Public Health England

Protecting and improving the nation's health

Dental public health epidemiology programme

Oral health survey of older people, 2015-2016

National protocol

Version 2

21st September 2015

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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Published September 2015
PHE publications gateway number: 2015283

Contents

1 Introduction

It is a requirement of local authorities in England to undertake dental health needs assessments for all population groups.[1] The increasingly large number of older people in the population who are living longer and tending to have multiple medical conditions leads to increased interest in their oral health status and treatment needs.

Several surveys of older people living in residential and nursing care homes have been undertaken in the UK as well as surveys of providers of services for this population and much can be learned from these. However, a far greater proportion of older people live in their own homes, either alone or with family members and their oral health needs also need to be measured. In particular the needs of older people with dependency on outside services are of interest as effective preventive approaches at this stage could avoid additional problems in their futures.

The Adult Dental Health Survey (ADHS) is a decennially run national epidemiological study of the dental health of the adult population living in private households, but it does not record the level of dependency a participant has so cannot be used to provide information on this specific group in the population. This survey can only report down to government regional level so may not provide sufficient detail for local planning.

There is therefore a need to run surveys at local level to provide robust, comparable information about older adults with some degree of dependency. Those in this group are more likely to become more heavily dependent in the future yet there is potential to improve their oral health before this occurs. This segment of older people has not been surveyed before with regard to oral health. Only by undertaking a national, standardised survey of this group can dental health need, inequalities of dental health, their impact and requirements of dental treatment services be identified. National coordination and collaboration of such a survey is essential to ensure comparable, robust information is produced. The Public Health England (PHE) Dental Public Health Epidemiology Team (DPHET) is the body with the responsibility to fulfil this coordination function.

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1. Statutory Instrument 2012 No 3094. National Health Service, England Social Care Fund, England Public Health, England. The NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Health watch) Regulations 2012. Available at : http://www.legislation.gov.uk/uksi/2012/3094/regulation/35/made

This protocol describes an approach which will allow collection of dental health information about older people (aged 65 years or older) who live in their own homes in the community but who have a mild level of dependency on external services to allow them to do this. This is a pilot survey to test methodology and utility of data.

The governance of the data arising from this survey will become the responsibility of the DPHET and Knowledge and Intelligence Team North West (KIT NW) who will collate the results from each fieldwork team centrally. Analysis will be undertaken and widespread dissemination is planned. Access to the raw data will be facilitated via an agreed process.

2 Aims and objectives of the survey

The main aim of the survey is to:

- provide information on the oral health of adults aged 65 years or older with mild dependency

Objectives:

- to sample and recruit older people living in ‘extra care’ housing establishments and undertake a clinical examination and questionnaire
- to describe the broad oral health status and treatment need through epidemiological clinical examination
- to establish, by interview, use of clinical treatment services, degree of dependency and the impact of poor oral health

3 Roles and responsibilities

DPHET will take responsibility for coordinating and preparing the material for the surveys. They will distribute protocols, provide national training, develop training materials and all necessary paperwork for PHE Dental Epidemiology Coordinators (DECs) who will pass these on to relevant fieldwork teams.

Commissioning of fieldwork according to the protocol will be the responsibility of all local authorities, in many cases in partnership with NHS England Area Teams.

Training will be provided at national level by DPHET to DECs and dental epidemiology trainers. This will be cascaded down at local events for fieldwork teams. In previous surveys PHE was able to compensate the employing organisations of the dental epidemiology trainers for the associated costs of local training and calibration. It is hoped that this funding arrangement can be continued to support this survey.

Identification of the population sampling frame and grouping of ‘extra care’ housing for each local authority, along with noting the types of establishment, tenure allocations and landlords will be the responsibility of the DPHET, working with the Elderly Accommodation Counsel (EAC).

Fieldwork will be the responsibility of the clinical teams commissioned to undertake this. Each fieldwork team is responsible for undertaking the survey as described in the protocol and enter their results into the centrally prepared format before sending anonymised results to DECs for uploading to the DPHET.

DPHET will collate, check, analyse the data and report according to agreed systems.

The chief investigator for the survey is:

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4 Methodology

The survey will have two components; a face-to-face interview with the volunteer adult using a short questionnaire and a very simple dental examination using appropriate standardised methods and equipment. Both the questionnaire and the examination will take place on the same occasion where possible and in the volunteer’s own home.

Trained administrative assistants or dental nurses will carry out face to face interviews and act as data recorders for the dental examination.

The survey is observational rather than experimental, and although the examination requires access to the participant's mouth in order to make the observations, the survey is non-therapeutic and non-interventional. The purpose is to measure the dental health in the specified population, so the survey can be described as descriptive.[2]

The survey procedure is very simple and designed to involve "minimal risk", where minimal risk is defined as "the probability of harm or discomfort anticipated … are not greater in and of themselves than those ordinarily encountered in daily life or during the performance of routine physical or psychological examination or tests".[3] The survey is also consistent with the Council of Europe definition of minimal risk, which is "the research bears minimal risk if it is to be expected that it would result in, at the most, in a very slight and temporary negative impact on the health of the person concerned".[4]

4.1 Fieldwork

The fieldwork will be coordinated by the DPHET with the assistance of DECs and will be carried out by local authority commissioned fieldwork teams. Most of these teams will have past experience of epidemiological fieldwork through involvement in previous national studies, and/or local oral health studies and will work with vulnerable adults on a regular basis.

The fieldwork teams will consist of registered dental clinicians and administrative supporters, all of whom have been specifically trained by DECs and dental epidemiology trainers to enable them to be able to undertake the survey according to the agreed methodology and standards laid out in this national protocol. The fieldwork period will start in September 2015 and finish in June 2016.

4.2 Sampling

The sample size will be a commissioning decision for local authority with advice from dental public health consultants in PHE centres in collaboration with NHS England Area Teams, where appropriate.

The sampling unit will be lower-tier local authority level as a minimum. Where it is not sensible for estimates to be provided for all lower-tier local authorities in a particular

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2 'Guidance on the practice of ethics committees in medical research with human participants', fourth edition, Royal College of Physicians, 2007, p.21

3 'Protection of Human Subjects', United States Office for Human Research Protections (OHRP), 1991 quoted in ibid, p.37

4 'Draft additional protocol to the Convention on Human Rights and Biomedicine on Biomedical Research', Steering Committee on Bioethics, Council of Europe, Strasbourg, 2003. Quoted in ibid, pg, 37.

area there should be discussion between the local authority director of public health, PHE centre director, consultant in dental public health and DEC to agree a reasonable sampling method to allow for local authority estimates and local planning.

Identification of the population sampling frame is challenging because of the nature of the adults under scrutiny. After consultation, one of several options to tackle this has been proposed as the most practical. This is to access older people living in 'extra care' housing, which includes sheltered, warden assisted and supported housing for older people. This approach could be assisted by endorsement and the support of local authorities.

The benefits of this approach are that older people are clustered together in such developments and there is usually a warden of some sort who is known to the residents who could broker initial contacts. The people who reside in such establishments have, by definition, a medical or social condition which means that they require support of some sort so it gives access to a large sample of the population of mildly dependent older people.

Table of descriptors:

Providers	This describes companies, individuals, charities, local authorities or other agencies that provide, oversee or run extra care housing for older people
Housing developments	Groups of houses, flats, apartments that provide some type of supported care for older people. These may be described as extra care or sheltered housing or sheltered accommodation or sheltered retirement or assisted living, or charitable provision or Alms houses or Abbeyfield houses. They provide support in a variety of ways including having a warden on site 24 hours a day, visiting support or available on-call or a housekeeper providing meals etc.
Housing units	Describes the individual dwellings within housing developments. They may be flats, houses or apartments, each with their own front door. They may house more than one occupant

Using a single database of all 15,585 extra care housing developments produced by the EAC, the DPHET will divide this to provide information into worksheets for each geographic region in a useable format. These will be sent to DECs for forward

transmission to the fieldwork teams. Major providers of extra care housing will be contacted by DPHET to advise of the forthcoming survey and seek cooperation.

Fieldwork teams will randomly sample housing developments within their area and contact the warden or manager of each sampled development to seek cooperation.

Within each local authority a minimum total of 65 older people will be recruited and undergo the questionnaire interview and clinical examination, drawn from a minimum of 10 developments. In the few instances where there are fewer than 10 developments within a local authority area the sample will need to be drawn using all developments in the area.

The recommended minimum sample can be increased in size if local authorities require more detailed local information through their commissioning process with advice from consultants in dental public health based in PHE centres.

Fieldwork teams will use the centrally provided data base to undertake local random sampling. Within each local authority unique numbers will be given to each housing development and random number generation used to sample 15 or more and the order of selection recorded. This should allow for refusals on the part of providers or development managers.

The fieldwork teams will contact the provider of each of the sampled developments to explain the purpose and nature of the survey and seek their approval and support. Where this is given the contact details of the site manager will be requested to allow the next stage of communication.

The fieldwork teams will send a letter to the managers of the first four or five sampled developments to explain the purpose and nature of the survey and seek cooperation. This will be followed up a few days after the letter has arrived with a telephone call to the development manager to answer any questions they may have and confirm their willingness to assist.

Where development managers decline to take part, this should be recorded and the next sampled development on the list approached.

Where cooperation is agreed the development manager will be asked to provide a list of occupied housing units on the site. Where there are more than twelve housing units a random sampling method will be applied to select 10 housing units. Letters addressed to the occupier(s) of each sampled unit will be delivered either by the fieldwork team or the site manager. These will explain the purpose and nature of the survey, give contact details for questions the potential volunteer may have and include

a day and time when the development will be visited by the fieldwork team to undertake the questionnaire and clinical examination. A response slip will be included in this letter for potential volunteers to indicate their willingness to take part and provide contact details. These slips will be returned either to the manager or in a reply paid envelope, whichever method is agreed at each site.

This process of contacting sampled developments, seeking cooperation of the provider and then the manager and seeking consent of a sample of residents will be continued until the minimum sample requirements have been met. A maximum number of about 10 residents should be involved in each development, except where there are fewer than 10 developments within the local authority area.

The numbers of developments across England are large and most LAs have sufficient for the required samples. The status of the provider, state, charitable or independent, is not relevant to this survey. Developments which do not provide some type of support will not be included.

Numbers of extra care housing developments in England:

Descriptor	Numbers of developments
Enhanced sheltered accommodation	392
Extra care housing	803
Sheltered housing	14,390

4.3 Recruitment

The number of residents at each development receiving letters seeking cooperation should be recorded so that the numbers and proportions of those volunteering and those refusing can be recorded.

From the returned ‘willingness’ slips details of the volunteers, including methods of contact, will be recorded on the tracking sheet. The fieldwork team will contact each volunteer to arrange a suitable time to visit, respond to any questions, sign the consent form (see 4.4), run the questionnaire and carry out the short clinical examination. Small gifts to indicate appreciation for taking part may be given.

Dental epidemiology fieldwork teams will comply closely with the principles of ethical recruitment:

Figure 1
Principles of ethical recruitment

All prospective volunteers will be approached in a sensitive manner and asked if they would be willing to take part in a survey of adult dental health.

No coercion, inducement or financial reward will be provided.

The provision of dental treatment will be unaffected by the participation or non-participation of potential volunteers and this will be made clear to them.

Information sheets will be provided for all potential volunteers. A core information sheet is provided (Appendix J) and fieldwork teams should make minor amendments only to show their organisation details.

The information sheet should be read out to those who have difficulties reading English.
In circumstances where mental capacity or understanding is limited the survey team should explain the purpose and nature of the survey, in terms which are appropriate.

Potential volunteers should be given sufficient time to consider whether or not they wish to take part, three days as a minimum.

Positive consent should be obtained prior to commencement of the questionnaire or clinical survey. This should be written using the agreed consent form (Appendix K) which should be completed with a unique ID number of each volunteer. Where only verbal consent can be obtained this should be recorded and witnessed.

In cases where an adult is unable to give consent because of mental incapacity no other adult can consent on their behalf. This should be assessed using the guidance provided in Appendix P. In such cases the adult will not be recruited into the survey but recorded among all those approached.

Respondents will be provided with repeat opportunities to opt-out of participating in the survey, and those that do will be regarded as survey non-responders. It is expected that there will always be non-responders to voluntary sample surveys, but it is important to try to minimise non-response to maximise the confidence in the reliability of the survey estimates.

It is important that all steps are followed in the sampling and recruitment process to ensure maximum compliance whist upholding the ethical principles listed above.

4.4 Consent

Respondents will be given clear explanations, verbally and in writing, of the purpose of the study, confidentiality issues and the way in which the data would be used (Appendix J). All of the interviews and clinical examinations will be conducted on a voluntary basis and fieldwork teams will not interview or examine someone who is unwilling to take part.

The steps taken to ensure informed consent, without pressure or inducements, are described here which is to be read in conjunction with Figure 1.

Each fieldwork team will adapt all survey documents only in terms of the logo and details about their organisation.

Individuals who agree to participate will still have the opportunity to opt out of the dental examination, to refuse to answer a particular question and to withdraw from either interview or examination at any time.

4.4.1 Capacity to provide informed consent

Some adults may have limited capacity to provide consent. The protocol (Appendix P) outlines to interviewers, how to judge which volunteers should consent for themselves and which are unable to do this. In addition the process will be covered in the survey specific training provided to interviewers. In cases where it is judged that the potential volunteer does not have the capacity on that occasion to take part in the survey then the fieldwork team should not continue. Assent will not be sought.

4.4.2 Additional consents

In the event of any serious oral pathology being identified, written consent will be sought for information to be sent to the respondent's general practitioner (GP) and general dental practitioner (GDP) by the fieldwork team lead clinician or their clinical director (Appendix U and Appendix V) so that they can be referred using the local fast track process.

If the respondent does not have a GDP or GP or does not want their GP contacted, then they will be presented with an information letter urging them to pursue an examination with a dentist and information to facilitate this (Appendix W). In such cases the lead clinician should make repeated attempts over some days to explain the importance of seeking care.

4.5 Inclusion criteria

To be included in the interview:

- adults who come within the defined population (and have been selected as part of a random sampling procedure, where used)
- adults aged 65 or over
- those who have the ability to be able to understand the purpose and nature of the survey and be able to give informed consent to both the interview and the clinical examination
- adults who have the ability to either complete the questionnaire for themselves by providing answers that can be recorded by the interviewer or have answers provided by their carer or representative

To be included in the dental examination:

- the inclusion criteria above, plus
- the ability to co-operate sufficiently with the clinical examination for it to be completed satisfactorily and safely

Physical disability *per se* should not exclude anyone from taking part but may affect their choice about whether to do so.

In some circumstances the examination or the questionnaire may not be completed and this should be recorded using the coding provided. The number of part-completed questionnaire and clinical examinations will be reported.

Only completed questionnaires or completed examinations will be analysed, it will not be a requirement that both must be completed to be included in central analysis.

Where neither the clinical examination nor the questionnaire is completed a further randomly sampled and consented person should be a substituted.

4.6 Exclusion criteria

Adults who do not come within the defined population under scrutiny or have not been selected as part of a random sampling procedure, where used.

Individuals who are unable to understand the information detailing the purpose and nature of the survey and those for whom informed consent cannot be provided will be excluded. Those who cannot cooperate sufficiently for the clinical examination to be completed in a safe manner will be excluded from the clinical examination.

The number of potential volunteers who are unable to consent will be reported.

The number of consented volunteers who were unable to take complete both the clinical examination and the questionnaire, and who therefore should be substituted, will be reported.

No individual or group will be excluded on grounds of race, gender, religious beliefs or sexual orientation.

4.7 Survey procedure

4.7.1 Identification numbers

Each volunteer who agrees to be contacted must be given a unique identity number (ID) which, when used with the local authority code, will provide a unique ID for all participants in the nationally collated databases. For each local authority it is a simple matter of numbering their volunteers from 001 to 002 upwards.

For example, the third volunteer to agree to be contacted in Aylesbury Vale would have the following ID number:

Lower-tier local authority number									Number of participant		
E	0	7	0	0	0	0	0	4	0	0	3

The numbers of potential volunteers approached, agreeing and declining to take part will be recorded and details of willing volunteers will be recorded onto the tracking sheet and whether they were able to take part or not, with a reason code being given for the latter.

The name of willing people and contact details should be recorded only for approach and recruitment purposes. If the age band, gender and type of accommodation were also recorded this would facilitate the reporting of a measure of uptake. This information about numbers and proportions of consenters, their age and gender will be used centrally to assess the level of acceptance the survey was able to achieve. Residents of extra care establishments are likely to have the same postcode as many others so records will not be identifiable at individual level.

4.7.2 The interviewer administered questionnaire

The interview and clinical examination is expected to take no more than about 30 minutes for each adult. In some cases this may take longer depending on the needs of the volunteer.

The interview will be completed face to face and onto paper by the specifically trained fieldwork administrative supporter. A carer of someone who knows the volunteer well may help with answering the questionnaire.

The questionnaire will cover the following areas:

- a broad measure of dependency
    - services coming into the home to help
    - ability to maintain good oral hygiene
    - ability to access clinical treatment
- a measure of mobility
- a simple measure of recall ability
- current problems with teeth and mouth, including dentures
- the impact on eating and socialising of problems with teeth
- recent dental attendance
- barriers to dental attendance

4.7.3 The clinical examination

The examination aims to establish the general condition of the mouth and the need for treatment. It does not lead to a decayed, missing, filled teeth (DMFT) measure or detailed periodontal score but, rather, will provide information which is more useful about function, impact and treatment needs. A similar method was adopted for the supplementary adult sub-group (SASG) surveys. Details of the method are given in Appendix R.

The dental examination will be carried out on consenting respondents. The following data will be collected by the specifically trained dental clinician and recorded onto the data collection sheet:

- the number of natural teeth present
- presence and condition of dentures
- an assessment of the number of posterior segments with one or more tooth-to-tooth or tooth-to-replacement contacts
- the presence of visible plaque and calculus
- the need for treatment and type and suggestion method of provision
- any significant conditions with treatment implications such as soft tissue pathology

The dental examination is likely to take less than 15 minutes on average, depending on the number of natural teeth and the ability of the respondent to cooperate. Respondents with both natural teeth and dentures may have a slightly longer examination than those with just natural teeth. The clinical examination will be well within the normal competence of a qualified dental surgeon or therapist.

4.7.4 Equipment

The following equipment will be required by each survey dental clinician:

- head torch – no standard model suggested (Appendix L)
- No. 4 plane mouth mirrors
- straight probes (CPITN or standard probe blunted to 0.3 mm)
- paper covers and trays for instruments
- latex and powder free gloves
- sterile wipes and gel for hands

- yellow bags for disposal of waste[5]
- extension lead and circuit breaker – only if a laptop is being taken into the field
- protective spectacles for participant

Infection control will be a priority and will comply with local protocols. Each examining team will carry sufficient sets of pre-sterilised instruments to ensure that there are a fresh set of sterilised instruments for every examination. Examiners will wear a new, clean pair of rubber gloves for each examination.

4.8 Personnel and working safely

Each fieldwork team will include, as a minimum:

- a qualified dental surgeon or therapist, trained in the procedure for the survey clinical examination at a national training event provided by PHE or local training events overseen by DECs. Ideally the clinician should have experience of undertaking dental epidemiological surveys and working with vulnerable adults in a domiciliary setting
- an administrative support worker who has received training in carrying out the questionnaire at a national training event provided by PHE or local training events overseen by DECs. Ideally the administrative support worker should have experience of undertaking dental epidemiological surveys and working with vulnerable adults in a domiciliary setting

All team members will be required to have criminal records bureau (CRB) or disclosure and barring service (DBS) certificates, obtained or updated in the previous three years and vulnerable adult safeguarding training at a level commensurate with their role as clinicians, the majority of which will already be in place because of the clinical work they undertake on a daily basis and the vulnerable groups for whom they usually provide clinical care.

All team members will abide with their employing organisation's policies with regards to health and safety matters during their work, reporting accidents or safety issues including loss or theft of equipment and these will be followed. Particular attention should be paid to the circumstances they may face when working in private households

5 The dentist will be responsible for disposal of waste following the same procedure for domiciliary dental visits that they usually use, according to their employer's policy.

with the general public, including how to travel safely, staying safe in public places, how to approach addresses, and maintaining personal safety whilst interviewing.

Fieldwork teams will always undertake the two elements of the survey in pairs. They will abide by their own employing organisation's guidance on continually assessing risk whilst approaching an address, and during any time at the address.

The total resources involved in carrying out this clinical survey and the questionnaire are likely to be similar to that required for traditional child cohort surveys.

4.9 Training

The teams will receive training on the methodology and support material will be provided by PHE DPHET.

National and local training events will give details of the procedure of undertaking the questionnaire and the clinical examination.

The DPHET will provide national training for DECs and dental epidemiology trainers on the conduct of the survey. These centrally trained DECs and trainers will provide local training events for fieldwork teams in their allocated areas in a similar way to other surveys in the PHE Dental Public Health Epidemiology Programme (DPHEP). Only personnel who have been trained nationally or locally may undertake surveys using this protocol. Calibration is not therefore necessary for this survey.

Objectives of national and local training:

- to train DECs, epidemiology trainers and fieldwork teams to be able to work through the relevant processes of sampling, approaching, recruiting and surveying older people according to this protocol

- to train support staff to ask questions of volunteers from the questionnaire and record response data accurately

- to train clinical examiners to undertake reproducible examinations for the study

- to ensure fieldwork personnel know how to enter the data and handle it according to data protection guidelines

4.10 Confidentiality and data security

Security of data is of top priority and fieldwork teams will take seriously the pledges of confidentiality given to respondents and all legal and moral obligations placed upon them.

4.10.1 Confidentiality

All members of the fieldwork teams - administrators, recorders, and registered dental clinicians - will at all times work to the principles of confidentiality as laid out by the NHS Code of Practice which incorporates the Caldicott principles of confidentiality.[6] PHE partners will apply the PHE Information Security Policy.[7]

4.10.2 Data security

The employers of all fieldwork teams should be notified under the Data Protection Act as having data bases containing details of individuals. All staff should be aware of the obligations this act imposes on them. All the organisations involved are experienced in working in accordance with strict data management protocols within the health data field and will adhere to the best possible standards of data protection, privacy and ethical practice.

In the field all survey information will be collected onto paper using only ID numbers. No participant identifiable information will be recorded onto data collection sheets (except in the rare situation when oral pathology giving concern is noted, and it is in the participant's interest to ensure that rapid referral is made). Data will be transferred from paper records to a dedicated computer program at the fieldwork base as soon as is practically possible and the paper files kept securely and separately from the electronic records. No individual identifiable information will be recorded onto computer records and the computer program will be accessible only to those involved in dental epidemiological surveys and the computers used should be password protected.

In some cases data may be collected direct onto computer but this must be done with strict protocols in place for data protection and back up.

DECs will upload data from fieldwork teams to DPHET to a restricted access shared site. All confidential data and documents will be securely destroyed when no longer required, according to local protocols.

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6 Department of Health. Confidentiality NHS Code of Practice. (2003). Gateway Ref 1656
7 PHE Information Security Policy. Information Security Policy. March 2015. Document code: IG04 Version: 02.00

The collated data will be used for statistical research purposes only and no outputs will identify individual respondents.

4.11 Feedback on the clinical examination

In line with current ethical practice, feedback can be provided to each person who takes part in the examination. The procedure will follow that agreed for the 2009 ADHS. The administrator is permitted to say, when contacting potential participants, that the clinical examiner may be able to offer them some advice on the best way of looking after their mouth or teeth. If, after the examination, the subject wishes to know about the general condition of their dental health then the examiner can give an indication of whether there is room for improvement in terms of the general oral hygiene/ cleanliness using one of four statements, which generally categorise the respondent's dental health and treatment needs (category 4 is equivalent to the serious pathology procedure detailed in Appendix U).

Appendix T details the scripts that should be used for each category of volunteer, depending on the clinical findings.

The categories are:

- Category 1 No obvious oral problems (used for anyone with no obvious disease requiring further assessment)
- Category 2 Minor issues requiring a dental check-up (used for anyone with obvious disease requiring further assessment)
- Category 3 Obvious or progressive oral disease requiring a dental examination within one month (used for anyone who scores 1 on the PUFA index)
- Category 4 Suspected serious pathology (used if the examining dental clinician notices a lesion which he /she considers may be serious and potentially life threatening, such as a suspected malignancy)

The protocol for dealing with a suspected serious pathology is outlined within Appendix U and is consistent with the procedure in place for the 1998 and 2009 ADHS.

It should be noted that examiners are highly unlikely to encounter such serious pathology in this survey because:

- the incidence of such lesions is low

- the examination is not a screening exercise for such lesions
- the examination does not involve detailed examination of all the oral soft tissues

The lead clinician of the fieldwork team will take responsibility for taking appropriate action on any report of serious pathology, using normal local fast track protocols and pathways. If the respondent does not have a GP or a GDP or does not want their GP or GDP contacted, then they will be presented with an information letter urging them to pursue an examination (Appendix W).

4.11.1 Dealing with further questions

Examining clinicians cannot be specific about dental treatment need or on the standard of previous dental treatment because the examination is not designed to collect the information required to make these assessments. If the respondent probes for more specific detail on their dental health, dental examiners will respond, if appropriate, by using general principles to identify areas for improvement, but say that the person will need more specific advice from a registered dental clinician since there are many ways of achieving this. They will preface this response by saying:

'What I generally tell people is…….'

If asked to comment on specific aspects of past treatment, dental clinicians will respond along the lines of:

'This survey is limited and you need to see your (or a) dentist for specific advice and/or treatment'

The fieldwork team will ensure they have up to date information available to pass to volunteers about finding a dentist if they do not have one at the time of examination.

5 Reporting of data

Prior to sending on data files, each fieldwork team is responsible for checking their data for inaccuracies. Guidance will be provided which will give a step-by-step guide to the whole data handling process. This will be available from www.nwph.net/dentalhealth

Once data have been checked and errors corrected, files should be correctly labelled according to the guidance and sent on to PHE DECs to upload securely. Separate files should be formed for each local authority, labelled to indicate the local authority to which they refer.

The following will be reported using summary reporting sheet (Appendix X):

1) Start and finish dates of the period of examinations (dd/mm/yyyy–dd/mm/yyyy)

2) Total number of extra care housing sites in the local authority area

3) Number of extra care housing developments sampled

4) Number of sampled extra care housing developments contacted

5) Number of sites where warden or manager agreed to assist

6) Number of residents at sampled and contacted developments where manager agreed to assist

7) Number of residents who were contacted

8) Number of contacted residents who consented to take part with questionnaire

9) Number of contacted volunteers who consented to take part with clinical examination

10) Number of consented volunteers who could complete neither the clinical examination nor the questionnaire

Data will be submitted as cleaned Dental SurveyPlus 2 (DSP2) data files or Excel files using the centrally provided DSP2 or Access formats for data input. Summary reporting sheets will be submitted as completed Word documents using (Appendix X).

All returns should be made to DECs as soon as possible after completion of the survey and no later than 31st July 2016.

Files can be passed:

- by hand on password protected memory sticks directly to the DEC
- sent as e-mail attachments from an nhs.net address to an nhs.net address

- sent as e-mail attachments from a phe.gov.uk address to a phe.gov.uk address

and should include:

- the completed summary reporting sheet (Appendix X)
- the DSP2 survey files or Excel files labelled to indicate which local authority they refer

6 Table of appendices

* Documents available in Word format from www.nwph.net/dentalhealth
~ Available in large print version
^ Documents available in pdf format from www.nwph.net/dentalhealth

Appendix A. Statutory Instrument 2012, No. 3094 - **extract**

STATUTORY INSTRUMENTS

2012 No. 3094

NATIONAL HEALTH SERVICE, ENGLAND SOCIAL CARE FUND, ENGLAND PUBLIC HEALTH, ENGLAND

The NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations 2012

Made - - - - 12th December 2012
Laid before Parliament 17th December 2012
Coming into force in accordance with regulation 1(2)

Extract from pages 8, 9, 26 and 27

PART 4

DENTAL PUBLIC HEALTH FUNCTIONS OF LOCAL AUTHORITIES

Interpretation

16. In this Part—

"oral health promotion programme" means a health promotion and disease prevention programme the underlying purpose of which is to educate and support members of the public about ways in which they may improve their oral health;

"oral health survey" means a survey to establish the prevalence and incidence of disease or abnormality of the oral cavity;

"water fluoridation programme" means fluoridation arrangements made under section 87(1) (fluoridation of water supplies at request of relevant authorities) of the Water Industry Act 1991(**g**)[8].

8 (**g**) 1991 c.56. Section 87(1) is substituted by section 58(1) and (2) of the Water Act 2003 (c.37).

Exercise of functions of local authorities

17.—

(1) Each local authority (**h**)[9] shall have the following functions in relation to dental public health in England.
(2) A local authority shall provide, or shall make arrangements to secure the provision of, the following within its area—

(a) to the extent that the authority considers appropriate for improving the health of the people in its area, oral health promotion programmes;

(b) oral health surveys to facilitate—
(i) the assessment and monitoring of oral health needs,
(ii) the planning and evaluation of oral health promotion programmes,
(iii) the planning and evaluation of the arrangements for provision of dental services as part of the health service, and
(iv) where there are water fluoridation programmes affecting the authority's area, the monitoring and reporting of the effect of water fluoridation programmes.

(3) The local authority shall participate in any oral health survey conducted or commissioned by the Secretary of State under paragraph 13(1) of Schedule 1 to the 2006 Act (powers in relation to research etc.)(**a**)[10] so far as that survey is conducted within the authority's area.

Revocations and transitional arrangements

18.—

(1) The Functions of Primary Care Trusts (Dental Public Health) (England) Regulations 2006(**b**)[11] ("the 2006 Regulations") are revoked.

(2) This paragraph applies where, in the exercise of its functions under the 2006 Regulations, a Primary Care Trust—
(a) provided an oral health promotion programme or an oral health survey which was ongoing immediately prior to section 29 of the 2012 Act coming fully into force, or
(b) participated in an oral health survey required by the Department of Health which was ongoing immediately prior to section 29 of the 2012 Act coming fully into force.

(3) Where paragraph (2) applies, each local authority whose area fell wholly or partly within the area of the Primary Care Trust shall continue to carry out the oral health promotion programme or oral health survey, to the extent that the programme or survey relates to persons in the local authority's area.

Signed by authority of the Secretary of State for Health.

Anna Soubry
Parliamentary Under-Secretary of State for Health,
Department of Health

12th December 2012

9 (**h**) *See* section 2B(5) of the 2006 Act for the definition of "local authority", which is also applied to section 111 by virtue of section 111(3) of that Act.
10 (**a**) Paragraph 13 of Schedule 1 to the 2006 Act is substituted by section 17(2) and (13) of the 2012 Act.
11 (**b**) S.I. 2006/185.

EXPLANATORY NOTE

(This note is not part of the Regulations)

These Regulations make provision in relation to the designation of certain NHS bodies as Care Trusts, the public health functions of local authorities and Local Healthwatch organisations.

Part 4 specifies the functions to be exercised by local authorities in relation to dental public health in England.

The functions to be exercised by local authorities in relation to dental public health in England as specified in Part 4, relate to the provision of oral health promotion programmes and oral health surveys. In the case of oral health surveys, local authorities must make their own arrangements for oral health surveys and must also participate in any such surveys conducted or commissioned by the Secretary of State.

Appendix B1. Certificate indicating survey would not require research ethical approval if it is not considered to be research

NHS
Health Research Authority

MRC Medical Research Council

To print your result with title and IRAS Project ID please enter your details below:

Title of your research: Dental public health epidemiology programme. Oral health survey of older people 2015-16

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'No'** - Are your findings going to be generalisable?

Your study would NOT be considered Research by the NHS.

You may still need other approvals.

Researchers requiring further advice (eg those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of this results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at HRA.Queries@nhs.net.

For more information please visit the Defining Research leaflet

Follow this link to start again.

NOTE: If using Internet Explorer please use browser print function.

- About this tool
- Feedback
- Contact
- Glossary

Appendix B2. Certificate indicating survey would not require research ethical approval if it is considered to be research

NHS
Health Research Authority

MRC Medical Research Council

Do I need NHS REC approval?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research: Dental public health epidemiology programme. Oral health survey of older people 2015-16

IRAS Project ID (if available):

Your answers to the following questions indicate that **you do not need NHS REC approval for sites in England.** However, **you may need other approvals.**

You have answered ***'YES'*** to: Is your study research?

You answered ***'NO'*** to all of these questions:

Question Set 1

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?
- Is your study a clinical trial involving the participation of practising midwives?

Question Set 2

- Will your study involve research participants identified from, or because of their past or present use of services (adult and children's healthcare within the NHS and adult social care), for which the UK health departments are responsible (including services provided under contract with the private or voluntary sectors), including participants recruited through these services as healthy controls?
- Will your research involve collection of tissue or information from any users of these services (adult and children's healthcare within the NHS and adult social care)? This may include users who have died within the last 100 years.
- Will your research involve the use of previously collected tissue or information from which the research team could identify individual past or present users of these services (adult and children's healthcare within the NHS and adult social care), either directly from that tissue or

information, or from its combination with other tissue or information likely to come into their possession?
- Will your research involve research participants identified because of their status as relatives or carers of past or present users of these services (adult and children's healthcare within the NHS and adult social care)?

Question Set 3

- Will your research involve the storage of relevant material from the living or deceased on premises in the UK, but not Scotland, without an appropriate licence from the Human Tissue Authority (HTA)? This includes storage of imported material.
- Will your research involve storage or use of relevant material from the living, collected on or after 1st September 2006, and the research is not within the terms of consent from the donors, and the research does not come under another NHS REC approval?
- Will your research involve the analysis of DNA from bodily material, collected on or after 1st September 2006, and this analysis is not within the terms of consent for research from the donor?

Question Set 4

- Will your research involve at any stage intrusive procedures with adults who lack capacity to consent for themselves, including participants retained in study following the loss of capacity?
- Is your research health-related and involving prisoners?
- Does your research involve xenotransplantation?
- Is your research a social care project funded by the Department of Health?

If your research extends beyond **England** find out if you need NHS REC approval by selecting the *'OTHER UK COUNTRIES'* button below.

OTHER UK COUNTRIES

If, after visiting all relevant UK countries, this decision tool suggests that you do not require NHS REC approval follow this link for final confirmation and further information.

- NOTE: If using Internet Explorer please use browser print function.

- **About this tool**
- **Feedback**
- **Contact**
- **Glossary**

Appendix C. E-mail letter indicating response from the Social Ethics group

Dear Gill Davies,

Many thanks for your query. The Social Care Research Ethics Committee (Social Care REC) follows the same governance arrangements and standard operating procedures as other Health Research Authority/National Research Ethics Service (NRES) committees. Therefore if you have viewed the NHS Research Authority guidelines and deemed that this application does not need require review by an NHS REC the same will be true for the Social Care REC.

For information I am including the remit of the Social Care REC.

1. Social care studies funded by Department of Health.
   - Research commissioned directly through the Policy Research Programme.
   - Health and Social Care Information Centre (HSCIC) studies (ie those to be designed by HSCIC for implementation by Councils with Adult Social Services Responsibilities, who do not then individually need to seek additional review).
   - Studies commissioned by or through National Institute for Health Research (NIHR) School for Social Care Research.
   - Social care studies funded (in rare cases) through NIHR.
2. Social care research that involves people lacking capacity in England and Wales and requires approval under the Mental Capacity Act 2005. The Social Care REC is recognised by the Secretary of State as an Appropriate Body for this purpose.
3. Social care research involving sites in England and another United Kingdom country.
4. 'Own account' research undertaken by Councils with social services responsibilities, where the Chief Investigator and/or sponsor feels there are substantial ethical issues.
5. Studies of integrated services (health and social care), provided that there is no clinical intervention involved.
6. Studies taking place in NHS settings with NHS patients where the approach uses social science or qualitative methods, provided that the research does not involve any change in treatment or clinical practice.
7. Intergenerational studies in social care, where both adults and children, or families, are research participants.
8. Other social care studies not suitable for review by other NRES RECs, subject to the capacity of the Social Care REC. This could include service user-led research.
9. Adult social care research involving changes in, or the withdrawal of, standard care.

Social care research does not require review by the Social Care REC if it is reviewed by another committee operating in accordance with the ESRC's Framework for Research Ethics; unless sections 1 or 9 above apply or the research involves NHS patients or service users as research participants. A review is required if there is a legal requirement for REC review eg under the Mental Capacity Act. Student research within the field of social care should ordinarily be reviewed by a University REC (UREC). If a UREC review is not available to a student, they can contact the Co-ordinator for advice.

The Social Care REC does not consider any research involving clinical interventions. Such research should be reviewed by another appropriate REC within the NRES.

I have also attached two documents which state which studies need to be reviewed by a REC – Governance Arrangements for RECs (GAfREC) and an algorithm - Does my project require

review by a REC? These documents also give details of the exemption for review if studies are reviewed in accordance with the ESRC's Framework for Research Ethics.

As you will see paragraph 2.3.8A of GAfREC provides an exception from the normal requirement for review by a REC within the UK Departments' Research Ethics Service where a research project (adult social care) is reviewed by another committee operating in accordance with the Economic and Social Research Council's Framework for Research Ethics, unless any of the following apply:

a) the research involves withdrawing standard care;
b) the research involves NHS patients or service users as research participants;
c) the research is a social care research project funded by the Department of Health in England; or
d) there is a legal requirement for REC review of the research (eg the research involves those lacking capacity to consent, which requires review in accordance with the Mental Capacity Act 2005)

The effect of this exception is that some social care research (eg student research) does not require REC review, provided that it is reviewed by a committee operating in accordance with the ESRC Framework (for example, a UREC). Projects meeting these criteria should normally be reviewed by a UREC or another committee where possible. However, applications may be made to the Social Care REC where review by another committee is not available.

Further clarification can be found in the algorithm. The sections relating to social care can be found in Section C, page 8 and Section 7, pages14 and 15.

Researchers should note that REC review for social care research in England (adult social care only), Wales and Northern Ireland (adult and children' social care) is still required where:

i) a legal requirement applies (eg under the Mental Capacity Act)
ii) the study has DH funding
iii) the study involves withdrawing any aspect of standard care from social care users
iv) the study involves NHS patients recruited in the social care setting, or a mix of NHS patients and social care users; or
iv) review by another REC operating in accordance with the ESRC Framework is not available

Ultimately, it is up to the chief investigator and the sponsor to decide if a study needs an ethics review. From the information you have supplied, especially that you do not consider this project to be research; my opinion would be that you do not require an ethics review from the Social Care REC.

Best wishes

Barbara Cuddon | Social Care Research Ethics Committee Co-ordinator | Social Care Institute for Excellence | T: 020 7535 0900 | F: 020 7535 0901 | Direct Line: 020 7535 0905 | W: www.scie.org.uk | Second Floor, 206 Marylebone Road, London NW1 6AQ

Appendix D. Letter of support from Director of Dental Public Health, Public Health England, to Directors of Public Health and Directors of Adult Services

Protecting and improving the nation's health

Dental Public Health,
Skipton House,
80 London Road,
London, SE1 6LH

Tel: +44 (0)20 7654 8179
www.gov.uk/phe

To: Directors of Public Health for forwarding to Directors of Adult Services

09 September 2015
Gateway number: 2015 - 305

Dear Director of Public Health and Directors of Adult Services,

Re: National oral health survey of older people in England

As the nation is living longer, concerns about the health needs of elderly people are becoming increasingly important. Oral health is central to this as a greater proportion of people now retain more of their natural teeth throughout their life.

Public Health England (PHE) is responsible for coordinating annual surveys of the nation's oral health to support local authorities to undertake a health needs assessments of their population. This year we would like to look at the oral health needs of older people living in extra care housing in England, the full protocol is available from the PHE website at http://www.nwph.net/dentalhealth/

This letter is to ask you to support the survey, which is the first of its kind, and confirm your support to local site providers and managers outside of your local authority, if needed.

How will this happen?

Local fieldwork teams employed by the NHS will randomly sample a small number of extra care housing sites within each local authority area and they will contact providers of sampled sites to seek agreement to proceed. We would ask that local providers of extra care housing be contacted and encouraged to assist the fieldwork teams, if required. The fieldwork teams will be able to provide the list of housing units sampled which should not be many more than ten venues.

The survey will consist of a brief dental examination and a short questionnaire to be carried out in the homes of volunteers by trained teams. The teams will include a dental clinician and a support worker who will be trained and experienced in working with vulnerable people.

Why are PHE organising this survey?

National surveys of children's oral health are undertaken regularly by PHE and the resulting information has helped the NHS to plan treatment services, and LAs provide programmes to improve oral health and reduce inequalities. Public Health England has developed good insight into the oral health of older people living in residential and nursing care but little is known about those who live more independently.

The survey results will inform specially commissioned dental care services and ultimately help to improve the oral health of older people who have a degree of dependency. The survey data a full report should be available in early in 2017 and will also be very valuable for local authorities and dental health professionals who will gain an understanding of the prevalence of oral conditions among this group and subsequently will be able to target resources effectively.

We would very much welcome your expressed support so that providers respond positively and make this survey a success.

Yours sincerely,

Dr Sandra White,
Director of Dental Public Health
E: sandra.white@phe.gov.uk

Appendix E. Letter of support from Director of Dental Public Health, Public Health England, to major providers of extra care housing

Public Health England

Protecting and improving the nation's health

Dental Public Health,
Skipton House,
80 London Road,
London, SE1 6LH

Tel: +44 (0)20 7654 8179
www.gov.uk/phe

25 August 2015
PHE Gateway Number: 2015-283

Dear Sir / Madam,

Re: National oral health survey of older people in England

Taking part in the Public Health England oral health survey of older people
As the nation is living longer, concerns about the health needs of elderly people are becoming increasingly important. Oral health is central to this as a greater proportion of people now retain more of their natural teeth throughout their life.

Public Health England (PHE) is responsible for coordinating annual surveys of the nation's oral health to support local authorities to undertake a health needs assessments of their population. This year we would like to look at the oral health needs of older people living in extra care housing in England. This letter is to ask your organisation, as an important provider of extra care housing, to support the survey, which is the first of its kind, and confirm your support to local site managers.

How will this happen?
Local fieldwork teams employed by the NHS will randomly sample a small number of extra care housing sites within each local authority area and contact providers of sampled sites to seek agreement to proceed. We would ask that the local managers of the sampled sites be contacted and given permission to assist the fieldwork teams as required.

The survey will consist of a brief dental examination and a short questionnaire to be carried out in the homes of volunteers by trained teams. The teams will include a dental clinician and a support worker who will be trained and experienced in working with vulnerable people.

Why are PHE carrying out this survey?
National surveys of children's oral health are undertaken regularly by PHE and the resulting information has helped to plan treatment services, provide programmes to improve oral health and reduce inequalities. Public Health England has developed good insight into the oral health of older people living in residential and nursing care but little is known about those who live more independently.

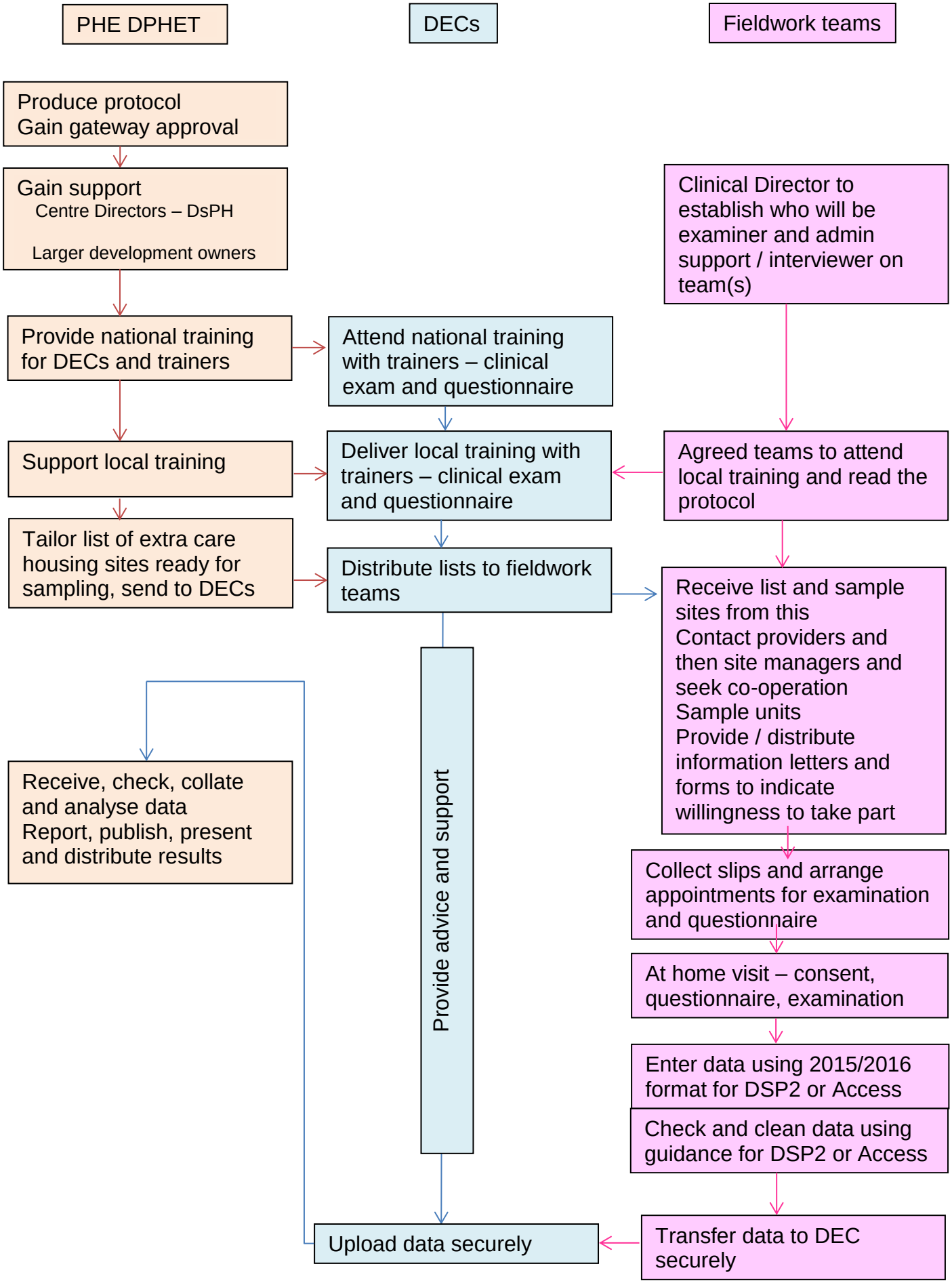
The survey results will inform specially commissioned dental care services and ultimately help to improve the oral health of older people who have a degree of dependency. The survey will also be incredibly valuable for local authorities and dental health professionals who will gain an understanding of the prevalence of oral diseases such as tooth decay among this group and subsequently will be able to target resources effectively.

We would very much welcome your organisation's support should some of your sites be randomly sampled.

Yours sincerely,

Dr Sandra White,
Director of Dental Public Health at Public Health England
E: sandra.white@phe.gov.uk

Appendix F. Stages to undertake the survey



Appendix G. Operational timetable

Training for dental epidemiology coordinators (DECs) and trainers – national protocol	3 July 2015
Local training for fieldwork teams	As soon as can be arranged following national training
Data collection and ongoing data entry	To start as soon as possible and completed by 30 June 2016
Completion of data checking and labelling of local authority data files. Secure forwarding of cleaned data files to DECs as soon as possible before deadline.	By 31 July 2016
DECs to upload summaries and copies of local authority data files to the dental public health epidemiology team (DPHET) shared folder - DEC upload files	To be uploaded as and when they have been checked, completed by 31 August 2016.
DPHET - Checking of data, returning errors for clarification by fieldwork teams via DECs, and collation of clean, verified data	As and when data files arrive.
Knowledge and Information Team North West (NW KIT)/DPHET – compute estimates for local authorities	From September 2016.
Publication of results on website www.nwph.net/dentalhealth	December 2016 or four months after receipt of last data set dependent upon PHE gateway.
Feedback of cleaned data – to be advised	Quarter 1 or 2 of 2017 or five months after receipt of last data set.
Publication of results in 'Community Dental Health'	June 2017 dependent upon receipt of last set of data.

Appendix H. Sample letter for site managers

Local logo
Address of local epidemiology team lead
and tel number

Date

Dear

I am writing to you to ask if you would be willing to help with a national survey of adult dental health. We would like to include a sample of the residents at the extra care housing site you cover. The survey itself would consist of a questionnaire about dental health and dental treatment services and an easy check of the volunteer resident's teeth, both of which we can do in their home.

This is part of a national survey and will help to give your local NHS information to help them provide services to suit the needs of the older population. Local authorities are required by law to assess the health needs of the population and this survey is a way of doing this.

We would ask managers of extra care sites to list the numbers of residential units at their site and help to distribute invitations to a small sample of residents, and then collect the response slips of those who wish to take part. We will not ask you for names or contact details of residents – these would only be provided by those who send back their reply slips and agree to take part.

The accompanying information sheet should answer most of your questions but if you have any others please telephone the number above.

You are free to choose whether to take part or not and the future treatment of residents will not be affected in any way by your or their choice.

I do hope you will feel able to help with this and improve the planning of dental services for older people. Someone from the local fieldwork team will telephone you in a few days to see if you have any further questions and find out if you are happy to help.

Yours sincerely

Survey dentist

Appendix I. Sample letter of invitation for potential volunteers - can use larger font

Local logo
Address of local epidemiology team lead
and tel number

Date

Dear

I am writing to you to ask if you would be willing to take part in a national survey of adult dental health. This would consist of a questionnaire about your dental health and dental treatment services and an easy check of your teeth, both of which we can do in your own home.

This is part of a national survey and will help to give your local NHS information to help them provide services to suit the needs of the population. Local authorities have to assess the health needs of the population and this survey is a way of doing this.

The accompanying information sheet should answer most of your questions but if you have any others please telephone the number above.

You are free to choose whether to take part or not and your future treatment will not be affected in any way by your choice.

Please would you complete the form below and send it back using the stamped addressed envelope that has been sent with this letter.

If you agree to be contacted to take part a member of the team will get in touch to arrange the survey with you.

I do hope you will feel able to help with this and improve the planning of dental services.

Yours sincerely

Survey dentist

✂- -

Name ______________________________ Date of birth __ __ / __ __ / __ __

Address____

I am willing / I am not willing to take part in the survey of adult dental health being carried out by____________________________ NHS Trust.

To arrange a time to carry out the survey I can be contacted on ____________________ (telephone number) and the best time to do this is at _________ (time)

Appendix J. Volunteer information sheet

Public Health England
Dental Public Health Epidemiology Programme
Oral health survey of older people, 2015-2016

Why your help is important
This leaflet answers some of the questions you may have about taking part in this survey.

Who are we?
A team, working in the NHS and trained to carry out surveys of dental health. Every year we help to provide information about dental health and use of dental treatment services to help the NHS with planning. Local authorities are now responsible for measuring the health of the population and they want to know about oral health as part of this responsibility.

There is a fully qualified and trained dental clinician on the team and others who help with questionnaires and organising the survey.

What is the survey about?
This year surveys are being carried out all across England to find out more about oral health among people aged 65 and older. This survey will investigate people's dental health and their preference about dental care, including access to dental services. The survey consists of two parts: a quick mouth examination using a mirror only and an interview about dental health with a few questions about your vision as well.

Why is the survey important?
The surveys will provide high quality information on the dental health of a very important group in the population. Information collected will be used to plan dental health services for them in the future.

Our survey partners
NHS fieldwork teams are carrying out this survey with the assistance of Public Health England (PHE) who has a Dental Public Health Epidemiology Team (DPHET) to make sure the survey is done to a high standard all over England.

They work with the Knowledge and Intelligence Team from PHE to collate the information collected and produces reports which are shared widely.

Who will use the results?
The results will be grouped together by PHE and then shared with a range of groups who will use the information to help with their work. This might be the Department of Health and the NHS.

A number of government departments and agencies may also use the results. Survey information may also be shared with researchers who are viewed by PHE as fit to carry out suitable research.

All the answers you give will be treated in strict confidence, as guaranteed under the Code of Practice for NHS agencies and the Data Protection Act, and will only be used for statistical research purposes.

Publications based on the data will be made available on PHE website and might be published in journals from the end of 2016.

None of the reports or publications will mention individuals; they will only talk about groups of people so your information will be anonymous.

Why did we choose you?
As it is not possible to ask everyone to take part in the survey, a sample of older people is selected to represent those in each area. Your housing development has been selected at random from a list of all ‘extra care’ housing sites.

You are important for the survey because the random sample is a cross-section of older people living in circumstances like yours.

Participation in the interview and examination is voluntary, although the success of the survey depends on the goodwill and cooperation of those invited to take part.

Is the survey confidential?
Yes, the information you give us will be treated as strictly confidential as directed by the Code of Practice adopted by the NHS. No identifying information like names or addresses will be recorded on the survey forms – just a number – so it will be anonymous on the paper sheets and when it is entered into the computer.

The information will be used to produce statistics that will not identify any individuals; instead information about groups of people is reported. Survey information is also provided to other approved organisations for statistical purposes only. All such statistics produced are subject to similar codes and the same standards of protection are applied to your information at all times.

Contact us
If you have any queries about taking part in this survey, or complaints, please call **[local number to be entered here]**. [Local availability here -Opening times are 9am–9pm on Monday to Thursday, 9am–8pm on Friday, and 9am–1pm on Saturday.

Alternatively, you can write to:
[Local details here]

Thank you for your help.

Statements in answer to possible questions: (taken from end of main ADHS questionnaire)

The dental clinicians carrying out the examinations work for the NHS salaried services (Community Dental Service) and are qualified to carry out the assessment. All equipment used will be sterilised.

Although this cannot take the place of a regular check-up, the dental clinician will be able to give you some feedback about the condition of your teeth and gums, and as a result give you a recommendation about when you should next visit the dentist.

No X-rays will be taken and the dental clinician will just be looking at your teeth – they may dry them first with cotton wool.

The information you give us will be treated as strictly confidential as directed by the Code of Practice for NHS agencies.

It doesn't matter about the condition of your teeth and gums - that is what we want to record.

The examiners are not looking for bad teeth or for healthy mouths – they just want to record what they find.

The results will help to estimate the NATIONAL requirements for dental treatment rather than your own requirements.

The questionnaire and check will take about 30 minutes at the most.

Your decision to take part will make no difference to the dental treatment you receive now or in the future.

Appendix K. Consent form

Local Trust logo here

Public Health England Dental Public Health Epidemiology Programme
Oral health survey of older people, 2015-2016

CONSENT TO TAKE PART

To be completed by interviewer and participant :

ID NUMBER

1. I (name) _____ have read and understood the information in the leaflet for the above survey. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I consent to take part in a questionnaire as part of this survey [delete this statement if the volunteer declines to take part with the questionnaire]
3. I consent to a dental examination of my teeth and dentures (where applicable) [delete this statement if the volunteer declines to take part with the examination]
4. I have agreed to take part in this study but understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my treatment or legal rights being affected
5. I understand that my information will be treated in strict confidence by the survey team
6. I understand that I may, under certain circumstances, be asked to give consent for my GP to be contacted

Signed _____ ***Date*** _____
(To be signed by participant)

Signed _____ ***Date*** _____
(To be signed by person collecting consent)

Name of person collecting consent: _____
If a participant wants a copy a second form should be completed and this copy left with them.

Appendix L. List of suitable types of headlamps

The clinical examination is not so exacting that a standard head torch is required. A list of suppliers follows for assistance but this is not exhaustive.

Cotswold outdoor
www.cotswoldoutdoor.com/equipment/torches-lanterns/head-torches

Go outdoors
www.gooutdoors.co.uk/walking/equipment/lighting/head-torches

Decathlon
www.decathlon.co.uk/Head_Torches

Millets
www.millets.co.uk/HeadTorches

Torch direct
www.torchdirect.co.uk/head-torches.html

Blacks
www.blacks.co.uk › Equipment › Torches & Lighting

Appendix M. List of codes for local authorities

Upper-tier local authority	Upper code	Lower-tier local authority	Lower code
Barking and Dagenham	E09000002	Barking and Dagenham	E09000002
Barnet	E09000003	Barnet	E09000003
Barnsley	E08000016	Barnsley	E08000016
Bath and North East Somerset	E06000022	Bath and North East Somerset	E06000022
Bedford	E06000055	Bedford	E06000055
Bexley	E09000004	Bexley	E09000004
Birmingham	E08000025	Birmingham	E08000025
Blackburn with Darwen	E06000008	Blackburn with Darwen	E06000008
Blackpool	E06000009	Blackpool	E06000009
Bolton	E08000001	Bolton	E08000001
Bournemouth	E06000028	Bournemouth	E06000028
Bracknell Forest	E06000036	Bracknell Forest	E06000036
Bradford	E08000032	Bradford	E08000032
Brent	E09000005	Brent	E09000005
Brighton and Hove	E06000043	Brighton and Hove	E06000043
Bristol, City of	E06000023	Bristol, City of	E06000023
Bromley	E09000006	Bromley	E09000006
Buckinghamshire	E10000002	Aylesbury Vale	E07000004
		Chiltern	E07000005
		South Bucks	E07000006
		Wycombe	E07000007
Bury	E08000002	Bury	E08000002
Calderdale	E08000033	Calderdale	E08000033
Cambridgeshire	E10000003	Cambridge	E07000008
		East Cambridgeshire	E07000009
		Fenland	E07000010
		Huntingdonshire	E07000011
		South Cambridgeshire	E07000012
Camden	E09000007	Camden	E09000007
Central Bedfordshire	E06000056	Central Bedfordshire	E06000056
Cheshire East	E06000049	Cheshire East	E06000049
Cheshire West and Chester	E06000050	Cheshire West and Chester	E06000050
City of London	E09000001	City of London	E09000001
Cornwall	E06000052	Cornwall	E06000052
County Durham	E06000047	County Durham	E06000047
Coventry	E08000026	Coventry	E08000026
Croydon	E09000008	Croydon	E09000008

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Cumbria	E10000006	Allerdale	E07000026
		Barrow-in-Furness	E07000027
		Carlisle	E07000028
		Copeland	E07000029
		Eden	E07000030
		South Lakeland	E07000031
Darlington	E06000005	Darlington	E06000005
Derby	E06000015	Derby	E06000015
Derbyshire	E10000007	Amber Valley	E07000032
		Bolsover	E07000033
		Chesterfield	E07000034
		Derbyshire Dales	E07000035
		Erewash	E07000036
		High Peak	E07000037
		North East Derbyshire	E07000038
		South Derbyshire	E07000039
Devon	E10000008	East Devon	E07000040
		Exeter	E07000041
		Mid Devon	E07000042
		North Devon	E07000043
		South Hams	E07000044
		Teignbridge	E07000045
		Torridge	E07000046
		West Devon	E07000047
Doncaster	E08000017	Doncaster	E08000017
Dorset	E10000009	Christchurch	E07000048
		East Dorset	E07000049
		North Dorset	E07000050
		Purbeck	E07000051
		West Dorset	E07000052
		Weymouth and Portland	E07000053
Dudley	E08000027	Dudley	E08000027
Ealing	E09000009	Ealing	E09000009
East Riding of Yorkshire	E06000011	East Riding of Yorkshire	E06000011
East Sussex	E10000011	Eastbourne	E07000061
		Hastings	E07000062
		Lewes	E07000063
		Rother	E07000064
		Wealden	E07000065
Enfield	E09000010	Enfield	E09000010

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Essex	E10000012	Basildon	E07000066
		Braintree	E07000067
		Brentwood	E07000068
		Castle Point	E07000069
		Chelmsford	E07000070
		Colchester	E07000071
		Epping Forest	E07000072
		Harlow	E07000073
		Maldon	E07000074
		Rochford	E07000075
		Tendring	E07000076
		Uttlesford	E07000077
Gateshead	E08000020	Gateshead	E08000020
Gloucestershire	E10000013	Cheltenham	E07000078
		Cotswold	E07000079
		Forest of Dean	E07000080
		Gloucester	E07000081
		Stroud	E07000082
		Tewkesbury	E07000083
Greenwich	E09000011	Greenwich	E09000011
Hackney	E09000012	Hackney	E09000012
Halton	E06000006	Halton	E06000006
Hammersmith and Fulham	E09000013	Hammersmith and Fulham	E09000013
Hampshire	E10000014	Basingstoke and Deane	E07000084
		East Hampshire	E07000085
		Eastleigh	E07000086
		Fareham	E07000087
		Gosport	E07000088
		Hart	E07000089
		Havant	E07000090
		New Forest	E07000091
		Rushmoor	E07000092
		Test Valley	E07000093
		Winchester	E07000094
Haringey	E09000014	Haringey	E09000014
Harrow	E09000015	Harrow	E09000015
Hartlepool	E06000001	Hartlepool	E06000001
Havering	E09000016	Havering	E09000016
Herefordshire, County of	E06000019	Herefordshire, County of	E06000019

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Hertfordshire	E10000015	Broxbourne	E07000095
		Dacorum	E07000096
		East Hertfordshire	E07000097
		Hertsmere	E07000098
		North Hertfordshire	E07000099
		St Albans	E07000240
		Stevenage	E07000101
		Three Rivers	E07000102
		Watford	E07000103
		Welwyn Hatfield	E07000241
Hillingdon	E09000017	Hillingdon	E09000017
Hounslow	E09000018	Hounslow	E09000018
Isle of Wight	E06000046	Isle of Wight	E06000046
Isles of Scilly	E06000053	Isles of Scilly	E06000053
Islington	E09000019	Islington	E09000019
Kensington and Chelsea	E09000020	Kensington and Chelsea	E09000020
Kent	E10000016	Ashford	E07000105
		Canterbury	E07000106
		Dartford	E07000107
		Dover	E07000108
		Gravesham	E07000109
		Maidstone	E07000110
		Sevenoaks	E07000111
		Shepway	E07000112
		Swale	E07000113
		Thanet	E07000114
		Tonbridge and Malling	E07000115
		Tunbridge Wells	E07000116
Kingston upon Hull, City of	E06000010	Kingston upon Hull, City of	E06000010
Kingston upon Thames	E09000021	Kingston upon Thames	E09000021
Kirklees	E08000034	Kirklees	E08000034
Knowsley	E08000011	Knowsley	E08000011
Lambeth	E09000022	Lambeth	E09000022
Lancashire	E10000017	Burnley	E07000117
		Chorley	E07000118
		Fylde	E07000119
		Hyndburn	E07000120
		Lancaster	E07000121
		Pendle	E07000122
		Preston	E07000123
		Ribble Valley	E07000124
		Rossendale	E07000125
		South Ribble	E07000126

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Lancashire	E10000017	West Lancashire	E07000127
		Wyre	E07000128
Leeds	E08000035	Leeds	E08000035
Leicester	E06000016	Leicester	E06000016
Leicestershire	E10000018	Blaby	E07000129
		Charnwood	E07000130
		Harborough	E07000131
		Hinckley and Bosworth	E07000132
		Melton	E07000133
		North West Leicestershire	E07000134
		Oadby and Wigston	E07000135
Lewisham	E09000023	Lewisham	E09000023
Lincolnshire	E10000019	Boston	E07000136
		East Lindsey	E07000137
		Lincoln	E07000138
		North Kesteven	E07000139
		South Holland	E07000140
		South Kesteven	E07000141
		West Lindsey	E07000142
Liverpool	E08000012	Liverpool	E08000012
Luton	E06000032	Luton	E06000032
Manchester	E08000003	Manchester	E08000003
Medway	E06000035	Medway	E06000035
Merton	E09000024	Merton	E09000024
Middlesbrough	E06000002	Middlesbrough	E06000002
Milton Keynes	E06000042	Milton Keynes	E06000042
Newcastle upon Tyne	E08000021	Newcastle upon Tyne	E08000021
Newham	E09000025	Newham	E09000025
Norfolk	E10000020	Breckland	E07000143
		Broadland	E07000144
		Great Yarmouth	E07000145
		King's Lynn and West Norfolk	E07000146
		North Norfolk	E07000147
		Norwich	E07000148
		South Norfolk	E07000149
North East Lincolnshire	E06000012	North East Lincolnshire	E06000012
North Lincolnshire	E06000013	North Lincolnshire	E06000013
North Somerset	E06000024	North Somerset	E06000024
North Tyneside	E08000022	North Tyneside	E08000022

Upper tier local authority	Upper code	Lower tier local authority	Lower code
North Yorkshire	E10000023	Craven	E07000163
		Hambleton	E07000164
		Harrogate	E07000165
		Richmondshire	E07000166
		Ryedale	E07000167
		Scarborough	E07000168
		Selby	E07000169
Northamptonshire	E10000021	Corby	E07000150
		Daventry	E07000151
		East Northamptonshire	E07000152
		Kettering	E07000153
		Northampton	E07000154
		South Northamptonshire	E07000155
		Wellingborough	E07000156
Northumberland	E06000048	Northumberland	E06000048
Nottingham	E06000018	Nottingham	E06000018
Nottinghamshire	E10000024	Ashfield	E07000170
		Bassetlaw	E07000171
		Broxtowe	E07000172
		Gedling	E07000173
		Mansfield	E07000174
Nottinghamshire	E10000024	Newark and Sherwood	E07000175
		Rushcliffe	E07000176
Oldham	E08000004	Oldham	E08000004
Oxfordshire	E10000025	Cherwell	E07000177
		Oxford	E07000178
		South Oxfordshire	E07000179
		Vale of White Horse	E07000180
		West Oxfordshire	E07000181
Peterborough	E06000031	Peterborough	E06000031
Plymouth	E06000026	Plymouth	E06000026
Poole	E06000029	Poole	E06000029
Portsmouth	E06000044	Portsmouth	E06000044
Reading	E06000038	Reading	E06000038
Redbridge	E09000026	Redbridge	E09000026
Redcar and Cleveland	E06000003	Redcar and Cleveland	E06000003
Richmond upon Thames	E09000027	Richmond upon Thames	E09000027
Rochdale	E08000005	Rochdale	E08000005
Rotherham	E08000018	Rotherham	E08000018
Rutland	E06000017	Rutland	E06000017
Salford	E08000006	Salford	E08000006
Sandwell	E08000028	Sandwell	E08000028
Sefton	E08000014	Sefton	E08000014

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Sheffield	E08000019	Sheffield	E08000019
Shropshire	E06000051	Shropshire	E06000051
Slough	E06000039	Slough	E06000039
Solihull	E08000029	Solihull	E08000029
Somerset	E10000027	Mendip	E07000187
		Sedgemoor	E07000188
		South Somerset	E07000189
		Taunton Deane	E07000190
		West Somerset	E07000191
South Gloucestershire	E06000025	South Gloucestershire	E06000025
South Tyneside	E08000023	South Tyneside	E08000023
Southampton	E06000045	Southampton	E06000045
Southend-on-Sea	E06000033	Southend-on-Sea	E06000033
Southwark	E09000028	Southwark	E09000028
St. Helens	E08000013	St. Helens	E08000013
Staffordshire	E10000028	Cannock Chase	E07000192
		East Staffordshire	E07000193
		Lichfield	E07000194
		Newcastle-under-Lyme	E07000195
		South Staffordshire	E07000196
		Stafford	E07000197
		Staffordshire Moorlands	E07000198
		Tamworth	E07000199
Stockport	E08000007	Stockport	E08000007
Stockton-on-Tees	E06000004	Stockton-on-Tees	E06000004
Stoke-on-Trent	E06000021	Stoke-on-Trent	E06000021
Suffolk	E10000029	Babergh	E07000200
		Forest Heath	E07000201
		Ipswich	E07000202
		Mid Suffolk	E07000203
		St Edmundsbury	E07000204
		Suffolk Coastal	E07000205
		Waveney	E07000206
Sunderland	E08000024	Sunderland	E08000024
Surrey	E10000030	Elmbridge	E07000207
		Epsom and Ewell	E07000208
		Guildford	E07000209
		Mole Valley	E07000210
		Reigate and Banstead	E07000211
		Runnymede	E07000212
		Spelthorne	E07000213
		Surrey Heath	E07000214
		Tandridge	E07000215

Upper tier local authority	Upper code	Lower tier local authority	Lower code
Surrey	E10000030	Waverley	E07000216
		Woking	E07000217
Sutton	E09000029	Sutton	E09000029
Swindon	E06000030	Swindon	E06000030
Tameside	E08000008	Tameside	E08000008
Telford and Wrekin	E06000020	Telford and Wrekin	E06000020
Thurrock	E06000034	Thurrock	E06000034
Torbay	E06000027	Torbay	E06000027
Tower Hamlets	E09000030	Tower Hamlets	E09000030
Trafford	E08000009	Trafford	E08000009
Wakefield	E08000036	Wakefield	E08000036
Walsall	E08000030	Walsall	E08000030
Waltham Forest	E09000031	Waltham Forest	E09000031
Wandsworth	E09000032	Wandsworth	E09000032
Warrington	E06000007	Warrington	E06000007
Warwickshire	E10000031	North Warwickshire	E07000218
		Nuneaton and Bedworth	E07000219
		Rugby	E07000220
		Stratford-on-Avon	E07000221
		Warwick	E07000222
West Berkshire	E06000037	West Berkshire	E06000037
West Sussex	E10000032	Adur	E07000223
		Arun	E07000224
		Chichester	E07000225
		Crawley	E07000226
		Horsham	E07000227
		Mid Sussex	E07000228
		Worthing	E07000229
Westminster	E09000033	Westminster	E09000033
Wigan	E08000010	Wigan	E08000010
Wiltshire	E06000054	Wiltshire	E06000054
Windsor and Maidenhead	E06000040	Windsor and Maidenhead	E06000040
Wirral	E08000015	Wirral	E08000015
Wokingham	E06000041	Wokingham	E06000041
Wolverhampton	E08000031	Wolverhampton	E08000031
Worcestershire	E10000034	Bromsgrove	E07000234
		Malvern Hills	E07000235
		Redditch	E07000236
		Worcester	E07000237
		Wychavon	E07000238
		Wyre Forest	E07000239
York	E06000014	York	E06000014

Source: From ONS Geographical Lookups.

Appendix N. Guidance and adaptation for IT support colleagues to allow DSP2 to run on new versions of Microsoft Windows. With thanks to colleagues at Cardiff University

32-bit and 64-bit Windows

The terms 32-bit and 64-bit refer to the way a computer's processor (also called a CPU), handles information. The 64-bit version of Windows handles large amounts of random access memory (RAM) more effectively than a 32-bit system.

Most programs designed for the 32-bit version of Windows will work on the 64-bit version of Windows. However, this is **not** true for 16-bit applications like DSP2 as the table below shows.

Table 1. Tests of installation of both versions of DSP2 on Windows 7 and 8 operating systems

	Windows 7	**Windows 8**
32-bit	Yes	Yes
64-bit	Yes if use deployment	No

To find out if your computer is running 32-bit or 64-bit Windows, do the following:

1. Open System by clicking the **Start** button, clicking **Control Panel**, clicking **System and Security**, and then clicking **System**.

2. Under **System**, you can view the system type.

DSP2 Deployment

As a short-term interim and somewhat cumbersome measure, DSP2 may be deployed on 64-bit Windows 7 by using Windows XP Mode. This comes as a separate download and works only with Windows 7 Professional, Ultimate, and Enterprise.

Machines purchased from retail outlets will be running the consumer versions of Windows 7. A Windows Enterprise licence will be required and the Windows operating system will need to be re-installed. It is recommended that professional IT support is provided for this process.

Windows XP mode is not present in Windows 8 though it may be possible to deploy this using Microsoft's virtualisation technology Hyper-V.

64-bit Windows machines are becoming very common and it is likely that the next version of Windows will be 64-bit only. Because of this, and the extra support required to deploy DSP2 on Windows 7 there is a clear need to update or replace DSP2.

Summary

- Existing installations will continue to work. However Microsoft is withdrawing support for Windows XP. Corporate type environments will be replacing Windows XP with Windows 7, and in many cases this will be 64-bit Windows 7 (eg Cardiff University).

- Both versions (1.1 and 2.1) of DSP2 install on 32-bit Windows 7 and 8.

DSP2 will install on 64-bit Windows 7 but will require IT support to install, and an enterprise licence of Windows will need to be acquired.

Appendix O. Tracking sheet to record details of all people who agree to be contacted *(example records shown in pale font - to be deleted before use)*

Address	Postcode	First name	Surname	Sex M/F	Consent for		Reason for non-participation*	ID number allocated to those who agree to be contacted	
					q're	exam^{n}		LA code	N
Unit 19 South Park, Newport	*NW2 5SU*	*Joan A.*	*Spencer*	*F*	*Y*	*Y*		*E06000005*	*001*
Unit 27 South Park, Newport	*NW7 8UU*	*Edith*	*Lewis*	*F*	*N*	*Y*		*E06000005*	*002*

*Non-participation codes : 1-contact could not be made; 2-consent could not be obtained; 3-volunteer declined to take part; 4-other

Appendix P. Protocol for assessing capacity to provide consent

What is meant by ‘capacity’ to provide consent?

‘Capacity’ refers to the person’s mental capacity.

Mental capacity refers to a person’s ability to make a decision.

This refers to any decision – whether to get up in the morning, what to wear or whether to go to the doctor when feeling ill – as well as more serious or significant decisions, for example, decisions that have legal consequences, like having medical treatment, buying goods or making a will.

For our purpose it relates to making an informed decision about whether to participate in the survey.

What does ‘lacking capacity’ mean and why is it important?

Section 2(1) of the Mental Capacity Act 2005 (MCA) states that:

“For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.”

This means that a person lacks capacity if:

- they have an impairment or disturbance (for example, a disability, condition or trauma) that affects the way their mind or brain works and
- the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made

It should be noted that the impairment or disturbance does not have to be permanent. A person can lack capacity to make a decision at the time it needs to be made even if:

- the loss of capacity is partial
- the loss of capacity is temporary
- their capacity changes over time

How to assess if a respondent lacks capacity to provide informed consent

You should assess whether the respondent lacks capacity before starting the interview.

The MCA states that the starting point must be to assume the respondent has the capacity to make a specific decision. Some people may require help to be able to make or communicate a decision. However, this does not necessarily mean that they lack capacity to do so. What matters is their ability to carry out the processes involved in making the decision.

The MCA also states that an assessment on whether a person lacks capacity should never be based simply on:

- their age
- their appearance
- assumptions about their condition
- any aspect of their behaviour

The word appearance is used because it covers all aspects of the way that people look, for example it includes the physical characteristics of certain conditions (scars, features linked to Down's syndrome or muscle spasms caused by cerebral palsy) as well as aspects of appearance like skin colour, tattoos, and body piercings, or the way people dress (including religious dress).

The word 'condition' is also wide-ranging. It includes physical disabilities, learning difficulties and disabilities, illness related to age, and temporary conditions (for example drunkenness or unconsciousness). Aspects of behaviour might include extrovert (for example shouting or gesticulating) and withdrawn behaviour (for example talking to yourself or avoiding eye contact).

The emphasis on this guidance is about treating everybody equally.

There are two stages in assessing whether a respondent lacks capacity. If the conditions of both stages are met, then you should consider the respondent to lack capacity.

Stage 1. Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?

Examples of an impairment or disturbance in the functioning of the mind or brain may include the following:

- conditions associated with some forms of mental illness
- dementia
- significant learning disabilities
- the long-term effects of brain damage
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness
- delirium
- concussion following a head injury, and
- the symptoms of alcohol or drug abuse

Stage 2. Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?

For a person to lack capacity to make a decision, the Act says their impairment or disturbance must affect their ability to make the specific decision when they need to. But first people must be given all practical and appropriate support to help them make the decision for themselves. This support might include the use of non-verbal communication such as signers (for sign language) or perhaps the use of an interpreter.

Stage 2 can only apply if all practical and appropriate support to help the person make the decision has failed.

What does the Act mean by ‘inability to make a decision’?

A person is unable to make a decision if they **cannot** do any one of the following:

A. understand information about the decision to be made

It is important not to assess someone's understanding before they have been given relevant information about a decision. You should provide respondents with information about the survey. You should make every effort to provide this information in a way that is most appropriate to help the respondent to understand. For example, a respondent with a learning difficulty may need you to read the purpose leaflet to them.

B. retain that information in their mind

The respondent must be able to hold the information in their mind long enough to make an effective decision.

C. use or weigh that information as part of the decision making process

For someone to have capacity, they must have the ability to weigh up information and use it to arrive at a decision. Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without understanding or using the information they have been given.

For example some respondents who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it.

D. communicate their decision (by talking, using sign language or any other means)

According to the MCA, if a respondent cannot communicate their decision in any way at all, they should be treated as if they are unable to make that decision. As mentioned previously, before arriving at this conclusion you should ensure that all practical efforts to make communication have been explored, for example the use of signers.

If a respondent is unable to perform any one of these four tasks, then they are unable to make a decision. If this is the case, you should treat them as being unable to consent for the survey.

If a respondent meets the criteria under stage 1 and stage 2 then you should assess them as lacking capacity to provide informed consent and kindly exclude them from the survey. Assent should not be sought.

Appendix Q. Survey questionnaire

Public Health England Dental Public Health Epidemiology Programme
Oral health survey of older people, 2015-2016

Questionnaire

	Lower-tier local authority code									Number of participant		
Unique ID number												

I would like to ask you some questions about you and your dental health. Then I'd like to go on to some questions about using dental treatment services.

I won't write your name or address details on this form.

First an item that I can complete without asking you:

1 Sex of volunteer

☐ Male

☐ Female

☐ Not answered

Now could you tell me please -

2 What was your age last birthday?

☐ 65 – 74

☐ 75 – 84

☐ 85 or over

☐ Not answered

I am going to read you three words and I would like you to remember them for later, please : pear shoe table

3. Do any of these services regularly come to you in your home?

☐ Hairdresser

☐ Doctor

☐ Social services

☐ Nurse

☐ Dentist

☐ Other _____

☐ Not answered

Now I am going to ask you some questions about your health and lifestyle.

4. Do you have any long standing illness or disability that limits your ability to attend the dentist's practice for a check-up or treatment?

☐ Yes (go to question 5)

☐ No (go to question 6)

☐ Not answered

5. Are you limited to what you can do and where you can get to?

☐ No, but I can't get to the dentist for another reason

Details of reason…….

☐ Yes, I can't sit in a dentist's chair

☐ Yes, I can't climb stairs so need a downstairs surgery

☐ Yes, I can't leave the house so need a dentist to come to me

☐ Yes, I am bedbound so need a dentist to come to me

☐ Not answered

I am now going to ask you some questions about your mouth and teeth

HOW OFTEN during the last year …	Never, or hardly ever	Occasionally	Fairly often or very often	Prefer not to answer
6… have you had **painful aching** in your mouth?	☐	☐	☐	☐
7… have you had to **interrupt meals** or avoid eating with others because of problems with your teeth, mouth or dentures?	☐	☐	☐	☐
8…have you had trouble **pronouncing any words** because of problems with your teeth, mouth, or dentures?"	☐	☐	☐	☐
9… have you found it **uncomfortable to eat any foods** because of problems with your teeth, mouth or dentures?	☐	☐	☐	☐
10… have you been **self-conscious or embarrassed** because of problems with your teeth, mouth or dentures?	☐	☐	☐	☐

11 Do you have a denture, even if you don't wear it?

☐ Yes – go to question 12

☐ No – go to question 15

☐ Not answered

12 Are you content with the fit of your denture(s)?

Yes ☐ So-so ☐ Not at all ☐ Not answered ☐

13 Is / Are your denture(s) comfortable?

Yes ☐ So-so ☐ Not at all ☐ Not answered ☐

14 Are you limited in your choice of foods because of your denture(s)?

Yes ☐ So-so ☐ Not at all ☐ Not answered ☐

I would now like to ask you some questions about going to the dentist.

15 Roughly how long has it been since you last saw a dentist?

☐ Within the last 12 months

☐ More than 1, but less than 2 years ago

If either of these are the answers go to question 17

☐ More than 2 years ago

☐ More than 5 years ago

If either of these are the answers go to question 16

☐ Not answered go to question 17

Ask volunteers who have not seen a dentist in the last 2 years

16 What are the reasons why you have not seen a dentist in the last two years?

Wait for volunteer response first, prompt only for clarification

TICK ALL THAT APPLY

- ☐ No need to see the dentist / nothing wrong with my teeth / no natural teeth
- ☐ I can't find an NHS dentist
- ☐ I can't afford the NHS charges
- ☐ I haven't got the time to see a dentist
- ☐ I am afraid of dentists / I don't like seeing the dentist
- ☐ Keep forgetting / Haven't got round to it
- ☐ It's difficult to get to and from the dentist
- ☐ I've had a bad experience with a dentist
- ☐ Dentist changed to private / refused to do NHS work
- ☐ Other (please specify) _____
- ☐ Not answered

I'd now like to ask you about your education

17 Do you have any educational qualifications for which you received a certificate?

- ☐ Yes, at degree level or above
- ☐ Yes, another kind of qualification but below degree level
- ☐ No
- ☐ Not answered

18 I asked you to remember three words at the beginning of this interview; do you remember what they were? (For interviewer to note - Pear, shoe, table)

☐ Yes (volunteer lists all three)

☐ Yes (volunteer can only remember two of the words)

☐ Yes (volunteer can only remember one of the words)

☐ No (volunteer can't remember any of the words)

☐ Not answered

19 We have asked you a lot of questions. Is there anything you would like to say that we haven't asked you about dental health and dentistry?

☐ No

☐ Yes – record these below

TICK ALL THAT APPLY

☐ No NHS dentist available

☐ Dislike drift from NHS

☐ Treatment should be free

☐ Costs too much (no mention of NHS/free)

☐ Can't get appointment

☐ Not answered

☐ Dentist over-loaded

☐ Satisfied

☐ Better than in past

☐ Frightened of dentist

☐ Other details _____

_____

_____

To finish I would like to ask three questions about your vision

20 Do you have difficulty seeing, even if wearing glasses?

☐ No – no difficulty

☐ Yes – some difficulty

☐ Yes – a lot of difficulty

☐ Cannot do at all

☐ Not answered

21 Do you have difficulty seeing and recognising a person you know from 7 meters (20 feet) away, even if wearing glasses?

☐ No – no difficulty

☐ Yes – some difficulty

☐ Yes – a lot of difficulty

☐ Cannot do at all

☐ Not answered

22 Do you have difficulty seeing the print in a map, newspaper, or book, even if wearing glasses?

☐ No – no difficulty

☐ Yes – some difficulty

☐ Yes – a lot of difficulty

☐ Cannot do at all

☐ Not answered

Thank you for completing the interview.

23 This questionnaire was ……

☐ Completed in its entirety

☐ Not started as the volunteer did not consent to take part in the questionnaire

☐ Not completed as the volunteer withdrew consent or decided not to continue

☐ Not completed as the volunteer could not cooperate

Appendix R. The conduct of the examination and clinical criteria used for the assessments

INTRODUCTION

These criteria are written for the use of the dental examiner prior to and during training and for consultation purposes during the fieldwork. They have been derived from the 2009 ADHS criteria but have been reduced and simplified.

These criteria have been simplified from the full ADHS methodology to reflect the adults being surveyed and the likelihood that detailed examination is unnecessary and might be difficult. It has also been recognised that calibration will not be possible for the 2015-16 survey so very straightforward measures have been derived by collapsing down ADHS criteria. Where this has been done the data should still be comparable with ADHS results.

Data will be recorded onto paper charts out in the field and transferred to computer on return to base as soon as possible.

PROCEDURE BEFORE THE EXAMINATION

Medical screening

There is no need to ask volunteers about any medical conditions prior to examination as no probing is used and in any case this does not pose a risk to patients with a previous history of Rheumatic Fever or other cardiac disorders, according to recent guidance from NICE.

Equipment set-up and seating the participant in a domiciliary setting

The participant should be seated in a comfortable chair which has good head support, and to which the examiner can get access. Individual examiner's preferences vary. Kitchens are sometimes difficult as the seats often have no head support. A comfortable chair in the sitting room is usually fine, but access and lighting can be a problem. A head lamp of specified type will be used instead of a fixed lamp to avoid the problems of positioning of the usual lamp, the availability of power points, and the risk of the clamp damaging surfaces. Suitable headlamps are listed in Appendix L.

Preparation for the examination

The instruments should be laid out on a clean tissue on a hard surface out of sight of the participant if possible, but allowing easy access. The light should be set up and adjusted and dark protective glasses placed on the subject. To ensure good lighting please change to new batteries frequently.

Distractions or extraneous noise should be tactfully removed to allow the examiner calls to be heard by the recorder, for example pets should be shut out and the television sound turned off or down.

The examination should only proceed once the volunteer is comfortably positioned and the oral cavity can be viewed by the examiner. The volunteer should be fully informed about the examination and have had the opportunity to ask questions, which have then been answered to their satisfaction.

Infection control

Each examiner will carry sufficient sets of sterile instruments to ensure that there are sterile instruments for every examination. Following the examination these will be placed in a sealed container for transport back to the clinical base or designated clinic where the instruments will be sterilised according to local procedures. Examiners will wear a clean pair of **latex free gloves** for the examination of each participant. These will be disposed of into a standard yellow bag with any tissues and wipes after the exam. This will be disposed of on return to the clinic along with normal clinical waste.

DIAGNOSTIC CRITERIA

The examiner should look and assess the overall distribution of natural teeth and dentures. Dentures should be left in place for stages 1, 2 and 3 of the examination <u>if they are normally worn</u>. If they are not normally being worn at the time of examination because of a need for repair they should be left out – but examined later as part of the assessment of condition of dentures.

Stage 1. Presence and absence of teeth or replacements, and debris score

Record in lines numbered ‘1’ which teeth are present using the following codes:

P = Natural tooth present with VISIBLE plaque (to naked eye, without running probe around)

C = Natural tooth present and clean, no plaque visible to the naked eye

Record in lines numbered ‘1’ which teeth are missing and which are replaced by fixed replacements:

M = Tooth missing, no replacement

F = Tooth replaced by bridge pontic, implant pontic or implant

D = Tooth replaced by denture tooth

If in doubt - score low (ie “least disease”).

Stage 2. Presence of calculus (lines 2 on chart)

A visual inspection only should be made for the presence of visible supra-and sub-gingival calculus in each sextant.

If there is a single tooth in a sextant the sextant will not be recorded and the tooth will be considered to belong to the adjacent sextant.

Start in the upper right sextant and visually inspect each tooth for calculus. Each surface, buccal on upper teeth, lingual on lowers should be examined for the presence of supra- or sub-gingival calculus, and a single code recorded for the sextant

Codes and criteria: calculus

0 = No visible supra- or sub-gingival calculus

1 = Any supra- or sub-gingival calculus visible with the naked eye

9 = Unscorable

Stage 3. Functional occlusal contacts (line 3 on chart)

The assessment of occlusal contacts refers to occlusal contacts between **upper and lower natural teeth and between natural teeth and denture or bridge replacements.** This short examination examines only the posterior (premolar and molar) regions. The examination is conducted with dentures in place if they are normally worn.

Procedure

A contact is the same as an occlusal stop. For the purposes of this examination you should get the subject to close together normally on the back teeth (sometimes the phrase “clench your back teeth together” is the most effective) and then, using a mirror

to hold back the cheek, look at the lower arch from the side and record the distribution of contacts.

In the posterior region we are looking for tooth to tooth contact involving one or more lower natural or artificial molars making contact with an upper natural tooth or artificial replacement. Similarly in the premolar region we look for a contact involving one or more lower premolars and a natural or replacement tooth in the upper arch. The presence of a contact is determined by the lower tooth.

Just look at each side in turn and work out whether or not there is a contact between a lower molar and another natural or artificial tooth in the upper arch, then between a lower premolar and another natural or artificial tooth in the upper arch.

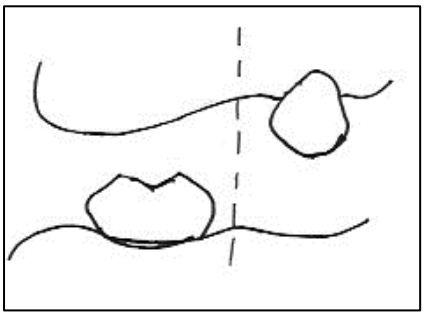
The scoring is quite easy, obviously if there is NO lower tooth or denture or bridge pontic in the area you are looking at there cannot possibly be a contact. Record contact between premolars (1 or 0), then between molars on the right and repeat on the left.

Codes and criteria: Posterior functional contacts

0 = No posterior functional contact

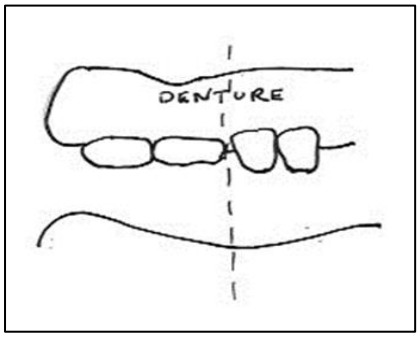
1 = Posterior functional contact present

Illustrative examples:



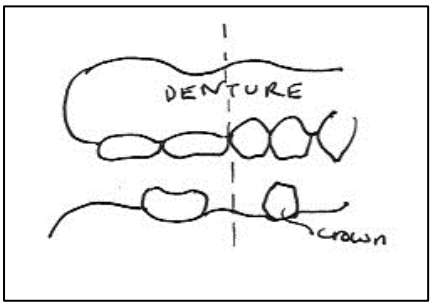
Molar area – no contact in upper for lower right molar, so no PFC
Premolar area – no premolar in lower so no PFC

3	Segments containing teeth with functional contacts against natural or replacement teeth	0	0	



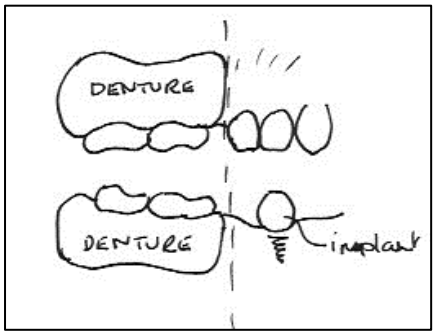
Molar area - no molar in lower so no PFC
Premolar area – no premolar in lower so no PFC

3	Segments containing teeth with functional contacts against natural or replacement teeth	0	0	



Molar area – lower natural tooth has functional contact with denture tooth in upper so there is a PFC
Premolar area – lower fixed replacement tooth has functional contact with denture tooth in upper so there is a PFC

3	Segments containing teeth with functional contacts against natural or replacement teeth	1	1	



Molar area – lower denture teeth have functional contact with denture teeth in upper so there is a PFC
Premolar area – lower implant retained crown has functional contact with natural upper teeth – there is a PFC.

3	Segments containing teeth with functional contacts against natural or replacement teeth	1	1	

Stage 4. Dentures

It is essential that any dentures are now removed for the rest of the examination

Codes and criteria: dentures

You will now have to hand any dentures the participant may have. The dentures, including full dentures opposed by natural teeth or partial dentures should be examined separately, upper and lower, for the following features.

Denture absent or present and type, material and condition recorded separately for upper and lower arches.

The material type should relate to the major structure of the denture:

- if the denture has a cast metal base then it should be recorded as being metal
- if the denture is mostly acrylic with metal clasps or rests then it should be coded as acrylic

If the denture is unequivocally in need of repair or relining or additions then this should be coded although it should be borne in mind that many people manage very well with

incomplete, old or broken dentures. The responses made by the volunteer in the questionnaire about their satisfaction with the comfort, function and appearance of their dentures can guide the coding here.

If the denture is no longer functional for chewing or appearance and could not be significantly improved by relining or repair or addition then it should be coded for replacement, particularly if the volunteer has stated earlier that the denture causes problems with eating, speaking.

Stage 5. PUFA index (Pain, Ulceration, Fistula, Abscess)

Examiners will ask the patient the following question:

Do you have any pain or discomfort in your mouth at the moment?

0 = No pain

1 = Yes pain

If yes, then ask

Do you think the pain is related to your teeth?

0 = No

1 = Yes

Examiners will then examine the soft tissues and record the presence or absence of any of the lesions listed below. The mouth should be examined in the same order as before (upper right, upper left, lower left, lower right), ensuring that the lips or cheeks are gently retracted to allow the soft tissues to be examined. The lesions to be looked for are:

P = open pulp in permanent dentition

U = traumatic ulceration in permanent dentition

F = fistula in permanent dentition

A = abscess in permanent dentition

Codes and criteria: PUFA

0 = No lesions evident

1 = A single lesion present

2 = 2 or more lesions present

Stage 6: Assessing general dental treatment need

The purpose of this section is to allow general assessments to be made about the types of treatment older people have and the particular needs they have to be able to access clinical dental care. It is not possible to lay out criteria for treatment need for all conditions that might be found and it would not be appropriate in all cases to seek to achieve a perfect dental state that might meet the expectations of a specialist. Instead examiners are asked to consider the needs of each individual volunteer to achieve a stable oral and dental condition, free of discomfort and able to eat, speak and socialise without restriction because of problems with their mouth or teeth. It is also appreciated that the brief examination in domiciliary conditions may leave some conditions undiagnosed so the examiner can only base their assessment on what they can see at the time.

The information from this section can only be analysed to make broad statements about need.

Items of treatment

Using the knowledge gained from the brief examination the examiner should record all the treatment, if any, that they consider the individual volunteer requires to maintain, stabilise or improve their oral condition so that it can remain or become stable, free of important progressive disease and allowing comfortable function.

The options are:

- No treatment
- Examination with or without further diagnostic tests
- Prevention advice – oral health, diet, additional fluoride
- Removal of calculus

- Minor restoration – simple direct fillings
- Major restoration – crowns/bridges/veneers/inlays, with or without endodontic treatment
- Extraction(s) or other minor surgery
- Minor prosthetic care – repair, reline, addition, repair, copy for existing denture
- Major prosthetic care – provision of one or more new partial or complete dentures
- Other treatment

One or more options can be selected.

Degree of urgency

The information derived from this section will be used to make broad statements about the proportion of mildly dependent adults who are in urgent need of clinical dental care.

Examples of a need for urgency would include overt malignancy, lesions that arouse suspicions of malignancy, uncontrolled swelling and uncontrolled bleeding. This list is not exhaustive.

Most other dental conditions would not require urgent care but can be dealt with when an appointment can be made by the volunteer.

Setting for care

This section allows an overall assessment to be made of the types of care that commissioners might need to commission in the future to meet the needs of this population, and the numbers that are likely to require special arrangements.

The coding should not be influenced by the current availability of care in the volunteer's area, real or imagined. Rather it should be coded under the assumption that care in each type of setting is currently available without limit. This will allow free and unfettered choice of the correct type of care to meet the needs of each individual volunteer at the time of examination, taking into account their general health, mobility, dependency and type of dental treatment that is required.

Examiners should not select a type of care for convenience or volunteer preference alone but what each volunteer needs according to their limitations. It is likely that a great many volunteers will be able to access clinical dental care through their own, current dental practice.

Appendix S. Clinical examination data recording sheet

Public Health England Dental Public Health Epidemiology Programme
Oral health survey of older people, 2015-2016

Examination data recording sheet

Unique ID number:	Lower-tier local authority code									Number of participant		

Home postcode : | | | | | | | | |

Clinical examination completion status

1 = No examination possible – volunteer did not consent
2 = No examination possible – volunteer unable to co-operate
3 = Full examination completed
4 = Partial examination completed – volunteer withdrew consent
5 = Partial examination completed – volunteer could not co-operate

UPPER

		Right								Left							
2	Sextants with calculus																
1	Present / clean / replaced																
		8	7	6	5	4	3	2	1	1	2	3	4	5	6	7	8

LOWER

		Right								Left							
		8	7	6	5	4	3	2	1	1	2	3	4	5	6	7	8
1	Present / clean / replaced																
2	Sextants with calculus																
3	Segments containing teeth with functional contacts against natural or replacement teeth																

Line 1 Codes :	P= Natural tooth present with VISIBLE plaque (to naked eye, without running probe around)
	C = Natural tooth present and Clean, no plaque visible to the naked eye
	M = Tooth missing, no replacement
	F = Tooth replaced by bridge pontic, implant pontic or implant
	D = Tooth replaced by denture tooth
Line 2 Codes :	0 = No visible supra- or sub-gingival calculus
	1 = Any supra- or sub-gingival calculus visible with the naked eye
	9 = Unscorable
Line 3 Codes :	0 = No posterior functional contact
	1 = Posterior functional contact present

Presence or absence of dentures

	Denture present 0 - no denture 1 - partial 2 - full 3 - overdenture 4 - implant retained	**Denture material** 1 - metal base 2 - acrylic base	**Status** 0 - intact 1 - needs repair 2 - needs replacement
Upper			
Lower			

PUFA index

Ask the question - Do you have any pain or discomfort in your mouth at the moment?

0 = No – do not ask next question
1 = Yes – ask next question
9 = Not answered

☐

Do you think that this pain is related to your teeth? ☐

0 = No / don't know
1 = Yes
9 = Not answered

No. of PUFA conditions ☐

0 = No lesions evident
1 = Single lesion present
2 = 2 or more lesions present

The four PUFA lesions are : Open pulp, traumatic ulceration, abscess, sinus or fistula

Is there pathology giving concern? – tick box if present and follow protocol ☐

Assessment of treatment requirements

Items of treatment this volunteer requires in the opinion of the examiner. TICK ALL THAT APPLY

No treatment indicated	
Examination with or without further diagnostic tests	
Prevention advice – OH, diet, additional fluoride	
Removal of calculus	
Minor restoration – simple direct fillings	
Major restoration – crowns/bridges/veneers/inlays, with or without endodontic treatment	
Extraction(s) or other minor surgery	
Minor prosthetic care – repair, reline, addition, repair, copy for existing denture	
Major prosthetic care – provision of one or more new partial or complete dentures	
Other treatment :	

Degree of urgency

Urgent	
Routine	

Setting for the provision of treatment which would best meet the needs of the volunteer

Wholly as a domiciliary care case as the volunteer cannot leave the house unless hospital treatment is required	
Attendance in dental surgery with or without ambulatory or transport support	
Attendance in a **downstairs** dental surgery with or without ambulatory or transport support	
Attendance at a hospital department	
Other – give details to describe requirements	

Appendix T. Giving feedback on the clinical examination - handling professional questions and reporting pathology

In line with current ethical practice, feedback will be given with each patient falling into one of three general categories. The feedback given should use the wording provided for categories 1, 2 and 3. If the participant asks about their dental treatment need, or if questions related to the standard of previous dental care arise, the response will be that the survey is not designed to collect the sort of information on which a treatment can be planned, and that visiting a general dental practitioner is the best way of ensuring a thorough dental check-up. This is not only a way of deflecting potentially difficult questions, it is also absolutely true.

The administrator is permitted to say, when recruiting participants, that the dentist may be able to offer them some advice on the best way of looking after their mouth or teeth. If, after the examination, the subject wishes to know about their mouth the dentists can give an indication of whether there is room for improvement in terms of the general oral hygiene / cleanliness and use the statements below to generally categorise the patient's dental needs.

Category 1. No obvious oral problems

Note: this code to be used for anyone with no obvious disease requiring further assessment.

"Thank you for taking part in this survey, the information that we collect is important. I am able to give you some feedback about the examination if you would like.

It is important that you understand that the survey is not designed to collect the sort of information on which dental treatment can be planned so this examination is not the same as visiting a high street dentist which is the best way of ensuring a thorough dental check-up. We cannot check the teeth as thoroughly as a dentist in a surgery and we cannot take x-rays.

However, having looked at your mouth today it does appear overall to be healthy. There are no teeth that obviously require urgent attention. However, current evidence based guidance suggests that you should see a dentist for a complete check-up at least once every two years. If you have not seen a dentist within the last two years you should do so in the coming months."

Category 2. Minor issues requiring a dental check up

Note: this code to be used for anyone with obvious disease requiring further assessment.

"Thank you for taking part in this survey, the information that we collect is important. I am able to give you some feedback about the examination if you would like.

It is important that you understand that the survey is not designed to collect the sort of information on which dental treatment can be planned so this examination is not the same as visiting a high street dentist which is the best way of ensuring a thorough dental check-up. We cannot check the teeth as thoroughly as a dentist in a surgery and we cannot take x-rays.

Having looked at your mouth today there are no teeth that require urgent attention, but I think you would benefit from a thorough check-up. I would recommend that you organise an appointment for a check-up in the next couple of months."

Category 3. Obvious or progressive oral disease requiring a check-up within 1 month

Note: This category is appropriate for anyone who scored 1 on the PUFA index.

"Thank you for taking part in this survey, the information that we collect is important. I am able to give you some feedback about the examination if you would like.

It is important that you understand that the survey is not designed to collect the sort of information on which dental treatment can be planned, we are not in a dental surgery and we do not have access to air (to dry the teeth) or radiographs(to help us see beyond a clinical examination in some areas). This examination is not the same as visiting a general dental practitioner which is the best way of ensuring a thorough dental check-up."

Either

"On the basis that you said you were having pain from your mouth you should arrange to see a dentist in the next couple of weeks to help you."

OR

"Having looked at your mouth there are some teeth that would benefit from a closer inspection and I would recommend that you make an appointment to see your dentist in the next couple of weeks."

If the participant does not have a dentist, you will have available a local contact telephone number in order for them to find a dentist.

If you are asked to comment on specific aspects of oral hygiene, we would suggest that you respond, if appropriate, by identifying areas for improvement but say that they will need more specific advice from a dentist or dental hygienist since there are many ways of achieving this. It is very important that you are not too prescriptive and that you adhere to general principles as there should be no scope for oral hygiene advice being given which conflicts with previous hygiene advice. You could preface this by saying:

'What I generally tell people is……..'

If you are asked to comment on specific aspects of past treatment, you need to say:

'This survey is limited and you need to see your (or a) dentist for specific advice and/or treatment'.

Appendix U. Protocol for serious pathology

Only if there is pathology which is suspected to be of a serious nature (eg suspected malignancy) is there an obligation to enter any data in this section. In such cases (which you are **very** unlikely to encounter) a separate pro-forma must also completed. The team will carry a proforma in case this situation arises. This should be done according to the detailed protocol described in the next section. Fieldwork teams should make themselves familiar with this protocol in case it is required.

Protocol: reporting serious pathology

In the extremely unlikely event that the examining dentist notices a lesion which he / she considers may be serious and potentially life threatening (such as a suspected malignancy) noted, they are obliged to follow this set protocol, which is designed to make sure that the participant's general medical practitioner is informed, whilst not causing the participant unnecessary worry.

The following wording is suggested to communicate the finding to the volunteer.

Category 4. Serious pathology

"Thank you for taking part in this survey, the information that we collect is important.

Before I discuss the findings with you it is important that you understand that the survey is not as thorough as a normal examination with your own dentist and it is difficult to examine all areas of the mouth in the same way.

In this survey our policy is to inform your family doctor of any ulcers or inflamed areas. There is an area like this in your mouth and because I am not sure exactly what it is I would like to arrange for your dentist or doctor to look at this for you. Are you happy for me to do that?"

It is most unlikely that any such lesions will be found, and it is also unlikely that, even those which are reported will turn out to be serious. **It is the responsibility of the examiner not to alarm the participant unduly.**

If the participant asks what the dental clinician thinks the lesion is, the dental clinician should answer honestly that they do not know, before re-iterating standard survey policy as above.

If the respondent does not have a GP or does not want their GP contacted, then they will be presented with an information letter urging them to pursue an examination.

Once this is completed the dentist will leave the house before filling out a pro-forma recording the site and nature of the suspect lesion. This is sent immediately, along with a copy of the signed consent form, to the fieldwork team lead clinician or Clinical Director who will contact the volunteer's doctor by letter with a copy of both the consent form and the dentist's record form as well as details of the nearest specialist unit where appropriate investigations can be undertaken.

Appendix V. Consent form for volunteer in case of serious pathology

Public Health England Dental Public Health Epidemiology Programme
Oral health survey of older people, 2015-2016

GP CONSENT FORM

Dental examiner to complete (please use capital letters and write in ink):

Unique ID Number

Volunteer Name _____

Volunteer address _____

_____

Sex Male 1
Female 2

Date of birth DAY | MONTH | YEAR

Print participant's name and instruct them to initial the box appropriate to their decision:

1. I (name) _____ consent to the Dental Survey Team informing my General Practitioner (GP) of any findings from the dental examination which might affect my general health. ☐

(If does not want GP contacted)

2. I confirm that I do not want my GP contacted about any findings from the dental survey which might affect my general health and I have been given an information letter and been urged to pursue a check-up. ☐

(If does not have a GP)

3. I confirm that I do not have a GP and have been given an information letter and been urged to pursue a check-up. ☐

Signed _____ ***Date*** _____
(To be signed by the participant)

Signed _____ ***Date*** _____
(To be signed by the dental examiner collecting consent)

Name of person collecting consent: _____

GP NAME AND ADDRESS:

Name of GP (Dr)_____Practice Name _____

Address _____

_____ Postcode:_____

Telephone number _____

Appendix W. Letter for volunteer in case of serious pathology

Local NHS logo
Address of local epidemiology team lead
and tel number

Date

Dear

Thank you for taking part in this survey, the information that we collect is important.

It is important that you understand that the survey is not as thorough as a normal examination with your own dentist and it is difficult to examine all areas of the mouth in the same way.

In this survey our policy is to inform your family dentist or your doctor of any ulcers or inflamed areas. There is an area like this in your mouth and because I am not sure exactly what it is I would like to arrange for your dentist or doctor to look at this.

If you do not want your dentist or doctor to be informed it is important that you arrange to have the area checked by a doctor or dentist in the near future.

A list of dentists is attached.

Yours sincerely

Survey dentist

Appendix X. Summary sheet

Name of lower-tier local authority :	
Total number of extra care housing developments in lower-tier local authority	
Number of extra care housing developments sampled	
Number of sampled extra care housing developments contacted	
Number of sampled sites where warden agreed to assist	
Total number of residents at sites where warden agreed to assist	
Number of residents who volunteered to be contacted at sites where warden agreed to assist	
Number of volunteered residents who were contacted to arrange visit	
Number of contacted volunteers who consented to take part with questionnaire	
Number of contacted volunteers who consented to take part with clinical examination	
Number of contacted volunteers who consented to take part but who could not complete the questionnaire	
Number of contacted volunteers who consented to take part but who could not complete the clinical examination	
Number of volunteers who agreed to be contacted but who did not participate for these reasons (taken from tracking sheet) Code 1 Contact could not be made	
Code 2 Consent could not be obtained	
Code 3 Volunteer declined to take part	
Code 4 Other reason	