	1,867	100
Residents lacking capacity to consent	521	68	740	73	1,276	68
Residents consenting to participate	185	24	187	18	196	10
Residents completing examination	183	23.8	181	17.8	196	10

*evaluated, then patients need to be examined. There is no hypothesis that is being tested here. There is no research question.*" (Personal communication: Chair of Newcastle & North Tyneside Research 2 Ethics Committee, 2011).

Care home managers were requested to identify residents who would not have the capacity to consent, after the sampling stage so that they could be substituted to ensure an adequate sample was achieved. Clinicians have reported that there was a difference in understanding of mental capacity criteria used by managers in comparison to dentists. More care home managers felt their residents were able to provide informed consent than the examining dentists. This may have resulted in inadequate substitution in the initial sample and contributed further to low participation rates.

The level and detail of clinical information required to plan services is quite different from the level of detail required to report on clinical conditions for an epidemiological survey. Having recognised this, the local protocol attempted to reduce and simplify both the clinical dataset and the questionnaire data collected. Despite this, the clinical examinations in the field were still very time-consuming because of the quantity of clinical data required to align the needs assessment dataset with that of the ADHS dataset. On analysis of the dataset it was evident that some of the detailed clinical data collected (e.g. individual tooth pocket depth measurements) could be simplified. Therefore, to reduce the length of time of the clinical examinations for the patient, increase efficiency of the dental epidemiology team and collect data that has reporting value the dataset in this protocol will need to be further refined.

### Future implications

It would be helpful for national protocols on this topic to be developed which can be submitted for opinion about the need for ethical approval.

There is a role for the Dental Observatory to act as a central repository for local protocols to enable sharing of information and dissemination of learning and to facilitate the development of national protocols for future adult surveys.

The Alzheimer's Society reports that 64% of people living in care homes have a form of dementia, therefore, it is hardly surprising that most of the older people in this

survey (69%) lacked the capacity to consent, resulting in low participation rates. These findings emphasise the need to consider alternatives to the consent process for people who lack the ability to give informed consent to enable them to be included in future surveys.

There is a need for greater clarity across the country regarding the need for ethical approval for health needs assessments, including those involving vulnerable groups, invasive tests or gathering sensitive data.

Future protocols for such a group should consider: combining data fields in both the clinical and questionnaire domains; replacing pocket depth measurements on individual teeth with a Basic Periodontal Examination sextant score; and provide further training and detailed guidance in the protocol on how to make treatment planning decisions.

Future protocols should consider building in training for care home managers on the Mental Capacity Act 2005 to aid robust initial sampling if residents without capacity to consent are to be substituted.

### Learning points

There are a variety of views about the need for ethical approval for a needs assessment. However, at the very least local protocols should go through a robust local governance procedure to ensure adequate safeguards are in place to protect vulnerable groups.

Had the high percentage of residents with lack of capacity of consent been known prior to the design phase of the protocol, staged sampling of residents would not have been undertaken as the survey protocol excluded residents unable to consent.

This needs assessment may not have identified the differing needs of this population sub-group given the high percentage of residents lacking the ability to consent (69%) and the subsequent low participation rate. There is a question mark about the sample being representative: it is possible that residents with lack of capacity to consent may be in poorer general health and therefore may have worse oral health than their counterparts. Therefore, future surveys may need to consider using alternative methods.

Training and standardisation of examiners should have been undertaken in a "real life" training environment not with PCT staff in PCT premises. Had this been done more realistically, difficulties of locating individuals, the

prolonged nature of the examination process and the lack of ability of residents to consent may have altered the nature of the protocol, as well as the nature and extent of the clinical data collected.

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