Protocol

Exploring the opportunities for co-production in oral health for people over 60

Background

A Welsh Government guideline has advocates a Prudent Healthcare approach to health services (1-2). Prudent Health has been defined as, "healthcare that fits the needs and circumstances of patients and actively avoids wasteful care that is not to the patient's benefit." (3) A key concept, which underpins this approach, is co-production in care. "Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours" (4). Co-production is an approach that can produce better health care outcomes for patients. Benefits of co-production include placement of the patient at the centre of any service with the opportunity for their need to be properly heard; it gives the patient the knowledge to take on the responsibility for their own health and rely less on services (1).

A literature search of oral health/ dentistry and co-production/ prudent healthcare returned four articles. On closer inspection none of these articles were of relevance to this project of oral health and co-production. This project would therefore provide new and current information to dental professionals on patient perspectives to oral health services. As prudent healthcare in the form of co-production is currently a very topical and new initiative to dental health services, patient perceptions would give vital new information to either support or discourage the move towards co-production.

The Community Health Council is currently developing questionnaires to explore patient experiences of health and care. (5) This initiative provides an opportunity to gather information to improve the relationship between the dental professional and the patient. Older adult oral health will be researched to gain a better understanding of patient experience and co-production in oral health. The Aneurin Bevan Community Health Council will be holding focus groups to gather information on experiences of health and care relating to oral health. The community health council has a network of volunteers who participate in this work and data will be collected through an established legal and ethical framework that allows the collection of data in an ethical manner. (5)

This study is designed to explore the barriers to co-production in oral health. This study will add insight into what it is that patients expect and will facilitate the collection of data regarding patient expectations related to co-production and oral health. The focus group data will be used to form the basis of a pilot questionnaire for oral health produced by the Community Health Council.

Aim

The aim of this project is to explore the opportunities for co-production in oral health and care in a population of older adults.

Objectives

- To explore how people choose to manage their oral health and oral health problems
- To identify the processes involved in finding help and information
- To illuminate factors which are important for improving oral health experience from a patient perspective

Method

Qualitative analysis of data collected by the Community Health Council.

Population

Older adults who volunteer to participate in a Community Health Council expert panel in the Aneurin Bevan Area.

Inclusion criteria:

Expert patient panel members of the Community Health Council who are older adults over the age of 60, relatives of people over 60 or those caring for older adults.

Exclusion criteria:

People without the capacity to consent.

Individuals with no experience of oral health in older adults.

Focus Group Conduct

Focus groups arranged with the Community Health Council expert panel members will be conducted to collect data. These will be run within the Community Health Council at a Community Heath Council meeting location. A member of the Community Health Council with experience in this area will facilitate the running of the focus group. The student will attend the meetings as an observer, note taker and assistant moderator. Participants will be older adults over the age of 60, relatives of people over 60 or those caring for older adults. Focus groups will last for approximately 2 hours and will involve approximately 8-10 participants. It is anticipated that 2 focus groups will be conducted.

Ethical approval

Data will be collected under a pre-existing legal framework present for the Community Health Council; this allows the collection, analysis and presentation of data

without the requirement of specific further ethical approval. This application is for permission to use this data for analysis as a research project. The legal framework in place does allow for this to be undertaken without further permissions, this application is to ensure all Cardiff University Governance arrangements for final year projects have been met.

Process

The Community Health Council will send out invitations to all participants for the focus groups via letter and email. Participants will be informed of the research project in advance of the meeting and participant information (appendix A) will be provided to all invited.

Participants will be informed of their right to decline the use of their data in this research. If any focus group participant refuses the use of their data, focus group proceedings will not be audio recorded and instead, detailed, manual notes will be used for analysis, omitting anyone who decides to decline. The Community Health Council have informed us that this is an unlikely event because participants volunteer as they wish for their views to be heard.

Participants will be asked to confirm that they have read the participant information and have felt all their questions regarding participation have been answered. They will then be asked to sign a consent form confirming their agreement to study participation. Participants will be informed of their right to withdraw at any time and of the option for their information to be removed from the transcript.

Prior to any focus group proceedings, a map of participants present will be drawn; participants will be asked to wear name badges so information can be attributed to each individual. This will allow the potential to remove a participant's data if they so wish.

If all participants agree to the use of their information, the focus group will be audio recorded and data will be transcribed. If any participant chooses not to share their data, detailed notes will be written and used for the analysis. Participants will be informed of their right to request a summary of the analysis on completion.

A brief question guide (Appendix C) will be used in these focus groups and all participants will be debriefed at the end of each focus group (Appendix E).

Data Management

Any detailed notes and/or audio recordings will be fully transcribed into a word document for analysis. Names will be fully anonymized with pseudonyms given for any transcripts.

All audio recordings and detailed notes will be managed in a password-protected file stored on a Cardiff University computer system. All data will be anonymised and made accessible only to the student and researcher.

Data will be destroyed in accordance with Cardiff University policies for data handling; data will be kept for a minimum of five years and will be destroyed at the ten-year point.

Analysis

Manual analysis will be undertaken of transcripts using a thematic approach. The themes arising from the focus groups will be identified and any further work to analyse this in detail will be identified at time.

Results

The results of this study will be presented in aggregate, as a final year project. A copy of the final year project will be shared with the Community Health Council in Aneurin Bevan area who have assisted with the project to aid the development of their questionnaires. Results may also be presented at conferences and in appropriate journals.

Ethical Considerations

This data can be collected without permission from the university ethics committee, as there is already an established ethics framework in place for the Community Health Council's research. This project proposal seeks permission to use this data for final year project research, analysis and presentation.

Data will be analysed and permission will be sought from participants.

No data will be collected without the permission from participants and the process for collecting data means that participants will be able to exclude their data from the analysis.

Data will be stored and retained within accordance of Cardiff University guidelines.

Participants will also be debriefed at the end of any focus groups.

References:

1. Anon putting co-production at the heart of public services in Wales [Online] Available at: https://allinthistogetherwales.wordpress.com/ [Accessed: 22 December 2015].

2. Anon Welsh Government | Prudent healthcare [Online] Available at: http://gov.wales/topics/health/nhswales/prudent-healthcare/?lang=en [Accessed: 22 December 2015].
3. Anon "Health in Wales." Web blog post. [online] Available at http://www.wales.nhs.uk/news/30952 [Accessed: 22 Dec. 2015]
4. In This Together | New Economics Foundation. [online]. Available at http://www.neweconomics.org/publications/entry/in-this-together [Accessed: December 23, 2015]
5. CHC, A. B. Aneurin Bevan CHC - Monitoring Health Services [online]. Available at: http://www.wales.nhs.uk/sitesplus/901/page/45211 [Accessed: December 23, 2015]

Appendix A: Participant Information

Exploring the opportunities for co-production in oral health for people over 60

Invitation

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study is looking at the possibility for dentists and their patients to form a more equal relationship with regards to treatment options. In order to provide patients with the dental results they desire it is important first to find out exactly what it is patients want from their dentist. This research will question the possibility of co-production i.e. how dental healthcare can fit the needs and circumstances of a patient through a better understanding of patient expectations.

Other areas of healthcare, such as optometry, have questionnaires already been put in place to explore patient experience in order to improve services. A better understanding of patient experiences and wants within

dental services is likely to result in an improved patient dentist relationship. The two-hour focus groups being held, aims to collect data for the Community Health Board to produce a pilot questionnaire researching dental patient experiences. The focus groups will allow for data collection exploring the possibility of co-production in oral care.

Why have I been chosen?

You have been chosen because you are a member of Community Health Council and you have personal experience or knowledge of the issues that relate to oral health for the over 60s. You either have your own personal experience of oral health care services or you are a carer or relative of someone over 60 with experience of oral health care services.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part then you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. You can decline to participate in the focus group. If you attend the focus group and you do not wish for your information to be shared, you data will not be used in the analysis.

You may decide to withdraw at a later date. However your data will still be used in the final analysis because participant information will be anonymised, thus making it impossible to identify an individual's data.

What will happen to me if I take part?

You will be invited to attend one of the focus groups that best suits your availability. The focus group is expected to last around two hours. It will be a normal focus group (similar to those frequently held by the Community Health Council). If you participate in the focus group you are welcome to take breaks, or sit out when required. If all participants agree, this meeting will be audio recorded for analysis. If not then detailed notes will be taken. A dental student from Cardiff University will attend the focus group.

What about confidentiality?

Any detailed notes and/or audio recordings will be fully transcribed with names fully anonymised with the use of pseudonyms for any transcripts. All audio recordings and detailed notes will be managed in a password-protected file stored on a Cardiff University computer system. Data will be made accessible only to the student and researcher of Cardiff University. Data will be destroyed in accordance with Cardiff University policies for data handling; data will be kept for a minimum of five years and will be destroyed after 10 years.

What do I have to do?

The Community Health Council will send out an invitation to you, asking for you to join a focus group. You will be informed of the research project via the participant information sheet prior to your decision to join the study.

On the day of the focus group you will be asked to confirm that you have read the participant information sheet and that any queries regarding the

study have been answered. You will be asked to sign a consent form and to wear a name badge. If all participants agree to the use of their information, the focus group will be audio recorded and data will be transcribed. The focus group will use a question guide to lead the discussion, and you will be asked to share your views on certain dentally related topics. There will be 8-10 participants per focus group with each session lasting up to 2-hours. At the end of the focus group, a debriefing will be given.

Are there any risks?

There are no risks involved in participating in this study. This is a normal Community Health Council participant focus group similar to those that you normally attend. Any information taken from these focus groups will be used to provide research data for analysis regarding oral health care experiences.

What will happen to the results of the research study?

The results of this research will be used to analyse the presence of common themes that are identified as providing a good oral health care experience. Once the analysis is complete, all information will be combined and a final year project completed for December 2016 by a Cardiff University Dental Student.

A copy of the final year project will be shared with the Community Health Council in Aneurin Bevan. Results may also be presented at conferences and in appropriate journals. Your details will not be present in the project and you may request a copy of the project outcomes by contacting the dental

student involved. These will be sent to you once the study has completed. (Details seen in further information)

Who is organising and funding the research?

The Community Health Council will organise and fund the focus group. A Cardiff University Dental student will undertake the research for this study as part of a Final Year Project.

Contact for Further Information

Student: Eilidh Thomas – thomasec4@cardiff.ac.uk

Supervisor: Dr Ilona Johnson (Senior Clinical Lecturer and Honorary Consultant in Dental Public Health) – johnsonig@cardiff.ac.uk

Cardiff University Dental Hospital:

University Dental Hospital,

Heath Park,

Cardiff,

South Glamorgan

CF14 4XY

Appendix B: CONSENT FORM

Title of Project: Exploring the opportunities for co-production in oral health for people over 60

Name and contact details of researcher(s):

Student: Eilidh Thomas – thomasec4@cardiff.ac.uk

Supervisor: Dr Ilona Johnson – johnsonig@cardiff.ac.uk

Please initial box

1. ☐ I confirm that I have read and understand the information sheet dated December 22nd 2015 (version 1.01) for the above study and have had the opportunity to ask questions.

2. ☐ I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

3. ☐ I agree to take part in the above study.

Name of Participant	Date	Signature
Name of person taking consent (if different from researcher)	Date	Signature
Researcher	Date	Signature

Appendix C: Question Guide

Checklist :

Participant consent complete and returned ☐
Voice recorder on ☐

Map of participant seating

1) In terms of dental health, what factors do you think have the most impact on day-to-day life?

   Probes about pain, function, aesthetics.

2) When you have a problem, to what extent do you manage this at home before getting help

   Probes for self-medication, advice from friends/family

3) When you are looking for advice or help, where do you look

   Prompt to see
   - Preferred sources of information
   - Order for seeking help/information
   - Which sources of help and information are most/least trusted
   - and why

4) If you needed dental treatment, how would you choose where to find care?

   Prompt for
   - Familiar place/person
   - Option of having only emergency treatment
   - Speed of getting an appointment
   - Recommendations
   - Location and convenience

5) In terms of dental treatment care, what information do you need to be available to make a decision about your treatment.

   Prompt for
   - Risk / benefit

- Cost
- Where this is found i.e. dentist/peers/family etc.
- What makes this information trustworthy/not trustworthy

6) What would help you feel in control of a decision about your care?

   Prompt for what would affect this and make you feel you were not in control?

7) If you needed to have dental care tomorrow. What would be important to make it a good experience?

   Prompt for pain free, aesthetics, speed, cost

8) What is the one thing that dentists could do to improve your oral health and care experience?

Thank you for your help

Appendix D: Questionnaire

This questionnaire will be for discussion with focus group participants in order to explore the questions for their appropriateness within a Community Health Council questionnaire.

Planned Care Programme

PREMS: Oral Healthcare Outpatient

1. Is this your first appointment with this oral healthcare service?
   Please tick one

Yes	No
☐	☐

2. For your appointment today were you? *Please tick one*

Referred by dentist	Referred by GP	Self referred	Longstanding patient	Other
☐	☐	☐	☐	☐

If other, please state here:

3. What is the nature of your appointment today? *Please tick one*

Emergency	Routine	Urgent	Don't know
☐	☐	☐	☐

4. How do you feel about the wait to receive your appointment today?
   Please tick one

I did not need to wait	☐
It was shorter than expected	☐
It was as long as I expected	☐
It was longer than expected	☐

Approximately how long (in weeks) did you wait to receive your appointment?

5. Were you given any help or advice while you were waiting to receive your appointment?

No, help was not available	☐
No, I did not need help or advice	☐
Yes, but it was not useful	☐
Yes, it was useful	☐
I cannot remember	☐

6. How do you feel about your wait to be seen today? *Please tick one*

I did not need to wait	☐
It was shorter than expected	☐
It was as long as I expected	☐
It was longer than expected	☐

About your oral health

7. At present, how would you rate your dental health? *Please tick one*

Very Good	☐
Good	☐
Fair	☐
Bad	☐
Very Bad	☐

8. How many natural teeth do you currently have? *Please tick one*

None	☐
1-9	☐
10-19	☐
20+	☐

9. Do you wear any of the following dental appliances?

Please tick all that apply

	Upper Mouth	Lower Mouth
Complete denture (all teeth replaced)	☐	☐
Partial denture (some teeth replaced)	☐	☐
No denture	☐	☐
Crowns	☐	☐
Fixed Bridges	☐	☐
Implants	☐	☐
Orthodontic braces (fixed)	☐	☐
Orthodontic braces (removable)	☐	☐
Other appliance Please specify.....	☐	☐

In the last 12 months, have you had any of the following problems because of your teeth, mouth, or dentures? Please tick all that apply

	Never	Hardly ever	Occasionally	Fairly often	Very often
Trouble speaking	☐	☐	☐	☐	☐
Pain or an aching feeling	☐	☐	☐	☐	☐
Discomfort eating	☐	☐	☐	☐	☐
Self-consciousness or embarrassment	☐	☐	☐	☐	☐
Change in diet	☐	☐	☐	☐	☐
Tension or irritability	☐	☐	☐	☐	☐
Unable to carry out normal tasks	☐	☐	☐	☐	☐

10. Have you been able to discuss any of your dental or oral health problems with your dentist during your visit today?

- No, I was not able to discuss these issues ☐
- No, I did not want to discuss this during my appointment ☐
- Yes, but I did not find this discussion useful ☐
- Yes, the discussion was useful ☐
- I cannot remember ☐

11. Have you received advice today?

- No, I have not received the advice I need ☐
- No, I did not want advice ☐
- Yes, but I did not find this advice useful ☐
- Yes, the advice was useful ☐
- I cannot remember ☐

Your usual dental care

12. At home, how often do you clean your teeth? *Please tick one*

Never	Occasionally	Regularly but less than once per day	Once per day	Twice or more per day
☐	☐	☐	☐	☐

13. When was the last time you saw your dentist? *Please tick one*

Less than 6 months	6-12 months	12-24 months	More than 2 years
☐	☐	☐	☐

About your health

14. At present, how would you rate your general health?

Please tick one

Very Good	Good	Fair	Bad	Very Bad
☐	☐	☐	☐	☐

15. Are you taking any of the following medications?

Please tick all that apply

	Yes	No	Don't Know
Asthma Inhalers *(blue/ brown/ red/ orange pump)*	☐	☐	☐
Oxygen Therapy	☐	☐	☐
Cancer Treatment Medications *(eg doxorubicin /asparaginase / methotrexate / cytarabine)*	☐	☐	☐
Blood Pressure Medications *(eg lisinopril / atenolol / amlodipine)*	☐	☐	☐
Antihistamines	☐	☐	☐
Decongestants *(Allegra-D / Benadryl Allergy Plus Sinus / Claritin-D / Zyrtec-D)*	☐	☐	☐
Anti-depressants *(sertraline / fluoxetine citalopram / mirtazapine / amitriptyline)*	☐	☐	☐
Liquid Medications	☐	☐	☐

16. Do you smoke? *Please tick one*

Yes	No, never	No, I have given up
☐	☐	☐

17. If you have given up smoking, when did you last smoke?

Please tick one

Under 3 months	3-6 months ago	6-12 months ago	12-24 months ago	Over 2 years ago
☐	☐	☐	☐	☐

About your care in hospital

18. Have staff asked you about your oral health and preferences during your time in hospital? *Please tick all that apply*

- No, I was not able to discuss this ☐
- No, I did not want to discuss this ☐
- Yes, but this was not helpful ☐
- Yes, the discussion was useful ☐
- I cannot remember ☐

19. Have you received an oral health assessment in hospital?
Please tick all that apply

- No, this was not offered ☐
- No, I did not want this ☐
- Yes, but this was not helpful ☐
- Yes, this was satisfactory ☐
- I cannot remember/don't know ☐

20. Have you felt in control of your oral health care during your time in hospital?
Please tick all that apply

- No, I have not been able to look after my mouth the way I want to ☐
- Yes, but not fully in control ☐
- Yes, I have felt in control ☐
- I cannot remember/don't know ☐

21. Have you be able to access oral hygiene aids (e.g toothbrushes and toothpaste) during your time in hospital?
Please tick all that apply

- I do not use oral hygiene aids ☐
- No, I was not able to obtain or access oral hygiene aids and toothbrushes ☐
- Yes, but this was not satisfactory ☐
- Yes, I was able to access everything I needed
- I cannot remember/don't know ☐

22. Have your dental appliances (e.g dentures) been looked after during your time in hospital?

Please tick all that apply

I do not have any dental appliances ☐

No, my appliance/s have been lost ☐

Yes, but not to my satisfaction ☐

Yes, to my satisfaction

I cannot remember/don't know ☐

23. Overall, are you happy with the oral healthcare being given to you while in hospital?

Yes ☐

No ☐

Rather not say ☐

24. How often would you want to clean your mouth? *Please tick one*

Never ☐

Every 2 months ☐

Once a month ☐

Once a week ☐

2-3 times a week ☐

Once a day ☐

More than twice a day ☐

Appendix E: Debrief

Thank you for participating in this study.

The purpose of this study is to try and encourage co-production by using patient experiences to shape the way that we provide dental care. We will provide the Community Health Council with a copy of this report and they will be able to use this in discussions about dental services.

If you have any concerns about your dental health or any questions about dental health care, please contact (Aneurin Bevan University Health Board 01633 744387).

If you would like a copy of the final year project report when the work has been completed, please contact for further information:

Student: Eilidh Thomas – thomasec4@cardiff.ac.uk

Supervisor: Dr Ilona Johnson – johnsonig@cardiff.ac.uk