

Appendix 1: Introductory letter



«Title» «FirstName» «LastName»

«JobTitle»

«Company»

«Address1»

«City»

«State» «PostalCode»

Dear «Title» «LastName»,

Re: Research on ‘Oral care for young adults with physical and intellectual disabilities’

I am a PhD student at The University of Adelaide, under the supervision of Professor AJ Spencer (Professor of Social and Preventive Dentistry) and Professor GD Slade (Professor of Oral Epidemiology). I am conducting a research on oral care for the physically and intellectually disabled young adults (18–44 years of age), living in different living arrangements, who require partial or complete assistance from their carer for their daily oral care.

Many such people depend greatly on their carers for oral care and for assistance with regards to dental visits and treatment. Due to the possible role of carers in maintaining good oral health of their charges, the study aims to investigate how carers can contribute to improved oral health of the disabled people.

It is anticipated that the results of the study can be utilised to provide guidelines for the development of appropriate oral health care plans across various residential settings to improve the oral health and quality of life of young adults with physical and intellectual disabilities.

The study will consist of two components.

1. A questionnaire to carers

The questionnaire will ask carers about their relationship with their care recipients, length of contact, their involvement in oral care and the residential setting in which the care is provided. Factors that might influence the care-giving role like reasons for being a carer will also be explored. It will take approximately 15 minutes to complete.

2. An oral examination of physically/intellectually disabled young adults between the ages of 18 and 44 who require partial or complete assistance from their carer for their oral care. This will be similar to a routine dental check-up and will take 15–30 minutes depending on the level of cooperation of the care recipient. No x-rays will be taken.

Confidentiality of the carers’ responses to the questionnaires and clinical observations of their care recipients will be maintained by secure storage of the data collected. Its use will be restricted to the research team for the purpose of the study only. No identifiable data will be reported.

I am seeking your organisation's assistance in approaching suitable participants for our study. We would be most grateful if you can provide us with some general information regarding the number of your care recipients and their living arrangements, as set out in the attached form. There is also an opportunity for you to indicate your organisation's willingness to be part of the selection process and ask questions or make any comments. This information will remain confidential. If your organisation agrees to be involved in this study we would appreciate your assistance in maintaining participant's privacy, by mailing out to care recipients and their carers the information package and the questionnaire.

The package will contain:

- an information sheet on the study for the carer
- an information sheet on the study for the care recipient
- a consent form for the care recipient
- a consent form for the parent/carer/guardian
- a pre-paid return addressed envelope

We will cover all the necessary costs for the postage and the time involved.

Those care recipients and carers willing to participate in the research can return consent and completed questionnaires directly to the researchers who will complete the necessary data collection directly with the carers and their care recipients.

Thank you very much for your co-operation.

Yours sincerely,

Dr Archana Pradhan (PhD scholar)
Ph: 83033065
Email: archana.pradhan@adelaide.edu.au

Professor AJ Spencer
Professor of Social & Preventive Dentistry
Ph: 83035438
Email: john.spencer@adelaide.edu.au

Professor GD Slade
Professor of Oral Epidemiology
Ph: 83033291
gary.slade@adelaide.edu.au

Australian Research Centre for Population Oral Health
Dental School
The University of Adelaide,
Adelaide 5005

Name of organisation.....

Address.....

.....

Number of care recipients (18–44 years of age)

Living with family	
Living in an institution	
Living in community housing	

☐

Yes, I am willing for my organisation to participate in this study.

☐

No, please do not contact me again regarding this study.

Comments/queries:.....

.....

.....

.....

.....

.....

.....

Appendix 2: Cover letter to participating organisations



«Title» «FirstName» «LastName»
«JobTitle»
«Company»
«Address1»
«City»
«State» «PostalCode»

Dear «Title» «LastName»,

Re: Research on 'Oral care for adults with physical and intellectual disabilities'

Thank you very much for your cooperation with the research. We now seek your assistance in the distribution of the information package and the questionnaire.

- Please make three sets of labels for each care recipient aged 18–44 years old.
- Please place the first label in the space provided on the first page of the questionnaire and distribute it to the primary (key) carers of all the care recipients, together with a covering letter printed on your organisation's letterhead and the information sheets. Please find enclosed a draft of the covering letter. Please feel free to make any changes as necessary.
- Please ensure that the label on the questionnaire is visible through the window of the C4 envelope. Please mail it by the 4th of February 2005.
- Please place the second set of labels on the DL envelope with the reminder postcard and post them to the primary carers of all care recipients on the 21st of February 2005.
- Please keep the third set of labels until further notice. We will inform you of who have responded, so you can then mail the follow-up letter to the non-respondents. Further instructions about the follow-up letter will be mailed to you in time for the final mail on the 7th of March.

We believe that it is better that the initial request came from the organisation for greater cooperation and higher response. We will interact with the carers and their care recipients directly once we get their consent.

Thank you very much for your assistance.

Yours sincerely,

Professor AJ Spencer
Professor of Social & Preventive Dentistry
Ph: (8) 8303 5438
Email: john.spencer@adelaide.edu.au

Professor GD Slade
Professor of Oral Epidemiology
Ph: (8) 8303 3291
gary.slade@adelaide.edu.au

Appendix 3: Information sheet for carers



Oral Care for Adults with Physical and Intellectual Disabilities

Information sheet for carers

The study is being conducted by Dr Archana Pradhan (PhD student) under the supervision of Professor AJ Spencer (Professor of Social and Preventive Dentistry) and Professor GD Slade (Professor of Oral Epidemiology) from The University of Adelaide. The research is on oral care for the physically and intellectually disabled adults (18–44 years of age), living in different living arrangements, who require some level of assistance from their carer for their daily oral hygiene care. The study aims to investigate how carers can contribute to improved oral health of the disabled people.

We are inviting you to participate in this study. Your participation is voluntary and you may withdraw from the study at any time without affecting your care recipient's dental treatment now or in the future.

It is anticipated that the results of the study can be utilised to develop appropriate oral health care plans across various residential settings to improve the oral health and quality of life of adults with physical and intellectual disabilities.

The study will consist of two components.

1. A questionnaire to carers.

We would like to ask you about your relationship with your care recipients, length of contact, your involvement in oral hygiene care and the residential setting in which the care is provided. Factors that might influence the care-giving role like reasons for being a carer will also be explored. It will take approximately 15 minutes to complete.

2. A dental inspection of randomly selected care recipients.

If your care recipient is selected for the study, we would like to conduct an oral examination of your care recipient at a convenient South Australian Dental Service Clinic. This will be similar to a routine dental check-up and will take 15–30 minutes. No x-rays will be taken. No dental treatment will be provided, however, a signed report of the findings will be given and a referral arranged if necessary or arrangements for routine oral care confirmed.

Confidentiality of your responses to the questionnaires and clinical observations of your care recipients will be maintained by secure storage of the data collected. Its use will be restricted to the research team for the purpose of the study only. No identifiable data will be reported.

If you have further queries on this study, please feel free to contact Dr Archana Pradhan on (08) 8303 3065, Professor John Spencer on (08) 8303 5438 or Professor Gary Slade on (08) 8303 3291. If you like to speak to someone independent, please refer to the attached document on 'Contacts for Information on Project and Independent Complaints Procedure'

A John Spencer
Professor of Social and Preventive Dentistry
The University of Adelaide

Gary D Slade
Professor of Oral Epidemiology
The University of Adelaide

Appendix 4: Information sheet for care recipients



Oral Care for Adults with Physical and Intellectual Disabilities

Information sheet for care recipients

The study is being conducted by Dr Archana Pradhan (PhD student) under the supervision of Professor AJ Spencer (Professor of Social and Preventive Dentistry) and Professor GD Slade (Professor of Oral Epidemiology) from The University of Adelaide. The research is on oral care for the physically and intellectually disabled adults (18–44 years of age), living in different living arrangements, who require some level of assistance from their carer for their daily oral hygiene care. The study aims to investigate how carers can contribute to improve the oral health of people with physical and intellectual disabilities.

We are inviting you to participate in this study. Your participation is voluntary and you may withdraw from the study at any time without affecting your dental treatment now or in the future.

It is anticipated that the results of the study can be utilised to develop appropriate oral health care plans across various settings to improve the oral health and quality of life of adults with physical and intellectual disabilities.

The study will consist of two components.

1. A questionnaire to carers.

We would like to ask them about their relationship with you, length of contact, their involvement in oral hygiene care and the residential setting in which the care is provided. Factors that might influence the care-giving role like reasons for being a carer will also be explored.

2. A dental inspection of randomly selected care recipients.

If you are selected for the study, we would like to conduct an oral examination for you at a convenient South Australian Dental Service Clinic. This will be similar to a routine dental check-up and will take 15–30 minutes. No x-rays will be taken. No dental treatment will be provided, however, a signed report of the findings will be given and a referral arranged if necessary or arrangements for routine oral care confirmed.

Confidentiality of your carers' responses to the questionnaires and clinical observations of your oral examination will be maintained by secure storage of the data collected. Its use will be restricted to the research team for the purpose of the study only. No identifiable data will be reported.

If you have further queries on this study, please feel free to contact Dr Archana Pradhan on (08) 8303 3065, Professor John Spencer on (08) 8303 5438 or Professor Gary Slade on (08) 8303 3291. If you like to speak to someone independent, please refer to the attached document on 'Contacts for Information on Project and Independent Complaints Procedure'.

A John Spencer
Professor of Social and Preventive Dentistry
The University of Adelaide

Gary D Slade
Professor of Oral Epidemiology
The University of Adelaide

Appendix 5: Information sheet on:

‘Contacts for information on project and independent complaints procedure’

THE UNIVERSITY OF ADELAIDE HUMAN RESEARCH ETHICS COMMITTEE

Document for people who are subjects in a research project

CONTACTS FOR INFORMATION ON PROJECT AND INDEPENDENT COMPLAINTS PROCEDURE

The Human Research Ethics Committee is obliged to monitor approved research projects. In conjunction with other forms of monitoring it is necessary to provide an independent and confidential reporting mechanism to assure quality assurance of the institutional ethics committee system. This is done by providing research subjects with an additional avenue for raising concerns regarding the conduct of any research in which they are involved.

The following study has been reviewed and approved by the University of Adelaide Human Research Ethics Committee:

Project title: Oral Care for Adults with Physical and Intellectual Disabilities

1. If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the project co-ordinators:

Name: Professor John Spencer or Professor Gary Slade

telephone: (8) 8303 5438 (8) 8303 3291

2. If you wish to discuss with an independent person matters related to
 - making a complaint, or
 - raising concerns on the conduct of the project, or
 - the University policy on research involving human subjects, or
 - your rights as a participant

contact the Human Research Ethics Committee’s Secretary on phone (08) 8303 6028



THE UNIVERSITY
OF ADELAIDE
AUSTRALIA

To the primary carer of:

Please affix care recipient label here

Oral Care for Adults with Physical and Intellectual Disabilities

Dear Carer,

We would like your help. If you are the primary (key) carer for the care recipient named above **and/or** provide assistance with his/her self-care **and** you and your care recipient are willing to participate in the study, please complete the questionnaire and return it to the researchers in the enclosed reply-paid envelope. If you receive a similar form from another organization as well, please mark it as duplicate and return it to the researchers. If you are not the primary (key) carer for the care recipient named above, kindly forward this to his/her primary (key) carer.

On receiving the questionnaires, we will randomly select some of the care recipients for a dental inspection. If your care recipient is included in the study, we will contact you to make an appointment for his/her dental inspection at the nearest South Australian Dental Service (SADS) clinic. If they are already regular patients at a SADS clinic, the appointment will be arranged at the time of their recall visit. The dental inspection involves collecting basic information about your care recipient's oral health. A signed report of the findings will be given and a referral arranged if necessary or arrangements for routine oral care confirmed.

As explained in the attached "Information sheet for carers", we hope to collect information about your care recipient's oral health and your involvement in caring for their oral hygiene.
All information you provide will be strictly confidential.

Please provide us with your contact details below. We need this information to contact you to arrange an appointment in case your care recipient is selected for the dental inspection part of the study.

GIVEN NAME: SURNAME:

ADDRESS: SUBURB:

STATE: POSTCODE: TELEPHONE: (____) ____-____-____
(Area code) (Number)

QUESTIONNAIRE

Please mark boxes ☐ with a "×" or a "✓" or write responses, where appropriate, in the space provided.

QUESTION	A. Your details	B. Your main care recipient's details
1. Age	<input type="text"/> <input type="text"/> Years	<input type="text"/> <input type="text"/> Years
2. Sex	<input type="checkbox"/> ₁ Male <input type="checkbox"/> ₂ Female	<input type="checkbox"/> ₁ Male <input type="checkbox"/> ₂ Female
3. Country of birth
4. General health	<input type="checkbox"/> ₁ Excellent <input type="checkbox"/> ₂ Very good <input type="checkbox"/> ₃ Good <input type="checkbox"/> ₄ Fair <input type="checkbox"/> ₅ Poor	<input type="checkbox"/> ₁ Excellent <input type="checkbox"/> ₂ Very good <input type="checkbox"/> ₃ Good <input type="checkbox"/> ₄ Fair <input type="checkbox"/> ₅ Poor
5. Source of income (Please mark all that apply)	<input type="checkbox"/> ₁ Wages or salary <input type="checkbox"/> ₂ Carer allowance <input type="checkbox"/> ₃ Carer payment <input type="checkbox"/> ₄ Other income (Please specify):	<input type="checkbox"/> ₁ No source of income <input type="checkbox"/> ₂ Disability support pension <input type="checkbox"/> ₃ Maintenance/workers compensation <input type="checkbox"/> ₄ Other income (Please specify):
6. Usual living arrangement (Usual refers to four or more days per week on average)	<input type="checkbox"/> ₁ Do not live with any care recipient <input type="checkbox"/> ₂ With main care recipient only <input type="checkbox"/> ₃ With two or more care recipients	<input type="checkbox"/> ₁ Lives alone <input type="checkbox"/> ₂ Lives with family <input type="checkbox"/> ₃ Lives in community housing <input type="checkbox"/> ₄ Lives in institution

C. Residential movements of your main care recipient

C1. Have there been any changes in the living arrangement of your main care recipient in the last five years?

☐₁ Yes (Please answer question C2)
 ☐₂ No
 ☐₃ Don't know (Please go to question D1)

↓

C2. Please indicate the length of time spent (six months or more) in the last five years.

Living arrangement of main care recipient	Length of time	From (Year)	To (Year)
<input type="checkbox"/> ₁ Alone			
<input type="checkbox"/> ₂ Family home			
<input type="checkbox"/> ₃ Community housing			
<input type="checkbox"/> ₄ Institution(s) (Please specify):			

D. More information about your main care recipient named in label

D1. What are his/her primary and other significant disabling condition (s)?

A) Primary disabling condition

B) Other significant disabling condition

Please tick one box only	<input type="checkbox"/> _1	Autism and related disorders	<input type="checkbox"/> _1	Please mark all boxes as applicable
	<input type="checkbox"/> _2	Cerebral palsy	<input type="checkbox"/> _2	
	<input type="checkbox"/> _3	Head injury/ brain damage	<input type="checkbox"/> _3	
	<input type="checkbox"/> _4	Intellectual/developmental disorders	<input type="checkbox"/> _4	
	<input type="checkbox"/> _5	Quadriplegia	<input type="checkbox"/> _5	
	<input type="checkbox"/> _6	Spina bifida	<input type="checkbox"/> _6	
	<input type="checkbox"/> _7	Other (Please specify):	<input type="checkbox"/> _7	

D2. How many carers provide care to your main care recipient on a daily basis?

 Please specify number

D3. How does he/she communicate with you?

☐_1 Verbally- English language

☐_2 Verbally- non-English language (Please specify):

☐_3 Non-spoken communication- Sign language

☐_4 Non-spoken communication- Picture cards/board, writing, typed/computer messages

☐_5 Little or no effective communication

☐_6 Other non-spoken communication (Please specify):

D4. How often does your main care recipient need personal help with the following activities?

	Always	Sometimes	Does not need help but uses aid or equipment	Does not need help and does not use aid or equipment
a) Mobility	<input type="checkbox"/> _1	<input type="checkbox"/> _2	<input type="checkbox"/> _3	<input type="checkbox"/> _4
b) Bathing/showering/washing	<input type="checkbox"/> _1	<input type="checkbox"/> _2	<input type="checkbox"/> _3	<input type="checkbox"/> _4
c) Eating/feeding	<input type="checkbox"/> _1	<input type="checkbox"/> _2	<input type="checkbox"/> _3	<input type="checkbox"/> _4
d) Toileting?	<input type="checkbox"/> _1	<input type="checkbox"/> _2	<input type="checkbox"/> _3	<input type="checkbox"/> _4

D5. How is he/she fed?

Feeds without assistance <input type="checkbox"/> _1	Feeds with assistance <input type="checkbox"/> _2	Is fed completely by tubes or intravenous fluids <input type="checkbox"/> _3
---	--	---

D6. How often does he/she have the following food and drinks?				
	Less than twice a week	2-4 times/week	5-7 times/week	More than once a day
1. Sweetened tea/coffee	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
2. Soft drinks, cordials a) diet	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
b) non-diet	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
3. Sweetened dairy products (ice-cream)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
4. Fruit juice	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
5. Biscuits, cakes, puddings	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
6. Flavoured milk (Milo, chocolate milk, Nesquik, etc.)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
7. Chocolate- and sugar-based confectionery	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄
8. Syrups, jams, and sweet spreads (Nutella, honey, jam, maple syrup etc.)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄

D7. Does he/she take any medications?	
<input type="checkbox"/> ₁ Yes (please list medications) →	
<input type="checkbox"/> ₂ No	

D8. Does he/she smoke cigarettes?			
	a) Number of cigarettes per day	b) Number of years smoked	c) Number of years quit smoking
<input type="checkbox"/> ₁ Yes	→ <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	
<input type="checkbox"/> ₂ No, but used to	→ <input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>	<input type="text"/> <input type="text"/>
<input type="checkbox"/> ₃ No, never smoked			
<input type="checkbox"/> ₄ Don't know			

D9. Does he/she have any of the following habits? (Please mark all that apply)	
<input type="checkbox"/> ₁ Regurgitates, rechews and reswallows food	
<input type="checkbox"/> ₂ Places food, medicine or other products in the mouth for lengthy periods of time	
<input type="checkbox"/> ₃ Clenches, grinds or taps teeth	
<input type="checkbox"/> ₄ Craves for and eats non-edible substances like gravel, sand, paint chips and tobacco butts (Please specify):	
<input type="checkbox"/> ₅ None of the above	

E. Questions involving you and your main care recipient

E1. Relationship to your main care recipient

<input type="checkbox"/> ₁ Spouse/partner of main care recipient	<input type="checkbox"/> ₅ Other relative/friend
<input type="checkbox"/> ₂ Parent of main care recipient	<input type="checkbox"/> ₆ Paid, Government employee
<input type="checkbox"/> ₃ Son/daughter of main care recipient	<input type="checkbox"/> ₇ Paid, Private employee
<input type="checkbox"/> ₄ Brother/sister of main care recipient	<input type="checkbox"/> ₈ Volunteer

E2. Length of contact with your main care recipient as a carer

<input type="text"/>	<input type="text"/>	Years	<input type="text"/>	<input type="text"/>	Months
----------------------	----------------------	-------	----------------------	----------------------	--------

F. Questions involving your tasks

F1. Number of care recipients under your charge

<input type="text"/>	<input type="text"/>	Please specify number
----------------------	----------------------	-----------------------

F2. How often do you provide assistance for your main care recipient with the following activities?

	Never	Sometimes	Always
a) Mobility	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
b) Bathing/showering/washing	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
c) Eating/feeding	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃
d) Toileting	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃

F3. Compared with the other tasks that you provide, how important do you think oral health care is for your main care recipient?

Not important	Somewhat important	Important	Very important	Extremely important
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

G. Questions relating to oral care of your main care recipient

G1. Does your main care recipient clean his/her own teeth?

<input type="checkbox"/> ₁ No
<input type="checkbox"/> ₂ Yes, without any assistance
<input type="checkbox"/> ₃ Yes, with some assistance. Please specify:

G2. How often are his/her natural teeth cleaned? (by the care recipient or another person)

- | | |
|---|---|
| <input type="checkbox"/> ₁ Not applicable (has no natural teeth) | <input type="checkbox"/> ₄ Several times a week |
| <input type="checkbox"/> ₂ Twice a day | <input type="checkbox"/> ₅ Less than once a week |
| <input type="checkbox"/> ₃ Once a day | <input type="checkbox"/> ₆ Don't know |

G3. How often are his/her dentures cleaned? (by the care recipient or another person)

- | | |
|--|---|
| <input type="checkbox"/> ₁ Not applicable (has no dentures) | <input type="checkbox"/> ₄ Several times a week |
| <input type="checkbox"/> ₂ Twice a day | <input type="checkbox"/> ₅ Less than once a week |
| <input type="checkbox"/> ₃ Once a day | <input type="checkbox"/> ₆ Don't know |

If your main care recipient has no teeth or dentures or you do not clean his/her teeth or dentures please go to Question G10

G4. What is used to clean his/her teeth? (Please mark all that apply)

- | | | | |
|---|--------|---|---|
| <input type="checkbox"/> ₁ Toothbrush only | —————→ | <input type="checkbox"/> _a Electric toothbrush | <input type="checkbox"/> _b Manual toothbrush |
| <input type="checkbox"/> ₂ Toothbrush and toothpaste | —————→ | <input type="checkbox"/> _a Electric toothbrush | <input type="checkbox"/> _b Manual toothbrush |
| <input type="checkbox"/> ₃ Gel | —————→ | <input type="checkbox"/> _a Chlorhexidine | <input type="checkbox"/> _b Fluoride |
| <input type="checkbox"/> ₄ Mouthrinse | —————→ | <input type="checkbox"/> _a Chlorhexidine | <input type="checkbox"/> _b Fluoride |
| <input type="checkbox"/> ₅ Other (Please specify): | | | |

G5. How much time do you take to clean his/her teeth/dentures per session?

<input type="text"/>	<input type="text"/>	Minutes
----------------------	----------------------	---------

G6. Do you get enough time to clean his/her teeth/dentures?

- ☐ ₁ Yes
- ☐ ₂ No (Please state why):

G7. How thoroughly are you able to clean his/her teeth? (Please mark all that apply)

- ☐ ₁ Able to clean only outer surfaces of teeth
- ☐ ₂ Able to clean only front teeth
- ☐ ₃ Able to clean some but not all teeth
- ☐ ₄ Able to clean all surfaces of all teeth

G8. How often do you encounter the following behavioural difficulties when providing oral hygiene care for your main care recipient?					
	Never	Rarely	Sometimes	Fairly often	Very often
1. Refuses oral hygiene care	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. Does not open mouth	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. Bites toothbrush/swab/carer	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. Kicks or hits during oral care	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
5. Faces head down towards chest	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
6. Uses offensive language	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
7. Drools	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
8. Moves head or body around excessively	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
9. Does not or is unable to spit after using toothpaste	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
10. Does not or is unable to rinse with mouth wash	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
11. Other (Please specify):	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

G9. How often do you encounter the following difficulties when providing oral hygiene care for your main care recipient?					
<i>(questions G9a and G9b are for all carers)</i>					
	Never	Rarely	Sometimes	Fairly often	Very often
a. Lack of time in your usual routine	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
b. Other (Please specify)	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
<i>(question G9c and G9d are for volunteers and paid carers only)</i>					
c. Lack of staff	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
d. Lack of communication among staff between shifts	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

G10. Do you think your main care recipient has any oral health problem(s) at present?

<input type="checkbox"/> ₁ Yes (please mark all that apply) → <input type="checkbox"/> ₂ No <input type="checkbox"/> ₃ Don't know	<input type="checkbox"/> ₁ Decay	<input type="checkbox"/> ₂ Bleeding gums	<input type="checkbox"/> ₃ Denture problem
	<input type="checkbox"/> ₄ Loose teeth	<input type="checkbox"/> ₅ Broken teeth	<input type="checkbox"/> ₆ Lost/broken filling
	<input type="checkbox"/> ₇ Bad breath	<input type="checkbox"/> ₈ Ulcers	<input type="checkbox"/> ₉ Abscess/infection
	<input type="checkbox"/> ₁₀ Other (Please specify):		

G11. Do you think your main care recipient needs any of the following dental treatment?

<input type="checkbox"/> ₁ Yes (please mark all that apply) → <input type="checkbox"/> ₂ No <input type="checkbox"/> ₃ Don't know	<input type="checkbox"/> ₁ Scale and clean	<input type="checkbox"/> ₂ Filling
	<input type="checkbox"/> ₃ Extraction	<input type="checkbox"/> ₄ Denture
	<input type="checkbox"/> ₅ Other (Please specify):	

G12. How often during the last year, has your main care recipient...

	Never	Rarely	Sometimes	Fairly often	Very often
1. Had trouble sleeping because of a dental problem	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. Had pain and discomfort because of a dental problem	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. Had unsatisfactory diet because of a dental problem	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. Been irritable because of a dental problem	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

G13. Have you had any training in oral care for people with disabilities?

☐ ₁ Yes, Topic:.....
 Organised by:.....
 Year:..... Training period:..... years/months/weeks/days

☐ ₂ No

G14. Would you be interested in attending a training session in oral care for people with disabilities?

☐ ₁ Yes (Please specify):

☐ ₂ No

G15. How often does he/she usually have a dental visit?☐₁ Never had a dental visit☐₂ Only with a dental problem☐₃ Every 2 years☐₄ Every year☐₅ Every 6 months☐₆ Don't know**Please give reason(s) marking all that apply**☐₁ No dental problem☐₂ Appointments for check-ups unavailable☐₃ Unable to find a dentist who will see people with disabilities☐₄ Care recipient can not tolerate dental procedures☐₅ Lack of time☐₆ Cost☐₇ Other (Please specify):**G16. How is the dental check-up/treatment usually done ?**☐₁ Check-up and treatment in the dental chair without sedation☐₂ Check-up and treatment in the dental chair with sedation☐₃ Check-up in the dental chair, but treatment under general anaesthesia☐₄ Check-up and treatment under general anaesthesia☐₅ Never had a dental visit**G17. What services are usually provided for your main care recipient?
(Please mark all that apply)**

Check-up only

☐₁

Scale and clean

☐₂

Filling

☐₃

Extraction

☐₄

Dentures

☐₅

Don't know

☐₆

Never had a visit

☐₇☐₈ Other (Please specify):**H. Your opinions about dental care provided to your main care recipient****H1. Do you take your main care recipient for his/her dental visit?**☐₁ Yes ☐₂ No (please specify why and go to question H3)

H2. At your care recipient's dental visit, the dentist/hygienist....					
	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1. Conducts a proper dental examination, diagnosis and treatment	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
2. Fully explains treatment choices to carer and care recipient	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
3. Shows sensitivity to the special needs of your care recipient	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
4. Offers clear oral hygiene instructions to carer and care recipient	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅
5. Arranges recall visits for care recipient	<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

H3. Which of the following problems do you encounter in obtaining dental care for your care recipient? (Please mark all that apply)	
<input type="checkbox"/> ₁	Lack of dentists willing to treat people with disabilities
<input type="checkbox"/> ₂	Transport difficulty
<input type="checkbox"/> ₃	Cost of dental treatment
<input type="checkbox"/> ₄	Inconvenient location of dental clinic
<input type="checkbox"/> ₅	Lack of dentists with adequate skills to manage and treat people with disabilities
<input type="checkbox"/> ₆	None of the above
<input type="checkbox"/> ₇	Other (Please specify):

I. Questions relating to your oral care

I1. How important do you think oral health is for you?				
Not important	Somewhat important	Important	Very important	Extremely important
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

I2. How often do you go for a dental visit?				
Every 6 months	Every year	Every 2 years	Only with a problem	Never
<input type="checkbox"/> ₁	<input type="checkbox"/> ₂	<input type="checkbox"/> ₃	<input type="checkbox"/> ₄	<input type="checkbox"/> ₅

I3. How often do you clean your natural teeth/dentures?	
<input type="checkbox"/> ₁ Twice a day	<input type="checkbox"/> ₄ Less than once a week
<input type="checkbox"/> ₂ Once a day	<input type="checkbox"/> ₅ Not applicable (have no natural teeth/dentures)
<input type="checkbox"/> ₃ Several times a week	

J. Your work details

J1. Which of the following factors influenced you to take on the caring role?

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree	Not applicable
1. To provide better care	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
2. Family responsibility	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
3. Emotional obligation	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
4. No other family or friends available	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
5. No other family or friends willing	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
6. Alternative care too costly	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
7. No other care arrangements available	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
8. Had no other choice	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6
9. To make a living	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	<input type="checkbox"/> 6

J2. Thinking generally about your caring role, how often do you feel...?

	Not at all	Rarely	Sometimes	Fairly often	Very often
1. Satisfied	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
2. Stressed	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
3. Angry	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
4. Frustrated	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
5. Weary/lack of energy	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
6. Muscle pain in neck/back/limbs	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
7. Uncomfortable providing oral care	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

J3. Weekly hours of care provided to your main care recipient

Less than 20 hours <input type="checkbox"/> 1	20 to 39 hours <input type="checkbox"/> 2	40-100 hours <input type="checkbox"/> 3	Over 100 hours <input type="checkbox"/> 4
--	--	--	--

J4. Your pay rate (before tax)

<input type="checkbox"/> 1 No pay (family/friend relative)	<input type="checkbox"/> 4 \$15-\$24 an hour
<input type="checkbox"/> 2 No pay (Volunteer)	<input type="checkbox"/> 5 \$25-\$40 an hour
<input type="checkbox"/> 3 Less than \$15 an hour	<input type="checkbox"/> 6 More than \$40 an hour

J5. Do you have a fall-back carer for your main care recipient?

☐₁ Yes ☐₂ No

J6. Do you need more support to assist in your caring role?

☐₁ No

☐₂ Yes, more respite care

☐₃ Yes, more financial assistance

☐₄ Yes, more physical assistance

☐₅ Yes, more emotional support

☐₆ Yes, other (Please specify):

Thank you for completing this questionnaire. Your contribution to this study is greatly appreciated.

Please return the completed questionnaire in the reply-paid envelope provided to:

**ARCPOH- Dental School
The University of Adelaide
Adelaide SA 5001**

Your comments

If you have any comments, please feel free to write them in the space provide below.

.....

.....

.....

.....

.....

.....

.....

ARCPOH OFFICE USE ONLY

Organisation ID:/03.....

Care recipient ID:

Appendix 7: Consent form for care recipient

CONSENT FORM

I, (*please print name*)
consent to participate in the research project entitled: Oral Care for Adults with Physical and Intellectual Disabilities. I acknowledge that I have read the attached Information Sheet on the study and that I may retain a copy of this Consent Form, when completed, and the attached Information Sheet. I have had the study, so far as it affects me, fully explained to my satisfaction by the researcher.

- I understand that the oral examination will be similar to a routine check-up and that the procedures used are not harmful.
- I have been informed that no x-rays will be taken.
- I understand that the purpose of this research project is to improve the quality of oral care of adults with physical and intellectual disabilities, and that my involvement may not be of any direct benefit to me.
- I have been informed that, while information gained during the study may be published, I will not be identified and my personal results will not be disclosed.
- I understand that I am free to withdraw from the project at any time and that this will not have any effect in the management of my oral health, now or in the future.
- My consent to participate in the study is given freely.

Name:

.....

(*signature*)

(*date*)

Appendix 8: Consent form for parent or guardian or person responsible

Consent by Parent or Guardian or Person Responsible

I, (*please print name*)
consent to allow (*please print name*)
to participate in the research project entitled: Oral Care for Adults with Physical and Intellectual Disabilities. I acknowledge that I have read the attached Information Sheet on the study and that I may retain a copy of this Consent Form, when completed, and the attached Information Sheet.

On behalf of (*please print name*),

I acknowledge the following:

- I am the parent/guardian or have the legal authority to consent on his/her behalf.
- I have had the study, so far as it affects him/her fully explained to my satisfaction by the researcher.
- The oral examination will be similar to a routine check-up and that the procedures used are not harmful.
- No x-rays will be taken.
- The purpose of this research project is to improve the quality of oral care of adults with physical and intellectual disabilities, and that his/her involvement may not be of any direct benefit to him/her.
- While information gained during the study may be published, he/she will not be identified and his/her personal results will not be disclosed.
- I understand that he/she is free to withdraw from the project at any time and that this will not have any effect in the management of his/her oral health, now or in the future. My consent for him/her to participate in the study is given freely.

Name:

.....

(*signature*)

(*date*)

Appendix 9: Reminder card



A Friendly Reminder

Recently a package was mailed to you for the study on: “Oral care for adults with physical and intellectual disabilities”.

If you have already completed and returned it to us, please accept our sincere thanks and ignore this friendly reminder. If not, could you please do so as soon as possible. Your participation is very important.

The study is being conducted by researchers from the Australian Research Centre for Population Oral Health, The University of Adelaide. Participation is voluntary and any information that you provide will be maintained in strict confidence.

If you did not receive the package, or if it was misplaced, please call Dr Archana Pradhan on (08) 8303 3065 for a replacement.

Your participation is greatly appreciated and your contribution is highly valued.

Professor AJ Spencer
Professor of Social & Preventive Dentistry
The University of Adelaide

Professor GD Slade
Professor of Oral Epidemiology
The University of Adelaide

Appendix 10: Final follow-up letter



Oral care for adults with physical and intellectual disabilities

Dear Carer,

A few weeks ago we sent you a questionnaire about an important study on: “Oral care for adults with physical and intellectual disabilities”, conducted by researchers from the Australian Research Centre for Population Oral Health, The University of Adelaide. Its purpose is to improve the oral health of disabled people. Your participation is voluntary and any information that you provide will be maintained in strict confidence.

As of today, we have not received your completed questionnaire. We understand that you may not have had the time to complete it. However, we would truly appreciate your views. Our past experience has shown that people who take longer to respond often have different opinions. Therefore, your response is very important to represent the views of all carers. We have enclosed a replacement questionnaire, in case the original was misplaced.

If you have already completed the questionnaire and returned it to us, please accept our sincere thanks and ignore this friendly reminder. If not, could you please do so as soon as possible. This will be our final request to you.

If you wish to know more about the study, please do not hesitate to call Dr Archana Pradhan on (08) 8303 3065, Professor Gary Slade on (08) 8303 3291 or Professor John Spencer on (08) 8303 5438.

Your assistance is greatly appreciated and your contribution is highly valued.

Professor AJ Spencer
Professor of Social & Preventive Dentistry
Ph: 8303 5438
Email: john.spencer@adelaide.edu.au

Professor GD Slade
Professor of Oral Epidemiology
Ph: 8303 3291
gary.slade@adelaide.edu.au

Appendix 11: Oral examination form

Given Name:.....

Surname:.....

Sex: Male

☐

Female

☐

Date of birth:/...../..... (Day/month/year)

Subject ID

Date of Exam:/...../..... (Day/month/year)

Examiner ID

Consent obtained from:

☐

Care recipient

☐

Parent

☐

Guardian or person responsible

Dental status

	18	17	16	15	14	13	12	11	21	22	23	24	25	26	27	28
Crown																
Root																

	48	47	46	45	44	43	42	41	31	32	33	34	35	36	37	38
Crown																
Root																

Tooth wear (code the most affected tooth in each segment)

	18-14	13-23	24-28
Maxilla			
Mandible			

Prosthetic Status

Full removable dentures (F)

Partial removable dentures (P)

Upper Lower

Periodontal Disease Index

	16	21	24	36	31	44
Plaque index						
Calculus index						
Gingivitis index						

Notes

Dental Status

Sound (S)
Decayed (D)
Filled, no decay (F)
Filled, with decay (FD)
Filling unsatisfactory (FU)
Missing (M)
Fissure sealant (FS)
Bridge abutment, special crown/veneer/implant (B/C/V/I)
Unerupted tooth (crown)/unexposed root (U)
Trauma (fracture) (T)

Tooth wear

Severity:

0= None-to-little (less than 2mm of dentine exposed)
1= Moderate (more than 2mm of dentine exposed in any dimension)
2= Severe (complete loss of enamel on incisal/occlusal surface or more than 3mm cervical wear)

Periodontal Disease Index

Plaque Index

0= absence of dental plaque
1= dental plaque present on some but not all interproximal, buccal and lingual surfaces of the tooth
2= dental plaque, present on all interproximal, buccal and lingual surfaces of the tooth, but less half of these surfaces
3= dental plaque covering all interproximal, buccal and lingual surfaces and more than half of these surfaces

Calculus Index

0= No calculus present
1= supragingival calculus extending only slightly below the free gingival margin (not more than 1mm)
2= moderate amount of supra and subgingival calculus or subgingival calculus alone
3= an abundance of supra and subgingival calculus

Gingivitis Index

0= absence of signs of inflammation
1= mild to moderate inflammatory gingival changes, not extending all around the tooth
2= mild to moderate severe gingivitis, extending all around the tooth
3= severe gingivitis characterised by marked redness, swelling, tendency to bleed and ulceration, whether or not it extends completely around the tooth.

Signs of inflammation include redness, blunted papilla and spongy consistency.

Appendix 12: Oral examination report

Findings from the dental inspection

Name:

Today, the above-named participant in the study titled 'Oral Care for Young Adults with Physical and Intellectual Disabilities had a dental inspection.

The following conditions were noted:

☐ Dental caries

☐ Gingivitis

☐ Plaque

☐ Calculus

☐ Other.....

☐ None of the above

I have advised the person and the carer that, in my opinion, he/she should seek dental advice/care.

☐ Immediately

☐ In the near future

Name of dentist:

Signature:

Appendix 13: Ethics approval



OFFICE OF THE DEPUTY VICE-CHANCELLOR (RESEARCH)

SABINE SCHREIBER
SECRETARY
HUMAN RESEARCH ETHICS COMMITTEE
THE UNIVERSITY OF ADELAIDE
SA 5005
AUSTRALIA

TELEPHONE +61 8 8303 6026
FACSIMILE +61 8 8303 3417
email: sabine.schreiber@adelaide.edu.au
CRICOS Provider Number 00123M

14 July 2004

Professor AJ Spencer
Dentistry

Dear Professor Spencer

PROJECT NO: *Oral care for young adults with physical and intellectual disabilities*
H-64-2004

I write to advise you that the Human Research Ethics Committee has approved the above project. Please refer to the enclosed endorsement sheet for further details and conditions that may be applicable to this approval.


Approval is current for one year. The expiry date for this project is 31 July 2005.

Where possible, subjects taking part in the study should be given a copy of the Information Sheet and the signed Consent Form to retain.

Please note that any changes to the project which might affect its continued ethical acceptability will invalidate the project's approval. In such cases an amended protocol must be submitted to the Committee for further approval. It is a condition of approval that you immediately report anything which might warrant review of ethical approval including (a) serious or unexpected adverse effects on participants (b) proposed changes in the protocol; and (c) unforeseen events that might affect continued ethical acceptability of the project. It is also a condition of approval that you inform the Committee, giving reasons, if the project is discontinued before the expected date of completion.

A reporting form is available from the Committee's website. This may be used to renew ethical approval or report on project status including completion.

Yours sincerely

 CE MORTENSEN
Convenor
Human Research Ethics Committee