# Protocol for Dental Health Survey of Care Home Residents in Wales 2010/2011

Author: Anup Karki, SpR in DPH, Nigel Monaghan, Consultant in Dental Public

Health

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**Intended Audience:** Survey examiners and recorders

#### **Purpose and Summary of Document:**

The use of the protocol ensures that data resulting from the survey can be used to make comparisons locally over time, and to compare findings from one locality to another.

This protocol outlines the process and standards which ensure that dental data is collected in Wales in line with the British Association of Study of Community Dentistry (BASCD) criteria.

#### **Publication/Distribution:**

Survey examiners and recorders

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#### **Key Personnel/ Contacts**

A 11 1 1		1.15.16.14.1	
All Wales Co- ordinator, Public Health Wales	Mr N Monaghan	NPHS Wales, Temple of Peace & Health Cathays Park, Cardiff CF10 3NW	Tel: 029 2040 2498 nigel.monaghan@nphs.wal es.nhs.uk
Public Health Wales	Mr Anup Karki	NPHS, Temple of Peace and Health, Cathays Park, Cardiff, CF10 3NW	Tel: 0779 219 7958 anup.karki@wales.nhs.uk
Welsh Oral Health Information Unit	Professor E Treasure	Dental School, Cardiff University, Heath Park, Cardiff CF14 4XY	029 2074 4090
	Mrs M Morgan	Dental School, Cardiff University, Heath Park, Cardiff, CF14 4XY	029 2074 4612 morganmz@cardiff.ac.uk
Regional Contacts	Dr H Bennett	NPHS Wales 21 Orchard Street, Swansea SA1 5BE	01792-458066
	Dr D Thomas	NPHS Wales Mamhilad Park Estate, Pontypool NP4 OYP	01495-332218 david.thomas@nphs.wales .nhs.uk
	Mrs S Sandham	Dental Administration Department, Royal Alexandra Hospital, Rhyl, LL18 3AS	01745 443104
ABM University HB	Dr David Davies	Dental Department, Central Clinic, 21 Orchard Street, Swansea, SA1 5AT	01792 517925
Hyel Dda HB	Dr Mary Dodd	Elizabeth Williams Clinic, Mill Lane, Llanelli SA15 3SE	01554 784700, Pond St 01267 242942
Betsi Cadwaldar UHB	Dr John Clewett	Alexandra Dental Care, Royal Alexandra Hospital, Rhyl, LL18 3AS	01745 443210
Powys THB	Dr Warren Tolley	Dental Department, Brecon War Memorial Hospital, Cerrigcochion Road, Brecon, LD3 7NS	01874 615640
Anuerin Bevan HB	Dr Julie Jobbins/ Sue Greening/ Vicki Jones	Community Dental Service, Tenby House, Llanfrecfa Grange, Cwmbran, NP44 7AE	01633 623728
Cardiff and Vale UHB (including Cwm Taf HB area)	Mrs Menna Lloyd/ Ceri Hoddell	Dental Department, First Floor, Dental Hospital, Heath Park, Cardiff, CF14 4NN	02920 744864

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#### 1. Introduction

This protocol has been drafted to support a survey of care home residents in Wales in 2010/11. The survey of care home residents is intended to complement the Wales component of the Office for National Statistics Adult Dental Health Survey (ADHS) in 2009/10.

The ADHS is an epidemiological study of the dental health of the adult population amongst private households, and has been run approximately every ten years since 1968. The ADHS survey will be carried out in 2009/2010 in England, Wales and Northern Ireland. A consortium comprising Office of National Statistics (ONS) as lead contractor, various national social survey groups and 5 universities have been awarded the contract to deliver the survey.

As with previous Adult Dental Health Surveys, the 2009/10 ADHS will exclude some adult groups because of the method of sampling by households. The excluded groups include the residents of care homes, who may well have worse levels of dental health and whose needs are unrecorded. There is, therefore, a need to run a supplementary survey of the care home residents. No such national survey has been carried out before. By carrying out this survey, status of oral health and its impact on this vulnerable group can be established. Information obtained from this survey will help in obtaining full picture of inequalities in oral health and thus will be invaluable for planning of services.

This protocol will explain how the survey of the care home residents will be carried out in Wales. This will ensure the standardisation of the processes and methods of data collection across Wales. Where possible, measures of dental health (oral health indices) will be the same as those used for the ADHS.

The survey will be co-ordinated by the Public Health Wales in collaboration with Welsh Oral Health Information Unit (WOHIU) and the Local Health Boards (LHBs) will be responsible for delivering the survey through the Community Dental Services which serve their local population.

#### 2. Aims

The main aims of the care home survey are to:

- collect accurate and up-to-date information on the state of oral health of care home residents in Wales.
- compare levels of oral health found among care home residents with those found in the main ADHS sample.
- provide LHBs with dental data to inform local planning of dental services.

#### 3. Objectives

**3.1.** To investigate, by structured interview, oral health behaviours and oral

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- health impact profile of the care home residents.
- **3.2.** To determine the condition of the natural teeth and surrounding tissue (gum), presence of any acute lesions and condition of the denture/s in care home residents.
- **3.3.** To establish the treatment need of the residents of care homes.
- **3.4.** To complement the data obtained from the questionnaire based survey of care home managers in Wales which was carried out in 2006/07.

#### 4. Background

- **4.1.** The survey will follow as far as is appropriate British Association of Study in Community Dentistry (BASCD) guidelines given in "Guidelines for prevalence studies of dental caries" published in Community Dental Health 1.1 (1984) 55-56 and subsequently modified in Community Dental Health Volume 14 Supplement No. 1 March 1997 6-9.
- **4.2.** Much of this survey content consists of a sub set of Adult Dental Health Survey indices. This will facilitate comparison of oral health status of care home residents with free-living peers.
- **4.3.** The survey will also collect a limited range of information on clinically indicated treatment for care home residents to provide information for planning of future service provision which cannot be derived from the Adult Dental Health Survey indices.
- **4.4.** Within Wales the survey findings will be used to aid planning and provision of dental services.
- **4.5.** The survey will be the responsibility of LHBs in Wales and will be undertaken through activity of community dental staff.
- **4.6.** All Wales co-ordination will be the responsibility of Public Health Wales, through Mr Nigel Monaghan. Data cleaning and analysis will be undertaken by the Welsh Oral Health Information Unit, through Professor E T Treasure and her staff.

#### 5. Sampling

- **5.1.** The sampling procedure will be as follows:
  - This survey aims participation from at least 600 residents across Wales. Number of residents to be examined in each unitary authority (UA) will be determined on the basis of their over 65 yrs population (Table 1). This will ensure that sample size per 100000 population of 65 years and over in each UA is same.

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- For simplicity and practical reasons, five residents will be examined per care home. The number of care homes in each UA to be involved in the survey for the required sample size is shown in Table 1.
- The total sample, if all residents consent to take part in the survey, will be 1160 (Table 1). This will allow for non-response rate of around 48% which is consistent with the Adult Dental Health Survey (ADHS) being carried out in 2009.

Table 1: Proposed sample size and number of care homes to be randomly selected from each unitary authority.

Unitary Authority	Sample size proportionate to the ≥ 65yrs population (residents)	No. of care homes to be selected	Sample based on five residents per care home
Isle of Anglesey	29	6	30
Gwynedd	48	10	50
Conwy	54	11	55
Denbighshire	51	11	55
Flintshire	51	11	55
Wrexham	45	9	45
Powys	58	12	60
Ceredigion	32	6	30
Pembrokeshire	50	10	50
Carmarthenshire	74	15	75
Swansea	85	17	85
Neath Port Talbot	52	11	55
Bridgend	48	10	50
The Vale of Glamorgan	45	9	45
Cardiff	90	18	90
Rhondda Cynon Taf	79	16	80
Merthyr Tydfil	19	4	40
Caerphilly	57	12	60
Blaenau Gwent	25	5	25
Torfaen	33	7	35
Monmouthshire	36	8	40
Newport	47	10	50
Total (All Wales)	1108	139	1160

 Names of the registered older adults care homes in each Unitary Authority will be obtained from Care and Social Services Inspectorate Wales (CSSIW) website.

Number of care homes as per Table 1 will be randomly selected by Mr

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Anup Karki from the list of care homes in the Unitary Authority area using computer generated random numbers.

- o If any of the selected care home choose not to be involved in the survey, it will be substituted with randomly selected another care home in the same unitary authority area. The list provided by the Mr Karki will include names of further substitute homes with the first home name being the first substitute to be used if necessary and so on.
- Within an individual care home an event such as an outbreak e.g. winter vomiting disease (noro virus) would lead to home being excluded and substituted with another care home.
- Survey examiners will liaise with care home manager and five residents will be randomly chosen to reach the required sample size.
- o Residents who cannot communicate in English or Welsh will also be excluded due to time and resource implications. If we were to include all residents who could not speak English or Welsh, resources would be required to translate information sheet and consent forms in various languages and interpreters. We will not be able to do so with the resources available for this survey. Moreover, we believe benefits from speaking various inclusion of residents languages disproportionate to the resources required to do so. Considering the demographical structures of Wales, we will not exclude many residents. Moreover, validity of the questions to determine the oral health impact profile of residents is unknown when translated into another language.
- Although, communications resources will be provided to participants in English and Welsh, where it is not possible to allocate a Welsh speaking examiner to a Welsh-only speaking participant, the participant will have to be excluded from this survey.
- Those residents who do not consent to take part in the survey will not be replaced by substitute residents. However, number of residents who refuse to take part in each unitary authority will be recorded. This is important for accurate analysis of the data (See Appendix 1).
- Name and postcode of the care homes that decline participation in the survey and their reason should be recorded (See Appendix 1).
- Training will be provided to all Dental Epidemiology staff (dentists and recorders) on the sampling procedure.

#### 6. Consent

**6.1.** Ethical approval for this survey has been sought via the Research Ethics Committee for Wales.

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- **6.2.** Dental epidemiology staff will comply closely with the principles of ethical recruitment and closely follow the sampling procedure described in section 5.
- **6.3.** Randomly selected care homes for older adults will be invited to participate in the survey through a standard letter (See Appendix 2: Sample letter of invitation to care homes to participate in the survey).
- 6.4. Once a care home manager or alternate responsible person at the care home agrees to participate in the survey, randomly selected residents or their Lasting Power of Attorney/Court Appointed Deputy will be informed the forthcoming survey by a letter (See Appendix 3 and 4: Sample letter of invitation to the participating residents/an appointed Lasting Power of Attorney/Court Appointed Deputy) and an information sheet (See Appendix 5: Information sheet for the care home residents). The dental epidemiology will liaise with the care home manager to find out if any of the selected residents have an appointed Lasting Power of Attorney or Court Appointed Deputy.
- **6.5.** Participant information sheet and consent forms will be translated into Welsh.
- **6.6.** It is suggested that the community dental services provide the participating care homes with stamped blank envelopes for the purpose of sending out information on the survey to the person with Lasting Power of Attorney/Court Appointed Deputy for any residents unable to consent to this type of survey.
- **6.7.** Residents should be given sufficient time to consider the information whether or not they wish to take part, 24 hours as minimum.
- **6.8.** Dental epidemiology team will liaise with the care home manager or alternate staff to find out if any of the selected residents have indicated that they do not want to participate in the survey. Those residents who have indicated that they do not wish to be approached by the epidemiology team should be approached for consent.
- **6.9.** No coercion, inducement or reward will be provided to participate in this survey. On the day of the survey, study participants will be given an explanation using a standard script (See Appendix 6: Standard Consent Script).
- **6.10.** Each individual participant should be asked if they have any questions and these questions should be answered prior to obtaining the consent.
- **6.11.** An informed positive consent should be obtained from those who volunteer to take part in the survey. This should be written using the agreed consent

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form (See Appendix 7). Where the consent is obtained verbally or through other modes of communication such as signs or signals, it should be recorded and witnessed.

- **6.12.** It is assumed that all staffs involved in this survey are aware of the Mental Capacity Act 2005 and its implications for obtaining consent for dental survey. Staffs are advised to refer to
  - Welsh Health Circular (2008)10. Reference Guide to Examination and Treatment
  - Welsh Health Circular (2008)36; Good Practice in Consent Implementation Guide: consent to examination or treatment.
- **6.13.** Capacity to consent should be decided on the basis of the Mental Capacity Act 2005 Code of Practice (See Appendix 8). Training will be provided to the examiners and recorders on Mental Capacity Act 2005 and its implications for the consenting procedure for this survey during the training and standardisation event.
- **6.14.** In cases where an adult is unable to give consent because of mental incapacity another adult already appointed as a person with the Lasting Power of Attorney/Court Appointed Deputy can consent to or decline participation on behalf of the adult with incapacity. Hence, if a participant without capacity has appointed a Lasting Power of Attorney/Court Appointed Deputy, dental epidemiology staff should seek consent from such person (See Appendix 9).
- **6.15.** When an adult without capacity to make decision does not have an appointed proxy, it is possible for an individual to be appointed as an advocate to seek views on decisions for their health or general welfare. Seeking views on new issues can take considerable time and resource and this survey is likely to be a new issue. In addition the survey will not directly and immediately benefit those examined. Hence, those residents who do not have capacity to consent and do not have an appointed Lasting Power of Attorney/Court Appointed Deputy, will be excluded from this survey.
- **6.16.** Residents who cannot communicate in English will also be excluded due to time and resource implications. Moreover, validity of the questions to determine the oral health impact profile of residents is unknown when translated into another language.
- **6.17.** Volunteer residents can opt out of the survey at any time. Incomplete data should be managed as per 17.2
- **6.18.** Consent for referral: If the examiner suspects a serious oral pathology in a resident, verbal consent should be sought from the resident or his/her

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appointed Lasting Power of Attorney/Court Appointed Deputy for referral to a local consultant/specialist for assessment. Protocol for suspected serious pathology should be followed in this case (See Appendix 10).

#### 7. Examiners and recorders

- **7.1.** The number of examiners will be kept to a minimum as recommended in Community Dental Health, Volume 14 Supplement No. 1 March 1997, 18-29. It is estimated that there will be 16 examiners covering Wales.
- **7.2.** Each dental epidemiological team will include, as minimum,
  - a qualified dental surgeon, ideally, with experience of providing care to the care home residents and with experience of undertaking dental epidemiological surveys and
  - an administrative support worker (recorder), ideally with experience of working in care home environment and experience of undertaking dental epidemiological survey.
- **7.3.** All members will be required to have CRB checks, 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.
- **7.4.** All team members should follow their health board's Health and Safety policy and procedures when carrying out field work for this survey.
- **7.5.** Policies regarding safe handling of data is of also relevance to the dental epidemiology team members (see section 16)

#### 8. Training and standardisation

- **8.1.** The cost of the training and standardisation exercise will be borne by the Welsh Assembly Government and organised by All Wales Dental Public Health Team.
- **8.2.** All examiners are expected to have understanding of Mental Capacity Act 2005 and its implications in obtaining consent for dental procedures and research. Training on this issue will be provided during the training and standardisation event.
- **8.3.** All examiners and recorders will attend training and standardisation event organised in South Wales by Mr. N Monaghan in March/April 2010.
- **8.4.** The objectives of the training and standardisation event will be:

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- To train the dental epidemiology team members to be able to work through the relevant processes of sampling.
- To train support worker/recorder in asking questions and record data accurately.
- To standardise the oral examination element of the survey.
- To ensure that all members understand how to enter the data on the Survey Plus 2 and handle it according to data protection.
- To provide training in all elements of the protocol contained within this document. Specific training will be given with regard to recruitment, consent, providing feedback, and handling of cases where serious pathology is suspected.
- **8.5.** Prior to the training and calibration exercise it is expected that all recorders will be trained in use of computers equivalent to the European Computer Driving License (ECDL) module two, and following that training, trained in data entry using Dental Survey Plus 2.

#### 9. The examination equipments required

- **9.1.** The examinations will take place in care homes for older adults.
- **9.2.** The participants should be seated in their most comfortable chair and environment.
- **9.3.** Equipment required includes:
  - i. Purpose-built (Daray) lamp (yielding 4000 lux at 1 metre) incorporating standard safety features plus protective foam for G-clamp. In the interests of comparability, fibre-optic light sources should NOT be used to trans-illuminate approximal surfaces. A spare bulb and a screwdriver should be included in case the light bulb has to be changed.
  - ii. No. 4 plane mouth mirrors
  - iii. Type C periodontal probe
  - iv. Sharp probe for radicular charting
  - v. Latex free gloves
  - vi. Cotton wool rolls or cotton buds
  - vii. Sterile wipes
  - viii. Yellow bags for disposal of waste. (The examiner will be responsible for disposal of waste following the same procedure for domiciliary dental visits that they usually use, according to their employer Health Board's

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policy)

- ix. Extension lead
- x. Circuit breaker
- xi. Protective spectacles for participant
- xii. Extension flex and plug adapter for use when necessary with the lamp
- xiii. Disposable paper roll for laying out instruments
- xiv. Disposable paper trays will be used to hold instruments.
- xv. Recording charts, pencils, rubber and sharpener for use in case of computer failure
- xvi. Portable microcomputer **using Dental Survey Plus 2** and appropriate extension and adapter leads and plugs

#### 10. Data Collection

- **10.1.** Data will normally be recorded at resident homes on a portable microcomputer using the Dental Survey Plus 2 programme. These computers will be password protected and only accessible to the epidemiology team members.
- 10.2. Dental Survey Plus 2 epidemiology data collection formats will be supplied by Mr N Monaghan/A Karki to district organisers and contacts. These should be used for data collection. The format should not be altered. A separate proforma (*Appendix 1*) should be used for recording of refusals/non-response by care homes and residents. These should be completed by local organisers and returned to the Welsh Oral Health Information Unit (WOHIU) with the secured epidemiology data file.
- **10.3.** Examiners and recorders will have paper formats for recording data in case of malfunction of the computer.
- **10.4.** Once consent has been provided, the examiner should attempt the examination and should not pre-empt the outcome.
- **10.5.** Once the examiner has obtained the consent, the standard sequence of data collection will be as follows.
  - a. Collection of any personal information/demographic details
  - b. Collection of questionnaire data
  - c. Examination of the mouth and dentures
  - d. Treatment need data

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- **10.6.** The recorder will be seated comfortably in a position to hear the examiner clearly.
- **10.7.** The participants should be seated in their most comfortable chair and environment.
- **10.8.** If needed, examiners should allow rest periods and complete the questionnaire and examination over a longer time frame.

#### 11. Personal information and the Questionnaire

11.1. Examiners should develop rapport with the participants and their carers before the start of the survey and explain what the survey involves. The examiners should familiarise themselves regarding the participants' communication and behavioural problems prior to the start of the survey.

#### **11.2.** Examiners should:

- begin each conversation by identifying himself/herself and asking if they know why the dentist and recorder are here today, this may highlight possible mental capacity issues.
- stand in front/side of person in line with their vision and maintain eye contact.
- o speak slowly, clearly and wait for a response to a question.
- o repeat question exactly if needed.
- o allow the participants to have rest periods if necessary.
- o maintain patience and a reassuring attitude.
- not assume that the participant does not understand what is happening.
- 11.3. Examiner code: Each examiner will be allocated a code that must be used consistently during the survey and is carried forward from previous record. This code will be allocated at the all Wales training and standardisation event.
- **11.4.** Record/resident number: It is a unique number for the participating resident. This can have up to five digits and must be specified during data collection.
- **11.5. Unitary Authority:** The unitary authority where the care home is located should be chosen from the pull-down menu. It is carried forward from previous record.
- **11.6.** Care home name and postcode: Nursing home name and post code (all characters) are entered on the computer. This information should be readily available from the manager or the staff at the care home. If a care home postcode consists of six characters; a space should be included between

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- the 3<sup>rd</sup> and 4<sup>th</sup> characters. It must be completed (use dummy characters AAAAAAA if postcode needs to be added later).
- **11.7. Residential/Nursing Bed**: Resident's type of bed on the care home should be entered either as residential (only) or nursing (residential nursing). This information can be obtained from the staff at the care home, if necessary.
- **11.8.** How long resident: Length of residential stay of the residents should be chosen from the pull down menu. This information can be obtained from the staff at the care home if necessary.
- **11.9. Date of examination:** It must be entered as DD/MM/YYYY, carried forward from previous record.
- **11.10.** If the examiner is unable to obtain answer for any of the multiple choice questions, option of 'no answer' from the pull down list should be chosen before moving on to the next question. However, every effort should be made to obtain the answer from the participant.
- **11.11.** Resident's general health: "How is your health in general; would you say it was.... Running prompt: very good, good, fair, bad or very bad?" If the resident does not/can not answer, option of 'no answer' should be chosen.
- **11.12. Dental Health**: "Would you say your dental health (mouth, teeth and/or dentures) is... Running prompt: very good, good, fair, bad or very bad?" If the resident does/can not answer, option of 'no answer' should be chosen.
- **11.13. Date of birth**: must be entered as 11/MM/YYYY (11<sup>th</sup> of month chosen for ease of data entry and to reduce amount of identifiable information). This information can be obtained from the care home staff, if necessary.
- **11.14. Gender:** Gender is entered as male or female.
- **11.15. Mobility:** "How they normally move about?" Options given from the pull down menu.
- **11.16. Dry Mouth:** "How often does your mouth feel dry?" Options from the pull down menu are read out for the resident to choose one of them.
- 11.17. Oral Health Impact Profile (OHIP): Following questions are the contents of the Oral Health Impact Profile. These should be asked of the resident and options from the pull down menu read out so that he/she can chose one of the options from the list. The multiple choices for all these questions are same (never, hardly ever, occasionally, fairly often and very often, no answer)

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- 11.18. Trouble pronouncing words: In the last 12 months, that is since, (DATE) have you had trouble PRONOUNCING ANY WORDS because of problems with your teeth, mouth, or dentures?"
- **11.19. Sense of Taste**: "In the last 12 months, that is since (DATE), have you felt that your SENSE OF TASTE has worsened because of problems with your teeth, mouth or dentures?"
- **11.20.** Painful aching: "In the last 12 months, that is, since (DATE), have you had PAINFUL ACHING in your mouth?"
- **11.21.** Uncomfortable to eat any foods: "In the last 12 months, that is, since (DATE), have you found it UNCOMFORTABLE TO EAT ANY FOODS because of problems with your teeth, mouth, or dentures?"
- **11.22. Self conscious**: "In the last 12 months, that is, since (DATE), have you been SELF-CONSCIOUS because of your teeth, mouth or dentures?"
- **11.23. Tense**: "In the last 12 months, that is, since (DATE), have you FELT TENSE because of problems with your teeth, mouth or dentures?"
- **11.24. Diet unsatisfactory:** "In the last 12 months, that is, since (DATE), has your DIET BEEN UNSATISFACTORY because of problems with your teeth, mouth or dentures?"
- **11.25. Interrupt meals**: "In the last 12 months, that is, since (DATE), have you had to INTERRUPT MEALS because of problems with your teeth, mouth or dentures?"
- **11.26. Difficult to relax:** "In the last 12 months, that is, since (DATE), have you found it DIFFICULT TO RELAX because of problems with your teeth, mouth or dentures?"
- **11.27. Embarrass**: "In the last 12 months, since (DATE), have you been a bit EMBARRASSED because of problems with your teeth, mouth or dentures?"
- **11.28. Irritable**: "In the last 12 months, that is, since (DATE), have you been a bit IRRITABLE WITH OTHER PEOPLE because of problems with your teeth, mouth, dentures?"
- **11.29. Difficulty doing your usual jobs**: "In the last 12 months, that is, since (DATE), have you had DIFFICULTY DOING YOUR USUAL JOBS because of problems with your teeth, mouth, or dentures?"
- **11.30.** Less satisfying: "In the last 12 months, that is, since, (DATE), have you felt that life in general was LESS SATISFYING because of problems with

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your teeth, mouth or dentures?"

- **11.31.** Function: "In the last 12 months, that is, since (DATE), have you been TOTALLY UNABLE TO FUNCTION because of problems with your teeth, mouth, or dentures?"
- **11.32.** Following questions are on residents' oral health behaviours.
- **11.33.** Brush teeth/gum: "Can you manage to brush your teeth or gum (if fully edentulous)?" Options from the pull down menu are read out for the resident to choose one of them.

This question asks about the ability of residents to brush their teeth/dentures rather than the residents' current hygiene regime

11.34. Frequency of cleaning teeth/gum: "How often do you brush or your carer cleans your teeth or gum (if fully edentulous) nowadays?" Options from the pull down menu are read out for the resident to choose one of them.

If a resident has natural teeth but does not brush his/her teeth, option of 'never' should be chosen. If the resident is fully edentulous and does not brush/clean gum, again, option of 'never' should be chosen.

- **11.35. Denture hygiene**: "If you wear denture/s, how often do you or your carer clean/s your denture/s nowadays?" Options from the pull down menu are read out for the resident to choose one of them.
- **11.36.** Frequency of dental visit: "How often do you see a dentist?" Options from the pull down menu are read out for the resident to choose one of them.
- **11.37.** Reason for dental visit: "In general do you go to the dentist for..." Running Prompt. Never been to the dentist should only be coded for a spontaneous answer of never been to a dentist.
- **11.38. Time since last visit**: "About how long ago was your last visit to the dentist?" This is the last visit at which the respondent visited a dentist- it does not include a visit to the dental hygienist.

### 12. Examination procedure

- **12.1.** On commencing the session please ensure the Caps Lock is on. This will ensure that a consistent approach is used for surfaces coded T.
- **12.2.** Purpose built Daray lamp should be used for intra-oral examination. The resident should wear a protective safety glass. Fibre optic light should not be used to aid in diagnosis of dental decay.

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- **12.3.** Examiner should attempt the examination and should not pre-empt the outcome.
- **12.4.** All necessary steps must be taken to prevent cross-infection. A fresh set of previously sterilised instruments will be used for each survey participant.
- **12.5.** Diagnoses will be visual using a plane mouth mirror. A blunt probe may be used to remove debris.
- **12.6.** Any supernumerary tooth or a retained primary tooth should be ignored unless that tooth is occupying a permanent tooth's position and the corresponding permanent tooth is missing. In this case, such supernumerary tooth or retained primary tooth should be regarded as the permanent tooth missing from that position.
- **12.7. Oral hygiene**: Examiners are advised to make an overall assessment of the oral hygiene status of the resident. This includes intra oral cleanliness as well as denture hygiene. Options available are: examination not possible, very good, good, fair, poor, and very poor.
- **12.8.** Teeth will be examined for caries in the following order:
  - (a)upper left to upper right
  - (b) lower right to lower left
- **12.9.** Surfaces will be examined for caries in the following order: Distal, Occlusal, Mesial, Buccal, Lingual
- **12.10.** Each tooth will be identified and each surface recorded according to the diagnostic criteria for caries.
- **12.11.** The mouth will then be examined for oral lesions (open pulps, ulcerations, fistulae and abscesses) and periodontal health. Status of the denture is also recorded.
- **12.12.** Teeth must not be brushed but may be rinsed prior to examination. Debris or moisture may be removed from individual sites where visibility is obscured using cotton wool or blunt probe. Compressed air will not be used.
- **12.13.** X-rays will not be taken.
- **12.14.** Recent guidance from the National Institute for Clinical Excellence (NICE) now clearly states that there is no evidence that dental examination and procedures, including periodontal probing, pose a risk to patients with a previous history of Rheumatic Fever or other cardiac disorders. Specific questions are no longer required to identify these patients. If subjects raise

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the issue of not probing because of pre-existing medical conditions that following statement may be helpful. "In the past our dental survey policy was not to examine the gums of patients with various heart conditions as it was thought that it there was a possible risk from such examination. The National Institute for Clinical Excellence has recently reviewed the evidence in this area and concluded that there is no significant risk from the examination of teeth and gums, our policy is in line with this, BUT if you prefer us not to do the gum examinations please let us know."

**12.15.** During dental examination, if a participating resident appear to object or want to stop, the examiner will stop the examination immediately and address his/her objection.

# 13. Examination codes and diagnostic criteria for caries

The diagnosis of the condition of tooth surfaces will be visual.

The tooth should be identified by quadrant and number, 8 to 1 (or 1 to 8), followed immediately by the appropriate surface codes which should be entered in the appropriate space on the dental chart.

#### 13.1 Coronal and radicular charting

#### Code 6 – No natural tooth present: presumed extracted

This code should be used if there is no natural tooth present and there is no bridge pontic or implant either. If no natural tooth is present, all surfaces for the tooth in the coronal charting should be entered '6'. It will not be possible on this survey to tell if the missing tooth is due to impaction. Hence, all the missing teeth will be presumed to have been extracted.

#### Code 8: Bridge pontic

If there is a pontic as a part of the bridge (all types of bridges, including pontic off an adjacent implant) instead of a natural tooth, then code '8' is entered for all surfaces

#### Code 9: Implant

If an implant is present in place of a natural tooth, surface code 9 is entered for all surfaces.

#### Code 0 - Sound

A surface is regarded as "sound" if it shows no evidence of treatment or untreated clinical caries at the "caries into dentine" diagnostic threshold. The early stages of enamel caries, as well as other similar conditions, are excluded. Thus, surfaces with the following defects, in the absence of other positive criteria, should be coded as "present and "sound".

#### white or chalky spots

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- discoloured or rough spots
- stained pits or fissures in the enamel that are not associated with a carious lesion into dentine
- dark, shiny, hard pitted areas of enamel in a tooth showing signs of moderate to severe fluorosis

All questionable lesions should be coded as "sound".

In the unlikely event that it has not been possible to code a surface, they should be coded as 'sound'.

#### Code 1 - Arrested dentinal decay

Surfaces are regarded as falling into this category if, in the opinion of the trained examiner, after inspection there is hard arrested decay into dentine. The surface should be glossy and hard, despite being discoloured. There has been decay, but it is now arrested.

#### Code 2 - Decayed

Coronal surfaces are recorded in this category if, in the opinion of the trained examiner, after visual inspection there is a decay into dentine.

For root surfaces, any active decay on the root surface is coded '2'. This is any caries which is believed to be active on the basis of texture. Root surface texture is judged by using sharp probe. In some circumstances, it can be very difficult to tell decay from extrinsic staining. The texture is very important and probe must be used to determine this. Usually stained calculus and extrinsic staining will be fairly obvious, but if there is any doubt the texture is critical in deciding if the surface has a decay.

#### Code 3 - Decay with pulpal involvement

Surfaces are regarded as falling into this category if, in the opinion of the trained examiner, there is a carious lesion that involves the pulp, necessitating an extraction or pulp treatment. The examiner will not distinguish between different possibilities for treatment e.g. pulp therapy or extraction and involvement of the pulp will be the sole criteria. **Use this code for all surfaces when a root only is present**.

#### Code 4 - Filled and decayed

A surface that has any type of restoration (filling) and a decay, whether or not the decay is in physical association with the restoration(s), will fall into this category unless the lesion is so extensive as to be classified as "decay with pulpal involvement", in which case the filling would be ignored and the surface classified code 3.

#### Code 5 - Filled with no decay

Surfaces containing a satisfactory permanent restoration (excluding crowns and bridge abutments) of any material will be coded under this category. This category also includes those indirect restorations such as

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#### onlays, inlays and direct sealant restorations.

#### Code R – Filled but needs replacing (not carious)

A filled surface is regarded as falling into this category if, in the opinion of the examiner after inspection, it is chipped or cracked to the extent that it needs replacing, but there is no "caries into dentine" present on the same surface.

Cavities containing a temporary dressing (not temporary crowns), or cavities from which a restoration has been lost, will be regarded as filled needs replacing unless there is also evidence of caries into dentine in which case they will be coded in the appropriate category of 'decayed' (code 2/3).

#### Code C - Crowned/advanced restorative procedures

This code is used if there is either a permanent or a temporary crown (cap), including full coverage bridge abutments for conventional bridges. This is irrespective of the materials employed or of the reasons leading to the placement of the crown/bridge. (Note: code for a pontic is 8 and implant is 9)

#### Code T – Veneers, shims, retentive wing of adhesive bridges

These adhesive restorations are used simply to change the shape of a tooth or as adhesive retainers for resin bonded bridges. A shim is a thin metal restoration cemented onto a functional surface (such as the palatal surface of an upper anterior or a molar occlusal surface) to change its shape. These are rare. A veneer is usually placed buccally to improve colour or shape, these are fairly common. The difference between them is not important, but neither is placed to treat caries.

The difference between the code 5 and code T is that the restorations under code 5 are placed for caries treatment while restorations under code T are placed for to fulfil an aesthetic or occlusal need.

#### Code: \$ Sealant

This code is used if there is a partial or full sealant present. However, if the sealant was placed as a part of the underlying restoration (sealant restoration), the code 4 or 5 should be used depending on the presence of decay.

#### Code N: No exposed root surface

All surfaces of the roots which are not exposed should be coded as 'N'.

**Note:** Having completed the coronal surfaces the examiner should examine any exposed root surfaces. **On no account should you try to do the radicular charting at the same time as the crowns**. Each root surface of every tooth should be examined. If a tooth is missing, Code 6 should be used for radicular charting as well as coronal charting.

Diagnosis of root caries is different from that for coronal caries and requires

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the use of a sharpened probe because the textural changes are at the heart of diagnosis. The examiner will need to use sharp probe for radicular charting. However, the examiner should not push the tip hard into the dentine. Sharp probe should not be used for the coronal charting.

Anything exposed apical to the cemento-enamel junction (or when the CEJ has been replaced by a restoration, the apical margin of the restoration) is regarded as root surface.

#### 3mm rule:

Most fillings (restorations) are either clearly crown or root fillings (restorations), but some restorations and decay straddle the CEJ and these are difficult to call. Here the 3mm rule will apply, which is as follows.

- If the restoration is clearly a coronal restoration which encroaches on to the root, it should ONLY be coded as a coronal and root restoration if it extends 3mm or more beyond CEJ (or the estimated CEJ) onto to the root surface. Probe may be used to measure this, if necessary.
- If there is frank caries at the margin of the filling extending from the coronal onto the root surface then this will count as caries on the root, even where the restoration does not extend 3mm. In this case the condition of the coronal portion of the filling will be coded independently according to the condition of this part of the tooth.
- If a root restoration extends into the crown, the same 3mm rule applies in reverse (i.e. there must be 3mm beyond the CEJ on to the crown to count as a coronal restoration), but any caries occurring on the coronal portion of the root filling is recorded as coronal decay whilst the root filling is scored according to its condition.
- Some lesions and some fillings are smaller, they straddle the CEJ and it is difficult to be sure whether they are primarily on the root or the crown and do not extend 3mm onto either. In this case they should be recorded as root as this is the more vulnerable surface if it is exposed.
- Artificial crowns cause a particular problem because it is often impossible
  to identify the CEJ. Where there is a crown and the CEJ is covered, the
  margin of the crown should be considered the same as the CEJ, unless the
  contour of the crown indicates where the CEJ lies in which case the
  extension of the crown beyond this can be measured. On the rare occasion
  where this extends 3mm or more on to the root surface, the surface should
  be recorded as filled.

#### 13.2 Space charting

The participant would have removed any dentures but you may now need to look at them to help them decide on the correct codes.

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In this part of the examination, you are looking for spaces or spaces that have been filled by dentures/bridges/implants from 2<sup>nd</sup> premolar to 2<sup>nd</sup> premolar area in both arches. Spaces beyond 2<sup>nd</sup> premolar area should be ignored.

As you look around, you should look for spaces of half the width of the expected tooth at each area. If there is space present then call it out and the code depends on whether or not it is filled by an artificial tooth. If there is a natural tooth call it as 'no space' (code 0).

Note that because teeth drift you may have a space at (for example) the upper second premolar position even when that tooth is present (it may have drifted to a different position). What is important is that there is a space at that position, the teeth present are irrelevant. Your job is to map the spaces, you can completely ignore the tooth type.

#### Code 0: No space

This code is used if there is no space.

Code 6: Space equal to or more than half the size of the expected tooth

Code 7: Space restored by a removable prosthesis

Code 8: Space restored by a pontic off a fixed bridge

Code 9: Implant retained restoration replaces the tooth, so no space

#### 14. Other examinations

#### 14.1.1. PUFA

**P**= Open pulp in permanent dentition

**U**= Obvious ulceration

**F**= Fistula in permanent dentition

**A**= Abscess in permanent dentition

Examiner will first ask the participant:

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

i.No pain or problem,

ii. Yes, pain and/or problem

iii.No answer.

**Open pulp**: Examiners will choose one of the available options depending on the findings from examination. Available options are: Fully edentulous, no lesions evident, single lesion evident, two or more lesions and unable to

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examine. A tooth/root which has an exposed pulp will count as a lesion.

**Ulcerations**: Examiners will choose one of the available options depending on the findings.

#### 14.2. Periodontal Status

#### Pocket depths

Periodontal examination is not undertaken on implants. Please make sure that you have 'type C' probe which has marks at 8.5mm and 11.5mm as well as at 3.5mm and 5.5mm.

Pocket depths will be probed at two sites (mesial and distal) on each tooth; these two sites will be buccally on upper teeth and lingually on lower teeth.

The order of examination will be: Upper right sextant, upper central sextant, upper left sextant, lower left sextant, lower central sextant and finally lower right sextant.

The worst score on each sextant will be recorded. Gently insert the probe into the sulcus distally on the tooth and observe the pocket depth at which resistance is felt. The manoeuvre should not cause pain or blanching of the tissue. If it does, you are applying too much pressure. Repeat the process on the mesial side. Once the examiner has finished probing all the teeth on the sextant, he/she should call out the worst score for the pocketing.

Each sextant will have following options.

i.pocket depth up to 3.5mm (first probe band)

ii.pocket depth up to 4-5.5mm (dark band)

iii.pocket depth up to 6-8.5mm (first area above the dark band)

iv.pocket depth more than 9mm (second area above the dark band)

v.could not be probed

vi.less than two teeth in the sextant

The examiner may not be able to probe because of discomfort or because there is a physical barrier (e.g. a large shelf of calculus) or for other reasons such as patient's medical or physical condition makes it very difficult to probe. If there is only one tooth on a sextant, the tooth is considered in the next sextant.

#### Calculus

All sextants should be examined for the presence of supra- or sub-gingival calculus. Calculus can be detected visually and using a probe.

One option from below should be chosen.

i. Fully edentulous

ii.No visible or detectable supra- or sub-gingival calculus

iii.Calculus present on one sextant

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- iv. Calculus present on two sextants
- v.Calculus present on three sextants
- vi.Calculus present on four or more sextants
- vii.Could not examine

#### **Bleeding**

All sextants should be examined for sign of bleeding. It may take 20-30 seconds after probing for bleeding to be evident. One option from below should be chosen.

- i.No visible bleeding
- ii.Bleeding present on one sextant
- iii.Bleeding present on two sextants
- iv.Bleeding present on three sextants
- v.Bleeding present on four or more sextants
- vi.Could not examine.

#### 14.3. Denture status

The examiner should examine the dentures and note on the denture type, material, and denture status for both upper and lower dentures.

#### **Denture type**

- No denture
- ii. Partial
- iii. Full
- iv. Complete overdenture
- v. Implant retained

#### **Denture base material**

- No denture
- ii. Metal
- iii. Plastic

#### **Denture status**

- i. No denture
- ii. Intact
- iii. In need of repair

#### 15. Treatment need

In this section, the examiner dentists are required to decide on the treatment need of the participant based on the information gathered and examination. The purpose of this section is to get overall view of treatment need of the resident population rather than individualised treatment plans.

Firstly, the examiners are asked to choose dental treatments they believe are appropriate for the participating resident and feasible considering their

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overall health.

#### Treatment plan includes

- i. Examination
- ii. Radiograph/s
- iii. Oral hygiene instructions (to the resident or carer)
- iv. Sub and/or supra-gingival debridement
- v. Filling/s
- vi. Simple extraction/s
- vii. Copy dentures
- viii. New denture/s, not copy
- ix. Denture adjustment/repair
- x. Soft tissue minor oral surgery
- xi. Hard tissue minor oral surgery
- xii. Sealing of root/s
- xiii. Supplemental fluoride
- xiv. Sedation
- xv. General Anaesthesia
- xvi. Other treatment/s

Soft tissue minor oral surgery includes intra-oral soft tissue surgeries such as soft tissue biopsy, removal of hyperplastic tissue etc. Hard tissue oral surgery includes surgical removal of teeth, minor dentoalveolar surgery etc. The examiners are also required to decide if the any of the treatment will require general anaesthesia or sedation. All treatments not covered by the available options will fall under the category of 'other treatment's'.

#### Case complexity

Examiners decide on the complexity of providing treatment to the participant/resident by choosing one or more of the following options.

- i. Communication requiring special arrangements
- ii. Treatment planning complicated by medical history
- iii. Patient is at high risk of dental disease
- iv. Capacity/consent and/or best interests issues
- v. Co-operation requires general anaesthetic or sedation
- vi. Extra visit or longer appointments
- vii. No case complexity

**Note**: Although the examiners do not take any medical history as a part of this survey, a resident's physical and mental status will be obvious during the data collection. This should enable them to make a reasonable judgement if dental treatment of the resident will be complicated by the medical history. If the examiner is not able to make obvious judgement, he/she may ask the resident or his/her carer about medical conditions. This information should be treated as confidential and should not be recorded as a part of the survey.

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#### **Setting for dental treatment**

Examiners decide on setting/s that would be suitable for treatment of the participant/resident. The examiners can choose one or more settings for e.g. the resident may require minor oral surgery as an inpatient in a hospital and fillings in a special care dental surgery. In this case both options should be ticked.

- i. Domiciliary
- ii. Out-patient hospital
- iii. Day case hospital
- iv. In patient hospital
- v. Primary care dental clinic/surgery
- vi. Special care dental clinic/surgery

#### Dental staff required.

Examiners decide on the type of dental expertise is required to carry out treatment on the participating residents. Examiner can choose one or more of the following options.

- i. General dentist
- ii. Dentist with experience and interest in Special Care Dentistry
- iii. Specialist in Special Care Dentistry
- iv. Oral surgeon and other dental specialist

Examiners should also record if the participating resident requires urgent referral for suspected serious pathology. A box is also provided at the end for examiners to comment.

#### 16. Data Protection and Confidentiality

- **16.1.** The protocol for the 2010/2011 All Wales survey of care home residents was taken to the All Wales Medical Research Ethics Committee on 11<sup>th</sup> of March 2010. The committee advised (to be added).
- **16.2.** Dental epidemiology team will take data protection and confidentiality issues seriously. They will fully comply with the data protection and confidentiality pledge given to the participating residents and all legal, moral and professional responsibility placed upon them.
- 16.3. All members of the team will at all time work to the principles of confidentiality as set out in the Confidentiality: Code of Practice for Health and Social Care in Wales, which incorporates the Caldicott principles of confidentiality.
- **16.4.** All organisations involved in this survey are experienced in data management within health and will strictly adhere to the best possible data protection practice.
- **16.5.** When portable computers break down, data will be collected on the paper sheets using only resident number. Resident names should not be recorded

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on the data sheets. Data should be transferred to the Dental Survey Plus 2 file in the computer as soon as possible and paper files destroyed.

- **16.6.** Portable computers will be password protected and can only be accessed by dental epidemiology team.
- **16.7.** Data collected in the secured laptop will be immediately transferred to a secured desktop computer at the LHB work base and data on the portable computer destroyed as soon as possible using an appropriate data destruction software.
- **16.8.** The desk top computer data will only be accessible by those involved in the survey.
- **16.9.** The survey data will be transferred to WOHIU using an encrypted file.
- **16.10.** Data at WOHIU will only be accessible to staff involved in analysis of the data. Unit follows strict data protection procedures as per Cardiff University rules and regulations. Dental survey data will not be linked with other data sources.
- 16.11. Resident's name and address will only be collected for the purpose of urgent referral in the best interest of the participant resident with suspected serious oral pathology. Verbal consent for referral will be taken from the residents or their appointed Lasting Power of Attorney/Court Appointed Deputy. Name and address of the resident who has been referred for full assessment from a specialist/consultant will be destroyed as soon as acknowledgement of the receipt of referral is received by the survey examiner.

The collated data will be used for the statistical research purpose only and no outputs will identify individual participants.

#### 17. Data cleaning

To ensure data quality the data must undergo the following three-way data handling process:

- Those collecting the data should adhere to the guidelines within this protocol and those distributed at the annual training and calibration exercise.
- ii. The data must then be further processed by the local epidemiology co-ordinator to ensure consistency of approach across specific regions.
- iii. The data is processed once more by the WOHIU to ensure

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consistency of approach across the Principality.

**17.1.** District Organisers will also check for presence of care home postcodes (select for AAAAAAA postcodes) and insert them when they are missing. Postcodes can also be found by using the following internet site by clicking on postcode/address finder:

#### www.royalmail.com

17.2. Minimum data required on residents: Data collected on the residents can be divided into following sections: demographic details, questionnaire, clinical data and treatment need. For the data to be valid for the purpose of analysis, at least date of birth (month and year), postcode, gender and bed type plus one of the other sections (questionnaire/examination/treatment need) should be completed. All the residents where this minimum data is not available will be regarded as non-responders.

#### 18. Data processing

- **18.1.** Examiners will assemble the data into a file. There will be one file per examiner. The data needs to be cleaned at local level before sending it to the WOHIU.
- **18.2.** Second stage data cleaning will be carried out at WOHIU.
- **18.3.** Results will be prepared at Local Authority level and new Health Board level.
- **18.4.** Data will be analysed and a report prepared by the WOHIU at Cardiff University. The dataset is expected to cover
  - Names of the Local Authorities
  - Names of the Local Health Boards
  - Names of the care homes.
  - Start and finish dates of examinations
  - Sample size of the care homes
  - Resident sample examined
  - Non response rate of both care homes and residents
  - Questionnaire data
  - Examination data
  - Treatment need of the residents

All means and standard deviations will be recorded to two decimal places.

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#### 19. Presentation of results and timetable

- **19.1.** Local organisers should send their cleaned data file to the WOHIU, Dental School, UWCM, Heath Park, Cardiff by 30<sup>th</sup> of June 2011.
- **19.2.** The Welsh Oral Health Information Unit will prepare data for the Common Minimum Dental Data Set, by Local Authority Area, for the 3 regions in Wales by 31<sup>st</sup> December 2011. These will include all Wales values.
- 19.3. A report will be published and distributed to all stakeholders. It will also be published on the Public Health Wales website. Dental epidemiology team at the LHBs will be notified of such publication. Dental epidemiology team at the LHBs will, in turn, inform care homes involved in the survey of the published report.
- **19.4.** Findings from this survey may be presented in the relevant conferences and published in peer reviewed journals.

# 20. Urgent treatment and referral for suspected serious pathology

- **20.1.** When the examining dentist believes they have identified a potentially serious risk to health and wellbeing of a resident necessitating urgent dental examination or dental treatment, it is expected that the examiner will try his/best to organise for such examination or dental treatment through community dental services or a General Dental Service (GDS)/Personal Dental Service (PDS) provider.
- **20.2.** Examiners are not expected to organise routine dental examination and treatment for the survey participants who do not require urgent dental examination or treatment.
- 20.3. On rare occasions, the examiner might notice a possible serious oral pathology. In such cases, the examiner should follow the standard script (See Appendix 10) and urgently refer to the nearest specialist/consultant (See Appendix 11). A copy of the referral letter should also be sent to the resident's GP. A verbal consent for referral should be taken from the residents or his/her appointed Lasting Power of Attorney/Court Appointed Deputy. A standard letter should be given to the residents who do not provide consent for such referral (See Appendix 12). A separate proforma can be used to

#### 21. Indemnification

In the unlikely event that a participant claimed for damages against a dental epidemiology team member, as LHB employees, both the dentists and the recorder (dental nurse) will be covered by the normal NHS indemnity.

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#### 22. Feedback on the clinical examination

This survey will follow the same procedure as agreed for the main ADHS. The administrator is permitted to say, when contacting potential 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 the general condition of their dental health then the dentist 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 (See Appendix 13).

#### 23. Neglect Issues

Following examination of a resident if an examiner has concerns regarding possible abuse/neglect of the resident, they should follow their respective LHB's procedures.

#### 24. Premature end of the survey

An unexpected event such as an influenza pandemic could lead to the survey being prematurely abandoned. All survey examiners are advised to contact Mr Nigel Monaghan/Anup Karki at Public Health Wales in such circumstances for further advice.

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### **Appendices**

Appendix 1	Proforma to record the refusal by (or exclusion of) care homes and residents to participate in the survey.
Appendix 2	Sample letter of invitation to care homes to participate in the survey.
Appendix 3	Sample letter of invitation to the participating residents.
Appendix 4	Sample letter of invitation to the participating resident's appointed Lasting Power of Attorney or Court Appointed Deputy.
Appendix 5	Information sheet for the care home residents.
Appendix 6	Standard consent script.
Appendix 7	Consent form for residents with capacity to consent.
Appendix 8	Protocol for assessing capacity to provide consent.
Appendix 9	Consent form for residents who lack capacity to consent to take part in the survey.
Appendix 10	Protocol for suspected serious pathology.
Appendix 11	An example of referral proforma in case of suspected serious pathology.
Appendix 12	Letter for the resident in case of suspected serious pathology but the resident does not consent for urgent referral
Appendix 13	Examples of standard feedback to the participating residents.

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## Appendix 1 Proforma to record the refusal by/exclusion of care homes and residents to participate in the survey

Name of Care home	Local Authority	LHB	Reason given for not participating in the survey or exclusion	Comments

Name home	of the	care	Local authority and LHB	No. of residents who refused to participate	Reason for refusal (if given)	Number of residents excluded from the survey	Reason for exclusion (for e.g. incapacity to consent and no appointed Lasting Power of Attorney (PoA)/Court appointed deputy could not be contacted)

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# Appendix 2 Sample letter of invitation to care homes to participate in the survey

LHB Logo
Address of local epidemiology team lead
Telephone number

Date The Manager (Insert address)

#### Re: Dental Survey of Care Home Residents in Wales, 2010/11

Dear .....

We would like to invite you for your care home to take part in the above survey. Your care home was selected at random from the list of care homes in your unitary authority area.

Your decision to participate in this survey will be very important to achieve these aims.

If you agree to take part in the survey, we will randomly select some residents from your care home and seek their permission to take part in the survey. If the resident provides us with the consent, we will ask the residents few questions on their dental health and carry out dental examination. This will be carried out by a fully qualified dentist.

The dental examination carried out for this survey does not replace the resident's routine dental examination. We also do not offer any dental treatment for the residents. However, if the examiner (the survey dentist) thinks that the participating resident needs an urgent referral to a specialist/consultant, we will organise the referral with the resident's consent.

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

We hope you will agree to participate in this important national survey.

Yours sincerely,

(Name and position)

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#### **Appendix 3**

#### Sample letter of invitation to the participating residents

Date

**LHB Logo** 

Address of local epidemiology team lead

Tel number

#### Dear

I am writing to you to ask if you would be willing to take part in a national survey of care home residents. This would consist of a questionnaire on your dental health and use of dental services plus an examination of your teeth, both of which we can do in your care home.

This is part of a national survey and will give important information to your NHS Local Health Board (LHB) to help them provide services to suit the needs of the population. The LHBs have to assess the 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.

We will liaise with your care home manager and visit your care home for the survey. On the day of the survey, we will ask you if you are willing to participate in the survey. You will also have opportunities to ask any question before, during and after your participation in the survey.

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

Yours sincerely

(Survey examiner/dentist)

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#### **Appendix 4**

# Sample letter of invitation to the participating resident's appointed Lasting Power of Attorney or Court Appointed Deputy

Date

**LHB Logo** 

Address of local epidemiology team lead

Tel number

Dear

I would be grateful if you could contact us to discuss regarding a national survey of care home residents in Wales.

Randomly selected care home residents are being invited to take part in this survey. Mr/Mrs/Miss.....(insert resident's name) has been selected for this survey.

As an appointed Lasting Power of Attorney/ Court Appointed Deputy (delete as appropriate) for Mr/Mrs/Miss......(insert resident's surname), I am writing to you to consider providing consent for the participation of Mr/Mrs/Miss.....(insert surname) in this dental survey. This would consist of a questionnaire on dental health an examination of his/her teeth and gum both of which we can do at the care home.

This is part of a national survey and will give important information to the NHS Local Health Board (LHB) to help them provide services to suit the needs of the population. The LHBs have to assess the needs of the population and this survey is a way of doing this.

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

You are free to choose whether or not to provide consent for participation of Mr/Mrs/Miss.....(insert resident's surname) on this survey. If you do, we will need you to sign a consent form to record this.

We are looking forward to hearing from you and discuss this further.

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

Yours sincerely

(Survey examiner/dentist)

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#### Appendix 5

#### Information sheet for the care home residents

### Dental Health Survey of Care Home Residents in Wales, 2010/11

#### Why your help is important

This leaflet answers some of the questions you may have about taking part in this survey.

#### Who are we?

We are a team, from the Local Health Board, 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.

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

#### What is the survey about?

This year a national survey about the dental health of adults (Adult Dental Health Survey, 2009/10) is being carried out in England, Wales and Northern Ireland. This survey does not include the dental health of care home residents. In Wales, this survey is being carried out, in addition to the main Adult Dental Health Survey, to collect information on the dental health of the care home residents. The survey consists mainly of two parts: an interview and a limited dental examination.

#### Why is the survey important?

This survey will provide information on the dental health of care home residents in Wales. Information collected will be useful for local health boards to effectively plan local dental health services.

Currently we do not have much information on the dental health of care home residents. This survey will provide us with information on dental disease and treatment need and allow comparisons to be made with the dental health of adults not living in care homes.

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#### Our survey partners

The Community Dental Service Teams within the newly formed Health Boards are carrying out this survey with the assistance of The Welsh Oral Health Information Unit, Cardiff University and Public Health Wales. Information from the survey will be shared among these organisations and with the Welsh Assembly Government.

#### Who will use the results?

The results will be shared with Voluntary Sector bodies with an interest in care homes, Local Health Boards, Local Authorities, Care Home Professional Bodies and the Welsh Assembly Government. A number of government departments may also use the results. Anonymous survey findings may also be shared with researchers who can analyse the data in various ways.

#### Will information I give be confidential?

A minimum of personal information is collected and this is not shared. This information 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. All participants are randomly selected. The information you provide will be combined with that from up to 4 other residents in your home and up to 5 residents from the other randomly selected homes to estimate the nature and quantity of dental problems and treatment need among care home residents across Wales. Findings from the survey may also be published on a scientific journal.

None of the information (analysed or published) will include identifiable details about the survey participants.

#### Why did we choose you?

As it is not possible to ask everyone to take part in the survey, a sample of residents is selected to represent the entire country. Your care home was selected at random from the list of care home in your Local Authority area and you were selected at random from the list of residents at your care home.

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You are important for the survey because the random sample is a cross-section of a particular sub-group. If you do not take part in the survey, there is no plan to replace you with another resident.

Participation in the interview and examination is voluntary. The success of the survey depends on the goodwill and co-operation of those invited to take part. Even after agreeing to take part in the survey, you can withdraw your consent. You can also choose to stop in the middle of the survey if you do not feel like continuing for whatever reason. You do not have to tell us the reason.

# 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. Your name will not be recorded on the survey forms or the computer. Data will only be accessible to dental epidemiology team at the LHB, staff at Welsh Oral Health Information Unit at Cardiff University and dental public health staff at Public Health Wales. These staffs are responsible for the data analysis and preparation of a report. The findings may also be published in a scientific journal. None of the information produced will identify individual participants.

The information should help planning of dental services for residents of care homes.

#### 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.

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# Appendix 6 Standard consent script

You have been chosen to take part in a dental survey. The survey will help us to obtain the picture of dental health of care home residents and plan dental services accordingly.

A dentist/I will ask you a series of questions followed by inspection of your teeth, mouth and dentures. No treatment will be done and it does not replace your regular dental care. The examining dentist will tell you if something in your mouth requires urgent dental care or referral to a specialist.

We will look at the information from the survey and will work out the results locally and for the whole of Wales.

You do not have to take part in this survey if you do not want to. You do not have to explain to us why you do not want to take part in this survey. Your future dental care will not be affected by your decision of not taking part in the survey.

For this survey we will not collect your name, so you cannot be identified by that information. However, if we see something in your mouth that requires an urgent referral to a dentist or specialist, we will seek your consent/permission for such referral and a copy of the referral letter will also be sent to your doctor (GP) and your dentist (if available).

All the information collected for this survey will be kept strictly confidential.

You can ask us any question about this survey before and after you have consented to take part.

Please help us by taking part in the dental survey. Thank you.

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Appendix 7		
Consent form for residents	s with capacity to consent LHB logo here	
Survey of Care Home Resi	idents, Wales, 2010/11	
To be completed by interviewer (plea Care home name and addres postcode	ase use capital letters and write in ink): ss including Record number	
Gender (please tick) Male Female	Date of Birth	
1. I (name)	confirm that I have read and	
	•	
opportunity to consider the answered satisfactorily.  2. I (name)	e information, ask questions and have had these consent to	
opportunity to consider the answered satisfactorily.  2. I (name)	in this study but understand that my participation is e to withdraw at any time without giving any reason,	

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survey. I give permission for these individuals to have access to these data.

team and will only be used for statistical and research purposes.

5. I understand that this information will be treated in strict confidence by the survey

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6. I understand that I may, under certain circumstances, be asked to give consent			
for referral to a specialist/consultant for further assessment.			
	_		
Name:			
Signature:	Date:		
(To be signed by the participant)			
If the participating resident has indicated	that he/she is willing to participate in the		
	ess should sign this form confirming such		
consent.			
Name of the Witness:			
Signature:	Date:		
Name of the Examiner (dentist):			
Signature:	Date:		
(When completed, 1 copy for participant; 1 copy	for survey team records)		

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# 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 and how not to identify whether someone has capacity to provide informed consent

The starting point is to assume the respondent has the capacity to make a specific decision, in this case to decide to participate in a dental survey. 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.

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You should use the interchange with the resident about their decision to participate as the test of capacity/incapacity to consent. Care home staff may provide information prior to meeting the resident which identifies individuals with greater or lesser ability to make decisions.

The assessment on whether a person lacks capacity should **never** be based simply on:

- their age;
- their appearance;
- assumptions about their condition, or;
- 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.

#### Impairment of or a disturbance in the functioning of, the mind or brain?

Examples of an impairment or disturbance in the functioning of the mind or brain which can result in incapacity to make decisions 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.

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 make it. 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.

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#### How to assess whether a respondent lacks capacity to provide consent

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 Mental Capacity Act, 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 and seek consent from the resident's appointed Lasting Power of Attorney/Court Appointed Deputy.

For individuals who lack capacity use the consent form designed for such residents (See Appendix 7).

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### LHB logo here

# Form for residents who lack capacity to consent to take part in the survey of Care Home Residents, Wales, 2010/11

Survey of Care Home Residents, Wales, 2010/11

To be completed by the examiner (please use capital letters and write in ink):

Name and Postcode of the Care Home	Record number
Gender (please tick)	Date of Birth
Male Female	3000.3.11

#### Print participant's name:

## A. Assessment of the resident's capacity (to be filled in by the examiner)

I confirm that the resident lacks the capacity to give or withhold consent to this survey because of an impairment of the mind or brain or disturbance affecting the way their mind or brain works (for example, a disability, condition or trauma, or the effect of drugs or alcohol) and they **can not do one or more of the following**:

	Please tick relevant boxes
Understand information about the procedure or course of treatment	
Retain that information in their mind	
Use or weigh that information as part of the decision-making process,	
or	
Communicate their decision (by talking, using sign language or any other means)	

Further details: (for e.g. carers or colleagues consulted, what attempts were made):

I am satisfied that the resident has not refused to take part in this survey in a valid advance decision

As far as is reasonably possible, I have considered the person's past and present wishes and feelings (in particular if they have been written down) and any beliefs and values that would be likely to influence the decision in question.

I am satisfied that the lack of capacity is unlikely to change within the data collection timescale of this survey.

I have also consulted with the resident's attorney or deputy (section B).

Name of the Examiner (dentist):

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Signature: Date:		
in question under a Lasting Power of Attor authorised to make decisions about the pr	rney to make decisions about the procedure rney or a Court Appointed Deputy has been rocedure in question, the attorney or deputy g where a procedure/survey is in the best	
and understood the information in the	leaflet for the above study on behalf of opportunity to consider the information on these answered satisfactorily.	
or people li	consider that it is in the interests of living in similar circumstances, to take part in on by	
I have agreed for (resident's name) survey.	to take part in this	
from the team involved in data collection, s	g this study may be looked at by individuals staff at Welsh Oral Health Information Unit at alth staff involved in this survey. I give scess to these data.	
I understand that this information will be treated and will only be used for statistical research	eated in strict confidence by the survey team h purposes.	
referral to a specialist if the examiner dent assessment from a specialist.	rcumstances, be asked to give consent for tist finds any lesion or ulcer that requires an	
	ddress:	
	gnature:	
Date:	Attorney/Court Appointed Deputy; 1 copy for survey	

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# Protocol for suspected serious pathology

Only if there is pathology which is suspected to be of a serious nature (e.g. suspected malignancy) is there an obligation to follow this protocol. In such cases (which you are very unlikely to encounter) a referral pro-forma (*Appendix 11*) must be completed. The team will carry a proforma in case this situation arises. Examiners should make themselves familiar with this protocol in case it is required.

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), they are obliged to follow this set protocol, which is designed to make sure that the participating resident is referred to a specialist/consultant urgently and participant's general medical practitioner is informed by sending a copy of the referral letter, whilst not causing the participant unnecessary worry.

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

"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 refer to a specialist if we see any ulcers or inflamed areas that need to be examined by an expert/specialist for the definite diagnosis. There is an area like this in your mouth and, because I am not sure exactly what it is, I would like to arrange a referral to a specialist to look at this for you. We will also let your GP or dentist and your carer know about this referral. 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 referred will turn out to be serious. It is the responsibility of the examiner not to alarm the participant unduly.

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

Once the participating resident provides consent (verbal) for referral to a specialist/consultant, examining dentist should fill an urgent referral proforma/letter (*Appendix 11*) and post it immediately to the local specialist/consultant. A copy is also sent to the resident's GP and the dentist (if available).

If the respondent does not want to be referred and does not want their GP to be contacted, then they will be presented with an information letter (*Appendix 12*) urging them to pursue a check up.

If a participating resident who requires referral for a suspected serious pathology but lacks capacity to consent for referral, the examiner dentist should consult the participating resident's Lasting Power of Attorney or a Court Appointed Deputy in line with the Mental Capacity Act 2005.

Training on Mental Capacity Act 2005 and its implication for the survey will be provided to all dental epidemiology team members during the 'training and standardisation' event held prior to the survey.

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# An example of referral proforma in case of suspected serious pathology

0

LHB Log
Dental Epidemiology Field Team Addre
Telepho
Date
Name and address of local consultant
Re:
Name of the resident:
Date of Birth:
Address:
Dear
I would be grateful if you could assess and treat (insert title and surname) <b>URGENTL</b> (Insert title and surname) had dental examination on (insert date) as a part of the Ca Home Residents' Survey, Wales, 2010/11.
Details of (insert name) are as follows.
Medical History:
Dental history with details suspected serious pathology:

Social history: (including history of smoking and alcohol consumption)
Name and address of GP:
Many thanks,
Yours sincerely,
(Examining dentist)

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Letter for the resident in case of suspected serious pathology but the resident does not consent for urgent referral.

LHB logo

Address of local epidemiology team lead

Tel number

Date

(Participating resident's name and address)

Dear .....

Thank you for taking part in this survey, the information we have collected through this survey will be useful for planning of local dental services.

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 refer to a specialist if we see any ulcers or inflamed areas that need to be examined by an expert/specialist for the definite diagnosis. There is an area like this in your mouth and, because I am not sure exactly what it is, I would have liked to arrange a referral to a specialist to look at this for you. We also wanted your GP to know about this referral. However, you have indicated that you do not want us to make such referral to a specialist and inform your GP.

We advise you that it is important that <u>you</u> arrange to have the area checked by a doctor or dentist as soon as possible.

Yours sincerely

Survey dentist

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# **Examples of standard feedback to the participating residents**

Each person will get the following general statement to clarify the limitations of the examination:

"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."

Then the categories are:

## Category 1 No obvious oral problems

(used for anyone with no obvious disease requiring further assessment)

"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 meriting a dental check up

(used for anyone with obvious disease requiring further assessment)

"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 meriting a check up within 1 month

(used for anyone who has lesions under PUFA)

#### 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**

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"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."

The examiner should try his/her best for such resident to be seen by local community dental service or a GDS/PDS provider.

### Category 4 Suspected serious pathology meriting urgent referral

(Used if the examining dentist 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 9.** 

It should be noted that individual dentists are highly unlikely to encounter such serious pathology in this survey because the incidence of such lesions is low.

The suggested wording is:

"Before I discuss the findings with you it is important that you understand that the survey is not a substitute for normal examination which is supplemented by appropriate x-rays undertaken in a dental clinic.

In this survey our policy is to refer to a specialist if we see any ulcers or inflamed areas that need to be examined by an expert/specialist for the definite diagnosis.. There is an area like this in your mouth and, because I am not sure exactly what it is, I would like to arrange a referral to a specialist to look at this for you. We will also let your GP or dentist and your carer know about this referral. Are you happy for me to do that?"

The examiner or the Clinical Director of the LHB Dental Service will take responsibility for taking appropriate action on any report of serious pathology. If a resident does not consent for such referral, then they will be presented with an information letter urging them to pursue a check up urgently (See Appendix 12)

#### Dealing with further questions

Examining clinicians cannot provide an individualised dental treatment plan or on the standard of previous dental treatment because the examination is not designed to collect the information required to make these assessments or plans. If the respondent probes for more specific detail on their dental health, dentists 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 dentist or dental hygienist since there are many ways of achieving this. They will preface this response by saying:

'What I generally tell people is.............'

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If asked to comment on specific aspects of past treatment, dentists 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'.

Each examiner will suggest that the care home contact the Local Health Board for assistance in finding a dentist if a resident does not currently have one.

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