Chapter 2

Case example:
Participation of end-users in setup and topic selection for biomedical research

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Abstract

A case example of the participation of orthodontic end-users in selecting research topics is presented, in which patients, parents and care providers are involved in the set-up and topic selection of a part of this thesis, using a structured questionnaire. The questionnaire addressed different aspects of oral biofilm control in orthodontic patients and asked what aspects and new developments would be valued most by them as end-users. All respondents, including patients, parents of patients, orthodontists and paramedics, scored highest for ‘non-compliance’ bacterial-killing adhesives with lasting killing effect. The results demonstrate that end-users can make a valuable contribution for scientists in the selection for societally-relevant research topics, when the main purpose of the research work is to reach its potential end-users and provide benefit for their health and wellbeing. Moreover, public opinion can help scientists to better understand the needs of end-users.
Today, scientists are urged more than ever to demonstrate societal impact and economic value creation of their research work by scientific journals, university boards, research funding agencies, scientific output evaluation committees and the general public. In the early days, the only aspect of interest when measuring the impact of research was the impact on academia and scientific knowledge. Since the 1990s, trust in the value of science for society decreased and a visible trend emerged that evidence should be provided to demonstrate its value for society (Bornmann 2013). The significance of research can be evaluated by its scientific and societal impact. Research can be of low scientific quality while still having a large resonance in society and vice versa. In the academic world, scientific quality of a research work is often indicated by the impact factor of the journal in which it has been published (Eliades and Athanasiou 2001). Ideally, all scientific research should be of high quality and demonstrate considerable societal impact contributing to the well-being of the general public. In reality, however, scientific quality and social impact of a research work shows only a weak correlation (Mostert et 2010). Good scientific research with a well-designed methodology does not necessarily ensure a high societal impact. Relevance to society is an important objective for scientific studies in all fields including biomedical research. Evaluation of research work should therefore not be restricted to its scientific quality alone, but also take into account its impact outside the scientific domain (KNAW; 2001).

Societal impact can be divided in three levels, or so called end-users or general (lay) public, healthcare professionals and the private sector (KNAW; 2001). To achieve impact in society there must be some interaction between a research group and the potential end-users of their research work (ERiC; 2010). The public’s opinion is increasingly important as it gets a more demanding vote in the selection for research topics, which may eventually influence the policy makers in decisions on funding priorities. Therefore, the interaction between scientists and end-users becomes an important aspect for research, and scientists should be aware of the needs and preferences by end-users (Bouter 2010). Although real societal impact can often only be assessed many years after a research work has been published, the ‘productive interactions’ between researchers and ‘end-users’ may be considered as a proxy for further (future) impact (Wit and Merkx. 2010). To this end, a survey can be a suitable method to identify topics of importance as perceived by the end-users.
Here we present a case example on the participation of end-users in setup and topic selection of a research study on prevention of biofilm formation during orthodontic treatment. A questionnaire was developed to measure the needs and expectations of those who would be potentially affected by the outcomes of the research study.

A structured questionnaire with closed questions and pre-formulated answers were used in the survey. Survey respondents included patients, parents of the patients, paramedical personnel including oral hygienists, dental nurses and clinical administrative workers, and orthodontists. Patients, regardless their age, filled in the questionnaire by themselves and in addition, parents of patients younger than 16 (if present at the time of the survey), were also asked to filled in the questionnaire. All respondents were either patients and their families or employees working at the Department of Orthodontics at the University Medical Center Groningen. The survey consisted of two parts, with one part focusing on research topics (A), the other part on clinical applications (B). First, the preferences of the users for a research topic were measured; after that we continued with the preferences on clinical applications on the selected research topic. Respondents had to answer on a likert scale (Likert; 1932). Scoring a 10 indicates that the participant completely agreed, scoring a 0 indicates completely disagree. The questionnaire was explained by one of the researchers, and subsequently, the respondents filled in the questionnaire on their own and handed it in immediately afterwards.

Data were analyzed with the Statistical Package for Social Sciences (Version 16.0, SPSS Inc., Chicago, IL, USA). A one-way analysis of variance (ANOVA) was used to compare the mean scores. A post-hoc Bonferroni test was used for comparisons between the groups. Statistical significance was set at $p < 0.05$.

In total 91 subjects filled in the first part of the questionnaire (Fig. 1A), with an age range between 8 to 58 years. The respondents consisted of 28 patients, 26 parents of patients, 17 orthodontists and 20 paramedics. Figure 1-A shows the results on selection of research topics.

Patients, parents of patients, orthodontists and paramedics all gave a lowest score (mean score 5.6 ± 2.6) to free distribution of toothbrushes at schools. This is probably because toothbrushes in the Netherlands are relatively cheap and highly affordable. A difference can be seen in ‘educational websites’, on which medics and paramedics scored significantly ($p<0.05$) higher (mean scores 7.9 ± 1.3 and 7.9 ± 1.0
than patients and their parents (mean score 6.5 ± 2.3 and 7.0 ± 2.1). ‘Efficient E-brush’, on the contrary, scored significantly lower by medics and paramedics (p<0.01) than by patients and parents. With a mean score of 8.1 (± 1.5), ‘development of bacteria-killing braces’, scored the highest among all four topics without any significant differences between the groups (p > 0.05) indicating a clear preference by all different end-users for this topic.

Figure 1. a) Scores on selection of research topics by patients, parents, orthodontists and paramedics. b) Scores on selection of research aims of patients (mean age 16.4 ± 6.4, age range 10-35 years) and parents (mean age 43.5 ± 5.2 age range 36-58 years).
Bacterial-killing braces can have different applications in dentistry and orthodontics. Accordingly, to find out about preferences for applications by the potential users, 4 different clinical applications and 1 question on cost aspects were presented. 26 patients (mean age 16.4 ± 6.4, age range 10-35 years) and 16 parents (mean age 43.5 ± 5.2, age range 36-58 years) filled in this part of the questionnaire (B). There was no significant differences between the groups although all respondents scored highest for bacterial-killing adhesives and lasting killing effect, with a mean score of 8.0 ± 1.7 and 8.2 ± 1.6 respectively (Figure 1-B). Parents scored higher on the crown and bridge work than patients. This may have to do with a higher awareness of their dental conditions, while patients (mean age 16.4 ± 6.4), at a young age, often have relatively healthy dentitions and are less familiar with dental work options. The respondents scored lower (mean 7.2 ± 1.9) for a 3D printable material and scored the lowest on the extra costs (mean 5.9 ± 2.4). Accidentally, two parents indicated their considerations towards a lower score for the 3D printability: ‘3D’ sounded very hi-tech, and therefore its application must be quite costly. This argument fits well to the low scores on ‘extra costs’. The health care system in the Netherlands has somewhat encouraged the development of a common mentality of the public that health care is expensive and should be ‘free’ (NOS [internet]).

Although what is presented here is only one case example performed within one academic clinical department, the results reflect clearly the needs perceived by patients, their families and healthcare workers. Remarkably, even patients as young as 8 years old were able to indicate their needs and preferences independently. It is interesting to see that the needs and preferences of patients and parents differ significantly from orthodontists and healthcare workers, indicating false expectations may exist not only in researchers towards end-users, but also in indirect users (healthcare workers) towards direct users (parents and families). Awareness of this may help to improve the quality of care by healthcare workers. Even more interesting is that there exists a high agreement in almost all aspects between patients and parents, indicating patient families are generally more able to think in line with the needs of their family members. This is valuable information for clinicians to consider in their decision-making when more treatment options exist for a patient.

To summarize, we presented a case example on the participation of end-users, including patients, their families and their care providers, in setup and topic selection of a research study using a structured questionnaire. The results demonstrate that
end-users can make valuable contribution for scientists in selection for a research topic, when the main purpose of the research work is to reach its potential end-users and provide benefit for their health and or wellbeing. While the needs and preferences may differ between direct and indirect users, the outcome of this survey indicate clearly that public opinion is worth considering by scientists in the clinical downward translation of their fundamental research work.
References

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Rathenau Institute. 2010. Evaluating the societal relevance of academic research: A guide. ERiC.
Het probleem is vooral de groei van orale bacteriën op tandglazuur door slecht of onvoldoende tandpoesen. In ernstige gevallen kan dit leiden tot gaatjes. Het is onaangenaam en ongezond.

Wat voor soort onderzoek zal je voorstellen om dit probleem aan te pakken? Hoe hoger de score die je geeft, hoe meer je denkt dat je profiteert van dat onderzoek.

1. Ontwikkeling van een meer efficiënte tandenborstel voor makkelijker tandpoesen specifiek voor kinderen

2. Ontwikkeling van een patiënt educatieve website met video’s en foto’s voor een goede mondhygiëne

3. Ontwikkeling van anti-bacteriële beugels zodat bacteriën er niet op kunnen groeien (patiënten moeten goed blijven tandpoesen natuurlijk).

4. Ontwikkeling van een goedkope tandenborstel voor eenmalig gebruik met pasta en voor het gratis verdelen op school voor kinderen

Hartelijk dank voor uw medewerking!
Prof. dr. Y Ren, Orthodontist, Afdeling Orthodontie UMCG

Het probleem is vooral de groei van orale bacteriën op tandglazuur door slecht of onvoldoende tandpoesen. In ernstige gevallen kan dit leiden tot gaatjes. Het is onaangenaam en ongezond.

In het UMCG gaan we een onderzoeksproject beginnen over de ontwikkeling van anti-bacteriële beugelmateriaal, zodat bacteriën er niet op kunnen groeien. Er zijn verschillende benaderingen om een anti-bacteriële beugermateriaal te ontwikkelen. We willen graag uw/jouw mening hierover.

Hoe hoger de score die je geeft, hoe meer je denkt dat je/jouw patient profiteert van dat onderzoek.

1. Ontwikkeling van een anti-bacteriële lijn voor de "slotjes", waarop bacteriën niet meer kunnen zitten (bacteriën kunnen heel goed zitten op de huidige gebruikte lijn).

2. Ontwikkeling van een 3D printbare anti-bacteriële beugel, zodat een uitneembare beugel direct op maat gemaakt kan worden met eventueel gewenste kleur en/of smaak.

3. Ontwikkeling van anti-bacteriële materiaal dat niet alleen voor beugels, maar ook voor trones en bruggen gebruikt kan worden, zodat vele andere tandheelkundige patiënten van verschillende leeftijden hier ook van kunnen profiteren.

4. De anti-bacteriële eigenschap van het nieuwe beugermateriaal moet blijven bestaan tot de beugel behandeling klaar is.

5. Als het nieuwe anti-bacteriële beugermateriaal aan alle bovengenoemde eisen voldoet, mag het materiaal iets meer kosten (+10%).

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