Involving Stakeholders in Oral Health Surveys: an example from the UK

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Bratislava, 12th November 2015

Oral Epidemiology Workshop
Key Questions - outline

- Do we really need stakeholder involvement in the design and content of a national survey?
- How can it be done?
- Who needs to be involved?
- Which areas can it contribute?
- Relevant experience from the latest national survey of children in England, Wales and Northern Ireland
CDHS 2013 - Fifth survey in the series

1983
- The percentage of 15-year-olds with cavities into dentine: 42 per cent
- Mean average number of filled primary teeth in five-year-olds: 0.5

1993
- The percentage of 15-year-olds with cavities into dentine: 30 per cent
- Mean average number of filled primary teeth in five-year-olds: 0.3

2003
- The percentage of 15-year-olds with cavities into dentine: 13 per cent
- Mean average number of filled primary teeth in five-year-olds: 0.2

2013
- The percentage of 15-year-olds with cavities into dentine: ?
- Mean average number of filled primary teeth in five-year-olds: ?
Children’s Dental Health Survey (CDHS) 2013 Consortium

- ONS
- University Dental Centres
- NatCen
- Nisra

- Birmingham
- Cardiff
- Kings
- Newcastle
- UCL
Sample design and analysis

- England, Wales and Northern Ireland

- 5, 8, 12 and 15 year olds

- Random probability sample; oversampling; clustering using school groups in E & W; pupil sub-sampling from school registers; replacement for secondary schools

- National estimates and deprivation analysis a priority; regional estimates in England and Wales?
Why bother with Stakeholder Involvement?

✓ Contractual requirement?

✓ Political correctness? “Tick box” exercise?

✓ Public involvement - Survey reflects the “needs” and wishes of the people it is supposed to serve.

✓ Useful information
  ✓ “brainstorming”
  ✓ Consolidating
  ✓ Setting priorities
Project stages and timeline

Stage 1: Survey Development
- Phase 1.1: Project Initiation
- Phase 1.2: Complete Pilot
- Phase 1.3: Complete Survey Development

Stage 2: Complete Survey Collection

Stage 3: Produce Survey Outputs
- Phase 3.1: Produce and Publish
- Phase 3.2: Project Closure

Consultation: Feb 2013
Ethical approval: March/April 2013
Pilot exams: May/June 2013

Main survey exams: Oct 2013 – March 2014
Agree changes for main survey: July/August 2013
Published reports by: Feb 2015
Complete data processing: July 2014
Aspects of Proposed Methodology

- Clinically trained field force & ONS/Nisra interviewers for working with schools

- 3 components - dental exam, parent self-completion questionnaire as follow up, short pupil self-completion for 12 and 15 year olds (NEW for 2013 survey)

- Largely paper based collection - web option for parent questionnaire

- Positive consent for examination - parental for primary school cohorts
### CDHS 2013 Clinical criteria

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Age</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tooth condition</td>
<td>5,8,12,15</td>
<td>2003 revised to include visual dentine caries ? ICDAS (enamel caries coded) or NHS DEP</td>
</tr>
<tr>
<td>Tooth surface Loss</td>
<td>5,8,12,15</td>
<td>Upper incisors and in 2003 6's</td>
</tr>
<tr>
<td>Enamel defects</td>
<td>12</td>
<td>8 upper anterior teeth</td>
</tr>
<tr>
<td>Accidental damage</td>
<td>(5),8,12,15</td>
<td>Upper permanent incisors</td>
</tr>
<tr>
<td>Perio I</td>
<td>5,8,12,15</td>
<td>Visible gingivitis/plaque/calculus</td>
</tr>
<tr>
<td>Perio II</td>
<td>15</td>
<td>Gingivitis index teeth ? Simplified BPE</td>
</tr>
<tr>
<td>Orthodontic</td>
<td>12,15</td>
<td>2003 moved to simplified IOTN ? add overjet - linkage to trauma</td>
</tr>
<tr>
<td>NEW</td>
<td>5,8,12,15</td>
<td>PUFA index (Pulp involvement, Ulceration, Fistula, Abscess) (included in ADH 2009)</td>
</tr>
</tbody>
</table>

**Dilemma** = Balance need for backward compatibility : time available for each examination : need to reflect modern concepts of disease
CDHS 2013 Parental questionnaire

- **What to keep from 2003? Continuity with innovation**
  - Visiting the dentist / Last dental visit
  - NHS dental services and treatment
  - Anxiety
  - Looking after your child’s teeth
  - Tooth decay and bad teeth (preferences)
  - Crooked or protruding teeth / marks on teeth
  - Parental visiting patterns

- **Other themes? What to add?**
  - oral health behaviours
  - Family impact and quality of life
  - Type of care received - GA? NHS vs. Private?
  - ...

- **Length vs. response...**
CDHS 2013 Children’s questionnaire

- Overlap with parental Q? Which aspects?
- BASCD 12-year-olds Q: take anything? What?
  - Self-perceptions (opacities; conditions) and QoL
  - Tooth brushing freq
  - Ortho Qs

- Other themes?
  - Oral health behaviours
  - Perceived treatment need and quality of life
  - Dental anxiety
  - Dental visiting patterns and type of care
  - Nature of advice received from dentists
  - …?

- And all that in 2-3 pages! ...PRIORITIES...
How to find answers to these questions?

We hit the road!!

The CDHS 2013 Consultation Exercise
Consultation exercise

Different actions

1. Consultation events
2. Separate individual meetings - telephones
3. Professional bodies and societies - emails

<table>
<thead>
<tr>
<th>Consultation events</th>
<th>Place</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary school staff</td>
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<td>4/2</td>
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<tr>
<td>Secondary school staff</td>
<td>Birmingham</td>
<td>4/2</td>
</tr>
<tr>
<td>Secondary school young people</td>
<td>Birmingham</td>
<td>4/2</td>
</tr>
<tr>
<td>Secondary school parents</td>
<td>Birmingham</td>
<td>4/2</td>
</tr>
<tr>
<td>Dental Professionals</td>
<td>Cardiff</td>
<td>6/2</td>
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<tr>
<td>Dental Professionals</td>
<td>London</td>
<td>11/2</td>
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<td>Dental Professionals</td>
<td>Sheffield</td>
<td>12/2</td>
</tr>
<tr>
<td>School nurse</td>
<td>Chepstow</td>
<td>19/2</td>
</tr>
<tr>
<td>Secondary school head teacher</td>
<td>Newbury</td>
<td>25/2</td>
</tr>
<tr>
<td>Dental Professionals</td>
<td>Belfast</td>
<td>28/2</td>
</tr>
</tbody>
</table>
Agenda for a Consultation meeting

✓ Dental Professionals – Agenda items:

✓ Introductions
✓ CDHS 2013 overview
✓ Main Discussion
  ✓ Clinical examination
  ✓ Questionnaires
  ✓ Access to schools
✓ Recap on key issues

✓ Agendas varied for meetings with school staff; parents; young people
Dental Professionals: clinical exam

- Importance of **continuity** and trends / comparability (more so than in the questionnaires)

- Caries – no overall agreement, mostly “open” issues
  - Importance of recording enamel lesions (?)
  - Necessity to make it comparable with previous surveys – caries at the dentine level (agreement)

- Periodontal examination (simplified BPE): some concerns about probing (consent – response rate)
Dental Professionals: clinical exam

- **PUFA**: agreement about importance + inclusion (NEW)

- No need for:
  - tooth surface loss on 5-y-o (?);
  - opacities on premolars (?)

- Other NEW areas to consider
  - **Molar Incisor Hypomineralisation**: 12- rather than 15-y-o
  - **Overjet** (orthodontics) – link to trauma
Dental Professionals: questionnaires

- **Parental Q:** emphasis on innovation

- **Keep / revise**
  - Access to services - barriers to care
  - Dental attendance patterns (…not for both parents)
  - NHS vs. private

- **NEW themes to consider**
  - Impact of child’s oral health on the family well-being
  - Behaviours (oral hygiene, diet)
  - Anxiety of parents (?)
Dental Professionals: questionnaires

- **Children’s questionnaire:** positive - direct info

- **Children’s Q (12- and 15-y-o):** prioritised themes
  - Dental anxiety
  - Behaviours: oral hygiene, diet, smoking
  - Quality of life - impact - needs
  - Sources of info re: oral health

- **More detailed aspects considered**
  - Validated measures for UK - time & resource savings
  - Data linkage with other surveys (e.g. HSE; height & weight)
  - Anxiety measure: ideally use established cut-off points
  - QoL aspects: severity > frequency of oral impacts - better link to services / planning
School staff: main issues

- Support for the survey
  - Survey has a "moral purpose"; 10-year "gap" underlines importance

- Getting through to schools
  - Combination of contact modes (email/letter + telephone)
  - Use government support, NHS, ONS - not like any other survey...

- Establish and maintain close links throughout data collection

- Early planning / timetable
School staff: main issues

- **Make it easy for schools**
  - Pre-packed letters, minimal effort for schools, appropriate contact person
  - A clear pathway for Heads of 5 or 6 bullet points

- **Use school-parents communication links (text messaging - group emails)**

- **How could schools benefit?**
  - Career / higher education advice
  - School “badge” / acknowledgement about participation
  - Social media (e.g. podcast from survey team)
Young people: main issues

- **Importance of mouth and oral health**
  - Rated high as a priority
  - Appearance / aesthetics
  - Function, but also how you feel
  - Concerns about broader long-term effect on general health

- **Knowledge / information about mouth and oral health**
  - TV ads, social media

- **Confidentiality should be guaranteed**
  - Neither parents nor school should access / check answers

- **Privacy during data collection is important**
  - “do not like my classmates to look when I am being examined by a dentist”
Parents: main issues

- Support for the survey
  - Oral health is a priority
  - NHS support, government survey

- ...but facing information overload, so don’t overburden them
  - Concise communication, clear timelines, specific tasks, not time-consuming

- Initial contact is important
  - Use NHS logo
  - School support for the survey would help
Parents: main issues

- No perceived risks from clinical examination
  - Assurance that it is brief and visual (mostly)
  - If anything, they were generally positive / welcoming about it; seen as adding value

- Importance of socio-economic classification (postcode, NSSEC)

- Concerns about data linkage
  - Lack of trust about appropriate use of data
  - Negative effect on consent and response rates
Summary

✓ Stakeholder involvement is a challenging exercise...
   ... but very rewarding if carried out properly
✓ Generates public interest in the survey
✓ Provides an excellent opportunity for innovation and brainstorming to make the survey more relevant to:
   ✓ population
   ✓ health planners and
   ✓ researchers
✓ Used as another (not the only) source to help consolidate views and prioritise areas / themes

Definitely worth a try!
Thank you for your attention

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Questionnaire surveys: Subjective Perceptions and Behaviours

Georgios Tsakos
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Bratislava, 12th November 2015

Oral Epidemiology Workshop
Key Questions - outline

- Behaviours – the “usual suspects”?
- Dental Anxiety – the (not so) “new kid on the block”…
- Why measure subjective perceptions and (oral) health-related quality of life (OHRQoL)?
- Types of measures – examples
- Which are the necessary properties of composite measures (such as OHRQoL)?
- How have they been applied? The example of the CDHS 2013 (and ADHS 2009)
Health Behaviours

- Always measured (at least some of them)...
- ... but information further than simple descriptions generally remains untouched by the human brain... rarely involved in more complicated analysis - info not relevant for planning and services?

- Key oral health behaviours measured
  - Oral hygiene / tooth brushing (always) and hygiene aids
  - Dental attendance (always - see Ken’s lecture)
  - Smoking (sometimes)
  - Diet / sugar consumption (rarely)
  - Alcohol (almost never!)
CDHS 2013: Diet / Sugar (foods)

These questions are about what you eat and drink. We also ask you if you have ever smoked cigarettes or drunk alcohol.

Your answers will NOT be shown to anyone you know, or to the dentist you are seeing.

Q18 How many times a day do you usually eat...

Tick one box on each row

<table>
<thead>
<tr>
<th>Fruit (fresh, tinned, dried and frozen)</th>
<th>Four or more times a day</th>
<th>Three times a day</th>
<th>Two times a day</th>
<th>Once a day</th>
<th>Less than once a day</th>
<th>Rarely or never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cakes or biscuits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sweets (candy or chocolate)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

Self-reported frequency of:
- key sugary foods
- Fruits (healthy option)
CDHS 2013: Diet / Sugar (drinks)

Self-reported frequency of:
- key sugary soft drinks
- Separation from non-sugar soft drinks
- Water (healthy option)
CDHS 2013: Smoking

Q20 This question is about smoking. Please read the following sentences carefully and choose the one that best describes you.

Think about times you may have had a puff or two as well as smoking whole cigarettes.

Tick one answer only

- I have never tried smoking cigarettes
- I have smoked cigarettes only once or twice
- I used to smoke cigarettes but I don’t now
- I sometimes smoke cigarettes, but don’t smoke every week
- I smoke cigarettes regularly, once a week or more

Remember that your answers will not be shown to anyone you know, or to the dentist you are about to see

Self-reported smoking patterns:
• Never (or almost never) vs. Past vs. Current (different intensity grades)

Confidentiality !!!
As for smoking...
Health Behaviours measures: relevant info?

- Sugar consumption
- ... ask for frequency (easier to assess in questionnaires)
- ... but...

✓ unknown information reliability
- WHO guidance is on % energy intake (difficult to assess?)

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**Clinical Review**

**Effect on Caries of Restricting Sugars Intake: Systematic Review to Inform WHO Guidelines**

**INTRODUCTION**

Historically, numerous independent expert and consensus reports have concluded that sugars are the most important dietary factor to the development of dental caries (Sheiham, 2001; WHO/FAO, 2003). However, recommendations have not yet been developed through systematic review of the evidence.

In 2010, the World Health Organization (WHO) launched a Guideline Development Process defining a protocol for the process of reviewing and issuing dietary recommendations for populations (WHO, 2010). To update the recommendations for sugars through this process, WHO commissioned a systematic literature review. The objectives were to systematically review all available published data relating to the amount of sugars consumption and levels of dental caries and to report the findings for both adults and children. The WHO guideline development group formulated questions relating to the effects of sugars on dental caries (Table 1). These questions pertained to whether increasing or decreasing the amount of sugars intake affected measures of dental caries and whether the evidence supports a threshold for intake.

**METHODS**

Guided by the WHO Guideline development process, a systematic review was conducted and reported according to the PRISMA statement (www.prisma-statement.org).

All appropriate randomised controlled trials (RCTs) and intervention and observational studies, published since 1950, were sought. Reviews were included if they contained a new analysis of existing data.

Participants were healthy humans (without acute illness, but those overweight or with hypertension or diabetes could be included) in developing, transitional, or industrialized countries. All age groups were included. No language restrictions were used.

Studies were included if they reported any intervention intended to alter sugars intake in one arm of the study compared with diet with a different sugars content in another study arm, and also included information on dental caries, change in caries, or comparisons of higher to lower sugars as an outcome, with a timescale of at least one year. Observational studies were included if they reported absolute sugars or change in sugars intake and also included information on dental caries (as defined above). All timescales were included.

Sugars were defined as any of total sugars, free sugars, added sugars, sucrose, non-milk extrinsic (NME) sugars, expressed as g or kg/day or % or as percentage. This review, therefore, aimed to identify the evidence for total sugars (and any component thereof) on dental caries. Studies were also
Health Behaviours: measurement challenges

- Dilemma for surveys: Inconsistency across surveys (and maybe more relevant info?) OR continuity (and therefore comparability)?
- Questions suited for international comparisons (HBSC)?
- Some questions may be “saturated” because the “correct” answer is widely known?
  - How often do you brush your teeth?
- Others are sensitive (or at least perceived as such by oral health researchers)?
  - Alcohol?
  - No problem for info to be collected in other surveys!!!
  - Data linkage: logical but not straightforward
Key Questions - outline

- Behaviours – the “usual suspects”?

- Dental Anxiety – the (not so) “new kid on the block”...

- Why measure subjective perceptions and (oral) health-related quality of life (OHRQoL)?

- Types of measures – examples

- Which are the necessary properties of composite measures (such as OHRQoL)?

- How have they been applied? The example of the CDHS 2013 (and ADHS 2009)
Dental Anxiety: what is it exactly?

“Dental anxiety is an aversive psychological response to a poorly defined, or not immediately present dental stimulus interpreted as potentially harmful or dangerous, usually within a dental context”.

Dental anxiety is distinct from dental phobia

http://www.st-andrews.ac.uk/dentalanxiety/
Dental Phobia

Dental phobia is characterised essentially as an individual who avoids dental treatment and can be recognised with the following criteria:

- a marked and persistent fear of the specific object or situation that is excessive or unreasonable,
- an immediate anxiety response upon exposure to the feared stimulus, which may take the form of a panic attack, recognition that the fear is excessive or unreasonable, avoidance of the anxiety-producing situation, interferes with normal functioning or causes marked distress.

http://www.st-andrews.ac.uk/dentalanxiety/
Dental Anxiety: why is it important?

- Dental anxiety is related to psychological responses to stressors....
- ...but there are many stressful situations in life...

...and they can affect considerably the daily life of people...
Dental Anxiety: why is it important?

- Some stressors are really important…
- …and very intense…

…but they never (hopefully) last for long… and there may be a “happy end”
Dental Anxiety: why is it important?

- People that are dentally anxious may postpone dental visits
- May not co-operate fully, resulting in sub-optimal care
- At the extreme, dental phobics will just avoid dental visits and treatments altogether

= disadvantaged population group

- Important to target them for:
  - appropriate prevention and health promotion
  - behavioural interventions to address dental anxiety
Modified Dental Anxiety Scale (MDAS)

1. If you went to your Dentist for TREATMENT TOMORROW, how would you feel?

   Not Anxious □  Slightly Anxious □  Fairly Anxious □  Very Anxious □  Extremely Anxious □

2. If you were sitting in the WAITING ROOM (waiting for treatment), how would you feel?

   Not Anxious □  Slightly Anxious □  Fairly Anxious □  Very Anxious □  Extremely Anxious □

3. If you were about to have a TOOTH DRILLED, how would you feel?

   Not Anxious □  Slightly Anxious □  Fairly Anxious □  Very Anxious □  Extremely Anxious □

4. If you were about to have your TEETH SCALED AND POLISHED, how would you feel?

   Not Anxious □  Slightly Anxious □  Fairly Anxious □  Very Anxious □  Extremely Anxious □

5. If you were about to have a LOCAL ANAESTHETIC INJECTION in your gum, above an upper back tooth, how would you feel?

   Not Anxious □  Slightly Anxious □  Fairly Anxious □  Very Anxious □  Extremely Anxious □

Features of MDAS

- Quick to complete
- Widely used in surveys
- Reliability + Acceptability
- Numerous translations in other languages available
- Cut-off for extreme dental anxiety (≥19)
- NOT NECESSARILY dental phobia
- Population norms (for UK)
- ...But not equally developed for child populations

RESEARCH ARTICLE

UK population norms for the modified dental anxiety scale with percentile calculator: adult dental health survey 2009 results

Gerry Humphris, John R Crawford, Kirsty Hill, Angela Gilbert and Ruth Freeman

Abstract

Background: A recent UK population survey of oral health included questions to assess dental anxiety to provide mean and prevalence estimates of this important psychological construct.

Methods: A two-stage cluster sample was used for the survey across England, Wales, and Northern Ireland. The survey took place between October-December 2009, and January-April 2010. All interviewers were trained on survey procedures. Within the 7,233 households sampled there were 13,509 adults who were asked to participate in the survey and 11,382 participated (84%).

Results: The scale was reliable and showed some evidence of unidimensionality. Estimated proportion of participants with high dental anxiety (cut-off score = 19) was 11.6%. Percentiles and confidence intervals were presented and can be estimated for individual patients across various age ranges and gender using an on-line tool.

Conclusions: The largest reported data set on the MDAS from a representative UK sample was presented. The scale’s psychometrics is supportive for the routine assessment of patient dental anxiety to compare against a number of major demographic groups categorised by age and sex. Practitioners within the UK have a resource to estimate the rating of a particular patient’s level of dental anxiety, with confidence intervals, when using the on-line percentile calculator.

Keywords: Dental anxiety, Representative survey, Psychometrics, Percentiles, On-line calculator
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Interest in Assessing Subjective Perceptions

✓ Increasing interest about subjective perceptions of health (and oral health) has led to the development of a plethora of subjective measures of health and quality of life...

✓ Focus on measures for adults and elderly... followed by the development of measures for children

✓ Most of those measures have been validated as well as adapted for use in different settings and cultures

WHY NOW? Which factors have led to this?
Subjective Measures of Oral Health and QoL

1. Single standing questions
   - Self-Rated Oral Health
   - Perceived Dental Treatment Needs

2. Battery of questions
   - Pain (even for young children)
   - Dental Discomfort Questionnaire
   - Chewing Ability (usually for older adults)

3. Oral Health-Related Quality of Life (OHRQoL) indicators
   - Composite – different domains and age groups
     - Generic / Profiles (health status surveys)
     - Disease-specific (clinical trials)
Patient-based outcomes in dentistry: Number of papers published by year

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Number of Papers</th>
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<tr>
<td>Pre-1990</td>
<td>2</td>
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<td>1990-1994</td>
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<td>2000-2004</td>
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<tr>
<td>2005-2008</td>
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</table>
Health Outcomes

✓ Health outcome measurement has traditionally focused on survival periods, toxicity, biochemical indicators and symptom rates, and (more recently) a number of indicators of physical and psychological morbidity and social disadvantage.

✓ Incorporate both medical and patient's perspectives.

✓ Health status vs. Health-Related Quality of Life.

✓ Health status: focus on morbidity.

✓ Health-Related Quality of Life: encompassing physical health and functioning, social functioning, psychological and emotional well-being.
Different models of Health

A. Biomedical model
- Traditional approach – linear thinking (reductionism)
- Pathology, tissue damage etc.
- “find it and fix it” approach
- Emphasis on clinical data (disease-related)

B. Outcomes model
- Chronic diseases challenge biomedical model
- They have multiple causes, some in common (Common Risk Factor Approach)
- Value placed on self-reports (outcome-based)
- Emphasis on epidemiological data – broader determinants of health

Kaplan, 2003; Quality of Life Research
Why use HRQoL measures?

✓ Important for assessing impacts of chronic diseases
✓ Physiologic measures often correlate poorly with functional ability and well-being
✓ Two patients with similar clinical status often have dramatically different perceptions about their oral health

Guyatt, Feeney and Patrick, 1993; Annals of Internal Medicine

✓ Intended outcomes of health care are primarily changes in patients’ health status and quality of life

McCallion et al, 1993
Quality of Life Definitions

- Health-related quality of life is the value assigned to duration of life as modified by impairments, functional states, perceptions and social opportunities that are influenced by disease, injury, treatment or policy (Patrick and Erickson, 1993)

- Health-Related Quality of Life: a multifaceted concept that attempts to simultaneously assess (trade-off) how long and how well people live.

- Quality of Life: “An individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their personal goals, expectations, standards and concerns” (WHOQOL Group, 1995)
What are “Oral Health-Related Quality of Life” (OHRQoL) measures?

- Oral health-related quality of life: “The impact of oral diseases and disorders on aspects of everyday life that a patient or person values, that are of sufficient magnitude, in terms of frequency, severity or duration to affect their experience and perception of their life overall” – Linking oral health to quality of life (Locker and Allen, 2007)

- Subjective indicators that provide information on the impact of oral disorders and conditions, and the perceived need for oral health care.

OHRQoL indices are complementary to clinical measures.
Adapted World Health Organisation Model
(Locker, 1988)

Disease → Impairment → Functional Limitation → Disability → Handicap

Death

Discomfort
OHRQoL indicators

For adults ... (examples)

- General Oral Health Assessment Indicator (GOHAI); 12 items (Atchison and Dolan, 1990)

- Oral Health Impact Profile (OHIP); 49 items (Slade and Spencer, 1994); short-form OHIP-14 (Slade, 1997); edentulous population short-form OHIP-19 (Allen and Locker, 2002)

- Oral Impacts on Daily Performance (OIDP); 8 items (Adulyanon and Sheiham, 1997); elderly population version 8- or 10-items (Tsakos et al, 2001)
OHRQoL indicators

For children ...

- Child Oral Health Quality of Life (COHQoL; Jokovic et al., 2002); child perceptions, parental perceptions and family impact. Dimensions: oral symptoms, functional limitations, emotional well-being and social well-being.

- Child-Oral Impacts on Daily Performance (Child-OIDP; Gherunpong et al., 2004); Impact on 8 performances: eating, speaking, cleaning, sleeping, smiling, emotional stability, school work, social contact.

- Early Childhood Oral Health Impact Scale (ECOHIS; Pahel et al., 2007); Parental report - very young children

- Scale of Oral Health Outcomes for 5-year-olds (SOHO-5; Tsakos et al, 2012); self-report and parental reports
Oral Health-Related Quality of Life Indicators

- Eating without discomfort
- Limit food from dental problems
- Trouble in biting, chewing
- Trouble in speaking
- Uncomfortable eating with people
- Nervous / self-conscious
- Limit social contacts
- Worry / concern
- Use medication for teeth
- Sensitive teeth or gums
- Pleased with looks
- Swallow comfortably

Frequency of oral impacts

The Geriatric Oral Health Assessment Index (GOHAI)

Atchison and Dolan, 1990
(12 items)
Oral Health-Related Quality of Life indicators

The Oral Health Impact Profile (OHIP)

Slade and Spencer, 1994
(49 items)

- Functional limitation
- Physical pain
- Psychological discomfort
- Physical disability
- Psychological disability
- Social disability
- Handicap

- Short-form (OHIP-14); Slade, 1997
- Edentulous population (OHIP-19); Allen and Locker, 2002

Frequency of oral impacts
Oral Health-Related Quality of Life indicators

- The Oral Impacts on Daily Performance (OIDP)
  - Adulyanong and Sheiham (1997) - adults
  - Tsakos et al., 2001 - older adults
  - Gherunpong et al., 2004 - children (Child-OIDP)

- Frequency and Severity of oral impacts
  - Eating food
  - Speaking clearly
  - Cleaning teeth or dentures
  - (Doing light physical activities)
  - Going out
  - Sleeping
  - Relaxing
  - Smiling, laughing, showing teeth without embarrassment
  - Mood affected (becoming upset)
  - (Work or major role)
  - Enjoying contact with other people
OIDP index: Conceptual Framework

Impairment

Pain
Discomfort
Functional Limitation
Dissatisfaction with appearance

Impacts on Daily Performance
Physical  Psychological  Social
The Child-OIDP index

✓ Assesses the impacts of oral conditions in relation to the ability of the person to carry out 8 important daily activities and behaviours.

✓ In addition to the overall score, there is provision for condition-specific scores, whereby oral impacts are related to a specific dental condition, such as malocclusion, by directly asking the respondent.

✓ The Child-OIDP can serve both as a generic and condition-specific instrument.

✓ This condition-specific feature makes the index suitable for needs assessment.
HRQoL Indicators: Overview

Similarities in broader content themes
- physical well-being (physical health status and functioning)
- emotional and psychological well-being (life satisfaction, anxiety)
- social well-being (social functioning)

Differences
- precise aims (and potential applications)
- frequency and/or severity
- generic impacts or “linked” to oral conditions
- specific content (subjective ratings of importance?)
- technical characteristics (no. of items, response choices, subscales, administration method, “weights”)
Key properties of HRQoL measures

8 key attributes and criteria for HRQoL measures...

- Conceptual and measurement model
- Reliability
- Validity
- Responsiveness
- Interpretability
- Respondent and administrative burden
- Alternative forms
- Cultural and language adaptations (translations) (SAC, 2002)
Meaningless OHRQoL means?

✓ P values are not sufficient: size of differences?
✓ Mean change scores are “complex and controversial” ¹
✓ Change can occur in both directions - mean change scores just give average change
✓ Same mean change score - different change profiles
✓ Is the difference (change) meaningful?

“Differences or changes in scores... give the direction of difference, without any notion of scale or (more importantly) intrinsic meaning” ²

Interpretability of aggregate scores

✓ **Interpretability**: “the degree to which one can assign qualitative meaning – that is, clinical or commonly understood connotations – to quantitative scores” ¹

✓ Are changes **clinically significant** or **meaningful**?

✓ Both cross-sectional and longitudinal studies

➢ **Minimally important difference (MID)**: “smallest difference in score in the domain of interest which patients perceive as beneficial and which would mandate, in the absence of troublesome side-effects and excessive cost, a change in patient’s management” ²

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Key Questions - outline

- Behaviours – the “usual suspects”?
- Dental Anxiety – the (not so) “new kid on the block”...
- Why measure subjective perceptions and (oral) health-related quality of life (OHRQoL)?
- Types of measures – examples
- Which are the necessary properties of composite measures (such as OHRQoL)?

How have they been applied? The example of the CDHS 2013 (and ADHS 2009)
Perceptions of dental and general health

✓ Global item questions - Overall assessment

✓ Wording:
  • How would you rate your dental health?
  • How would rate your general health?

✓ Answers:
  • Very good .... Very poor
How do children rate their dental and general health?

<table>
<thead>
<tr>
<th>England, Wales and Northern Ireland 2013</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Children aged 12,15</td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 years</td>
</tr>
<tr>
<td></td>
<td>15 years</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>Dental Health</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>60</td>
</tr>
<tr>
<td></td>
<td>68</td>
</tr>
<tr>
<td>Female</td>
<td>72</td>
</tr>
<tr>
<td></td>
<td>81</td>
</tr>
<tr>
<td>FSM eligible</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>64</td>
</tr>
<tr>
<td>Not eligible</td>
<td>67</td>
</tr>
<tr>
<td></td>
<td>77</td>
</tr>
<tr>
<td>% Total</td>
<td>66</td>
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<td>General Health</td>
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<td>Male</td>
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<tr>
<td>Female</td>
<td>87</td>
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<td>87</td>
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<tr>
<td>FSM eligible</td>
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<td>83</td>
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<tr>
<td>Not eligible</td>
<td>86</td>
</tr>
<tr>
<td></td>
<td>90</td>
</tr>
<tr>
<td>% Total</td>
<td>85</td>
</tr>
<tr>
<td></td>
<td>88</td>
</tr>
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</table>
Appearance of teeth

✓ Self-reports (aged 12 & 15) and Parental proxy reports (all 4 ages)

✓ Satisfaction with appearance of teeth
  - 5 point scale: Very satisfied… satisfied… neither satisfied nor dissatisfied… dissatisfied… very dissatisfied

✓ Perceived need for orthodontic treatment
  - “teeth are all right”… “would prefer them straightened”… “already in treatment”
Children’s self-reports: Dissatisfaction with the appearance of their teeth

About 1 in 6 dissatisfied with the appearance of their teeth
Are children’s perceptions different from those of their parents?

<table>
<thead>
<tr>
<th>England, Wales and Northern Ireland 2013</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children aged 12,15 with a parent assessment</td>
<td>12 years</td>
</tr>
<tr>
<td><strong>Self Assessment</strong></td>
<td><strong>Parent Assessment</strong></td>
</tr>
<tr>
<td>My teeth are all right</td>
<td>Their teeth are all right</td>
</tr>
<tr>
<td>Would prefer them straightened</td>
<td></td>
</tr>
<tr>
<td>Child in treatment</td>
<td></td>
</tr>
<tr>
<td>Would prefer them straightened</td>
<td>Their teeth are all right</td>
</tr>
<tr>
<td></td>
<td>Would prefer them straightened</td>
</tr>
<tr>
<td></td>
<td>Child in treatment</td>
</tr>
</tbody>
</table>
Oral problems and Impact

- Self-reported oral problems (children aged 12 and 15)
- Parental proxy reports of children’s oral problems (children aged 5 and 8)
- Impact of oral health on the quality of life of children (aged 12 and 15)
- Impact of child’s oral health on the family life (parental reports – all 4 ages)
# Toothache in children in UK (CDHS 2013)

<table>
<thead>
<tr>
<th>England, Wales and Northern Ireland 2013</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>12 years</td>
</tr>
<tr>
<td>Children aged 12,15</td>
<td></td>
</tr>
<tr>
<td>Problems</td>
<td></td>
</tr>
<tr>
<td>Sensitive mouth</td>
<td>32</td>
</tr>
<tr>
<td>Mouth ulcers</td>
<td>20</td>
</tr>
<tr>
<td>Bad breath</td>
<td>20</td>
</tr>
<tr>
<td><strong>Toothache</strong></td>
<td><strong>18</strong></td>
</tr>
<tr>
<td>Bleeding or swollen gums</td>
<td>16</td>
</tr>
<tr>
<td>Broken tooth</td>
<td>8</td>
</tr>
<tr>
<td><strong>Any problem</strong></td>
<td><strong>68</strong></td>
</tr>
</tbody>
</table>

### Parental reports of child’s oral problems

<table>
<thead>
<tr>
<th>England, Wales and Northern Ireland 2013</th>
<th>Percentages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children aged 12,15</td>
<td>5 year olds</td>
</tr>
<tr>
<td>Toothache</td>
<td>14</td>
</tr>
<tr>
<td>Other pain in mouth</td>
<td>13</td>
</tr>
<tr>
<td>Bad breath</td>
<td>13</td>
</tr>
<tr>
<td>Broken tooth</td>
<td>5</td>
</tr>
<tr>
<td>Problems with appearance</td>
<td>5</td>
</tr>
<tr>
<td>Bleeding or swollen gums</td>
<td>3</td>
</tr>
<tr>
<td>Any problem</td>
<td>37</td>
</tr>
</tbody>
</table>

- **Toothache, other pain and bad breath from very young age**
- **Very clear social inequalities: 49% of FSM eligible and 34% of non-eligible with oral problems**
Oral Impacts in CDHS 2013

✓ To what extent the mouth affects the Quality of Life of the child

✓ Child-OIDP
  - 8 key aspects of daily life
  - How much the teeth and mouth affect them?... “not at all”... “a little”... “a fair amount”... “a lot”
  - Prevalence by impact; overall; extent (number of impacts reported)
### Oral Impacts on daily life (Child-OIDP) in UK

**England, Wales and Northern Ireland 2013**

<table>
<thead>
<tr>
<th>Children aged 12,15</th>
<th>12 year olds</th>
<th>15 year olds</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any difficulty in last 3 months</td>
<td>58</td>
<td>45</td>
</tr>
<tr>
<td>Difficulty eating</td>
<td>22</td>
<td>19</td>
</tr>
<tr>
<td>Difficult speaking</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Difficulty cleaning teeth</td>
<td>22</td>
<td>14</td>
</tr>
<tr>
<td>Difficulty relaxing</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>Felt different</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Felt embarrassed smiling or laughing</td>
<td>35</td>
<td>28</td>
</tr>
<tr>
<td>Difficulty doing schoolwork</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Difficulty enjoying being with people</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>

Quality of Life - CDHS 2013 key finding

More than a third of 12-year-olds embarrassed to smile because of their teeth

19 March 2015

More than a third (35%) of 12-year-olds and 28% of 15-year-olds say they have been embarrassed to smile or laugh due to how they felt about their teeth, finds a new UCL-led report commissioned by the Health and Social Care Information Centre.

The new report, Attitudes, Behaviours and Children’s Dental Health, reveals for the first time how children aged 12 and 15 feel about their dental health. It was written by Dr George Tsakos (UCL Epidemiology & Public Health) in collaboration with colleagues at the Universities of Birmingham, Cardiff and the Office of National Statistics.

58% of children aged 12 and 45% of those aged 15 reported that their daily life had been affected in some way by oral problems in the last three months. This was most commonly experienced as embarrassment when smiling, laughing or showing teeth, followed by difficulty eating, and difficulty cleaning teeth.

“Oral conditions can affect children’s quality of life in many different ways, not just with physical impacts such as eating but also psychologically and socially,” says Dr Tsakos. “We found that problems were much worse in those eligible for free school meals, with 33% of 15-year-olds eligible and 22% of those not eligible (for free school meals) saying that their oral health made their everyday life more difficult. This highlights the extent of social inequalities in oral health and quality of life among adolescents and the need for preventive strategies to improve oral health particularly for the more deprived children in the population.”

Other key findings from the report include:

- 44% of 12-year-olds and 28% of 15-year-olds reported that they would like to have their teeth straightened. Children eligible for free school meals were more likely to want their teeth straightened, but started treatment much later than children not eligible.

- Two thirds of 12 and 15 year olds reported a problem with their dental health in the last three months. The most prevalent problem was sensitive teeth, reported by 32% of 12-year-olds and 34% of 15-year-olds, followed by mouth ulcers, bad breath, toothache and bleeding gums.

- 71% of 12-year-olds eligible for free school meals reported brushing their teeth twice daily, compared with 78% of those not eligible.

“Urgent action is needed to tackle oral health inequalities. It is simply unfair and unjust that children from deprived households suffer so much from dental diseases that are largely preventable. Organisations such as Public Health England have a key role in addressing this problem.”

Professor Richard Watt
Inequalities in Oral Impacts on daily life (Child-OIDP) in UK

Free School Meals (FSM) eligibility does not fit well with good QoL, ... more deprived children are particularly vulnerable

Subjective oral health and quality of life by educational level among dentate

## Child’s oral health: Impact on family life

<table>
<thead>
<tr>
<th>England, Wales and Northern Ireland 2013</th>
<th>5 years</th>
<th>8 years</th>
<th>12 years</th>
<th>15 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children aged 5, 8, 12,15</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Time off work</strong></td>
<td>7</td>
<td>12</td>
<td>19</td>
<td>23</td>
</tr>
<tr>
<td><strong>Child needed more attention</strong></td>
<td>11</td>
<td>16</td>
<td>14</td>
<td>15</td>
</tr>
<tr>
<td><strong>Parent felt stressed or anxious</strong></td>
<td>11</td>
<td>18</td>
<td>15</td>
<td>13</td>
</tr>
<tr>
<td><strong>Parent felt guilty</strong></td>
<td>8</td>
<td>13</td>
<td>11</td>
<td>11</td>
</tr>
<tr>
<td><strong>Family activities interrupted</strong></td>
<td>5</td>
<td>5</td>
<td>6</td>
<td>8</td>
</tr>
<tr>
<td><strong>Parent’s sleep disrupted</strong></td>
<td>7</td>
<td>10</td>
<td>7</td>
<td>6</td>
</tr>
<tr>
<td><strong>Financial difficulties</strong></td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td><strong>Any Family Impact</strong></td>
<td><strong>21</strong></td>
<td><strong>32</strong></td>
<td><strong>32</strong></td>
<td><strong>35</strong></td>
</tr>
</tbody>
</table>

Conclusions

✓ Questionnaires provide unique information on national studies that goes beyond what clinical data offers
✓ Collected data needs to be relevant for needs assessment and planning services (not just research)
✓ Behaviours are important but their measurement challenging
✓ The whole spectrum of behaviours is usually ignored despite its relevance for oral health
✓ Dental anxiety “ticks many of the boxes” and seems to provide practical information, but not so much for child populations
Conclusions

- Oral symptoms are easy to measure and directly relevant for communication to the “external world” (public and policy makers)
- OHRQoL measures can bring out the subject-centred approach and re-orient focus on health
- Complex measures in surveys come with key choices:
  - Aim / focus of the survey
  - Severity (importance) vs frequency ratings – links to oral conditions
  - Content vs. length
  - burden to staff and respondents
  - COMPARABILITY and INNOVATION!!!
All these are important challenges and “answers” are almost never obvious...

... but seem very easy compared to the difficulty of using the survey information practically to improve the (oral) health of the population or even of individuals
Thank you for your attention

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