Agenda-setting for research in oral health care

CONNECTING PERSPECTIVES

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Colofon

The research in this thesis was carried out within the department of Oral Public Health at the Academic Centre for Dentistry Amsterdam (ACTA), the combined faculty of the University of Amsterdam and the VU University of Amsterdam, The Netherlands.

Publication of this thesis was supported by Onderzoeksinstituut ACTA and Koninklijke Nederlandse Maatschappij tot bevordering der Tandheelkunde (KNMT).

ISBN: 978-94-6361-699-7
Cover and design: Dennis van den Brink (Design inspired by Anthony Zinonos)

Layout and printing: Optima Grafische Communicatie, Rotterdam

Agenda-setting for research in oral health care – Connecting perspectives

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. ir. K.I.J. Maex
ten overstaan van een door het College voor Promoties ingestelde commissie,
in het openbaar te verdedigen in de Aula der Universiteit
op woensdag 29 juni 2022, te 11.00 uur

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CONTENTS

Chapter 1

General Introduction

RESEARCH WASTE

Worldwide, biomedical research accounts for large investments, approximately $240 billion in 2009.[1] It is therefore remarkable that an estimated 85% of biomedical research has been identified as being wasteful.[2] Research is qualified as waste when it concerns research that is not adding new relevant findings to existing knowledge.
Chalmers and Glasziou[2] identified causes for research waste in the biomedical field in the four stages of the research process as found in figure 1.1.

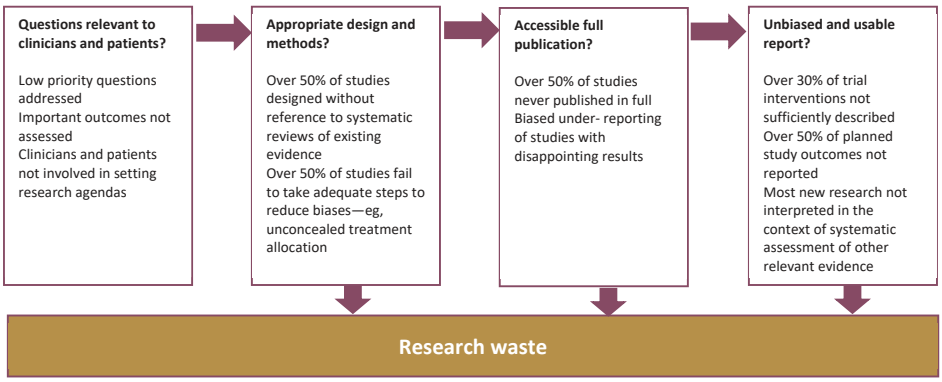


Figure 1.1: Stages of waste in the production and reporting of research evidence relevant to clinicians and patients (from *I. Chalmers and P. Glasziou 2009*, with permission)

While some research waste may be inevitable, it has been agreed upon that most of the problems causing the waste are avoidable or correctable.[2,3] Moreover, as research passes through all four stages shown in figure 1.1, the waste is cumulative. Consequently, valuable resources, time and efforts, required for scientific studies are wasted. The negative consequences of research waste, however, reach further, as it is not always easy to identify research waste is happening. Despite the wide advocacy of reporting guidelines and prepublication peer review, deficient and sloppy research practices most often remain unnoticed.[3] Through biased reporting, poorly designed studies can be presented as high-quality research with plausible outcomes. Such publications unjustifiably advocate low-value care and practices. This compromises the decision-making process of clinicians and reduces the quality of the health care. Thus, the impact of research waste not only extends to the waste of valuable resources, it can even result in negative consequences for patients.[4] A recent scoping review by Pandis[5] et al revealed research waste due to inappropriate design, conduct, analysis and reporting in the oral health research field.

In this thesis, we mainly focus on the research waste in the first stage of the research process (see figure 1.1): *Are the questions addressed in oral health research relevant to clinicians and patients?*

In biomedical research, research activity mainly focuses on basic and translational science and is very much focused on cure. Less activities focus on research in common diseases, prevention and care.[6,7] Currently, what is being researched is predominantly determined by researchers (often driven by interests or curiosity), funders (often using disputable evaluative criteria) and research policymakers, while the interests of patients and health care professionals are subordinate.[8,9]
The value of health care practice is determined by its effectivity, efficacy, and health outcomes [10,11], but the value of health care research is judged on very different criteria. The science system clearly functions as a reputation system, and researchers are inclined to choose research lines and publication that benefit their reputation.[12] This is enhanced by the fact that financial resources are either allocated to research areas that perform very well in terms of bibliometric indicators or previous successful funding applications.[7,8] Other criteria to evaluate and value research like valorization and societal value are underrepresented in this reputation system.[13,14] As such, the science system nowadays is driven more by an interplay of reputation and production to a larger extent than by a classical interplay of conjectures and refutations.

In recent years, criticism on the current research system, the evaluation of research and how research is valued is increasing.[15–17] Reliance on bibliometric indicators and criteria that assess the productivity of researchers instead of the quality of their research have far-reaching implications and stimulate incentives that indirectly disregard the key aim of biomedical research: answering questions relevant to the society that benefit the population and individuals. As the flaws due to this reputation system are identified and addressed, adaptation of directions for future research accordingly will be required.[8]

While nearly 60% of public and charitable investment in UK health research in 2009-2010 was allocated to pure basic science, formal evidence for the value of basic science is lacking.[18] Especially in biomedical research, the goal to benefit patients should be a priority. And although many researchers point out that basic science has provided important breakthroughs in biomedical research, only one report of more than 25.000 published in six leading basic-science journals between 1979 and 1983 led to the development of an intervention used widely.[6] Meanwhile, the call for relevant and useful research increases gradually.[6,19]

1991: TWO CALLS FOR RELEVANT RESEARCH

Already 30 years ago, in 1991, two papers were published that addressed the issue of relevance in medical research policy.
In March, Guyatt[20] introduced the term evidence-based medicine (EBM) by describing how clinicians would use new evidence from research to guide decisions making in patient care. Later, in 1996 this was further elaborated on by Sackett et al.[21] The evidence to inform evidence-based medicine was defined as relevant research on diagnostic tests, prognostic markers and therapeutic, rehabilitative and preventive regimes.
In August 1991, Peckham[22] explained the need to reform the research and development (R&D) strategy of the National Health Service (NHS), in the UK. Until then, innovation in medical research was mostly driven by the interests of clinicians and scientists. As a result, a large part of the research that was supported by the NHS, did not benefit the users of the NHS. In the new R&D programme, a needs-led programme of commissioned research was developed.[22]
Although these papers address two very different issues, both have contributed to a shift in the view on research in the biomedical field. With the introduction of EBM, the importance of research that informs medical professionals was emphasized and established. EBM combines evidence from high quality research with expertise of health care professionals and preferences and values of patients. However, the contribution of research is pivotal.[23,24] Research that provides answers to dilemmas in patient care has been increasingly important since the introduction of EBM. This implies that, in order to incorporate EBM, research that focusses on the questions that arise from patient care in daily practice should be a priority.
Peckham, not only addressed the issue of relevant health care research in his publication. In the new R&D programme, the Standing Advisory Group for Consumer Involvement was established. This group is the predecessor of INVOLVE, a national advisory group that promotes public involvement in health and social care research.[25] With the implementation of this new R&D programme, the interests of the users of research – both clinicians and patients - were acknowledged by the research policy makers as important to guide future research.

IDENTIFY RELEVANT RESEARCH QUESTIONS

Evidence from research will have less effect on patient care if the research does not meet the needs of the users of research. However, examples of mismatches between the research needs of the users of research like patients, carers and clinicians and the questions that researchers choose to investigate are widely available.[6,26–28]

To increase the value of research it is therefore important that relevant research questions are identified and prioritized through a transparent methodology. A research agenda setting process is often used to identify and prioritize research questions.
Traditionally, research agendas are determined by researchers, funders, research policy makers and incidentally clinicians. However, in recent years, due to advocacy from for example the James Lindt Alliance, the engagement of clinicians and patients has become more common.[28,29] In a number of countries, different methodologies and techniques are developed during the last 15 years.[30]
Other approaches to identify and prioritize research questions can be based on quantifiable epidemiologic needs and costs data for example the burden of disease or the cost-effectiveness of interventions. And although examples of these priority setting projects exist, the engagement of users of research is more and more regarded as indispensable.[2,26,31–33]

A GAP BETWEEN RESEARCH AND PRACTICE IN ORAL HEALTH CARE

While the societal demand for transparency on the quality of health care has increased, little is known about the quality of Dutch oral health care. It has been shown that the uptake and implementation of scientific knowledge on effective health care practice into patient care is rather slow.[34,35] In this, guidelines have been shown to serve in speeding up this uptake. Ideally, guidelines are based on the best available scientific evidence for diagnosis, prognosis, treatment, prevention, which is integrated with expertise of health care practitioners.[21,36] Guidelines provide recommendations to oral health care practitioners (OHPs) for the most appropriate care for their patients. They thereby reduce unwarranted variation in care practice and contribute to the transparency and quality of patient care.

An important reason for the lack of implementation of research findings into patient care is the existing gap between oral health research and daily practice. That is, the volume of oral health care research on diagnosis, prognosis, treatment, prevention that could serve to inform guidelines on effective oral health care is rather limited.[5,37,38] In the report *Perspectives on Oral Health care (2012)*, the National Health Council (NHC) of the Netherlands concluded that the evidence base for many oral health care treatments and interventions is lacking. This clearly contributes to variation in treatment that cannot be explained by variation in patient care.[34]

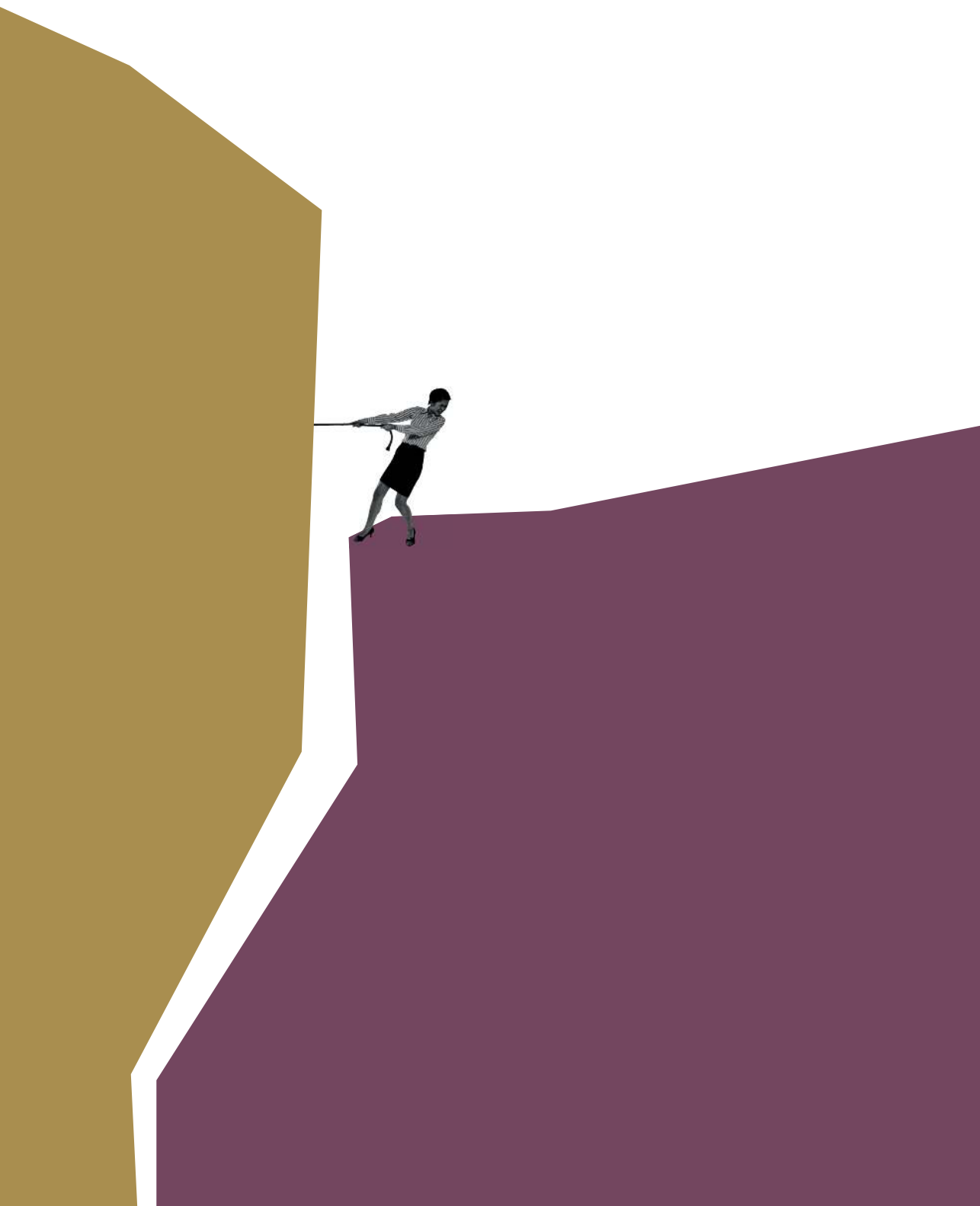
To date, the majority of oral health research focuses on basic science or on the development of new techniques.[34] Filling the existing prioritized knowledge gaps for patient

care is essential for the implementation of evidence-based practice.[23,34] It is therefore important to involve OHPs and patients in the identification and prioritization of evidence gaps and information needs of patient care. This will assist in reorienting the oral health research community towards research questions that are considered relevant for patient care and meet information needs of the end-users, patients and OHPs. In addition, it will help to restore the balance in the research portfolio which now has been dominated by a strong basic scientific orientation on oral health research.[34]
Moreover, in view of the scarce resources available for oral health research, careful reflection on the evident research waste in this research field is required. This necessitates careful programming (determination of the content of research on institutional or national level) and planning (scheduling) of future research. To avoid duplication of efforts, the added value of new research to what is already known should be a prerequisite, while more collaboration between researchers is needed.
To further increase the methodological quality and societal value of oral health research, efforts are required in the outlined second phase (appropriate design and methods) to third phase (accessibility of publications) of research waste (see Figure 1.1). New high-quality research that provides knowledge allowing improvement of patient care in oral health care, will contribute to closing the gap between research and daily practice.

OVERALL AIM AND OUTLINE OF THIS THESIS

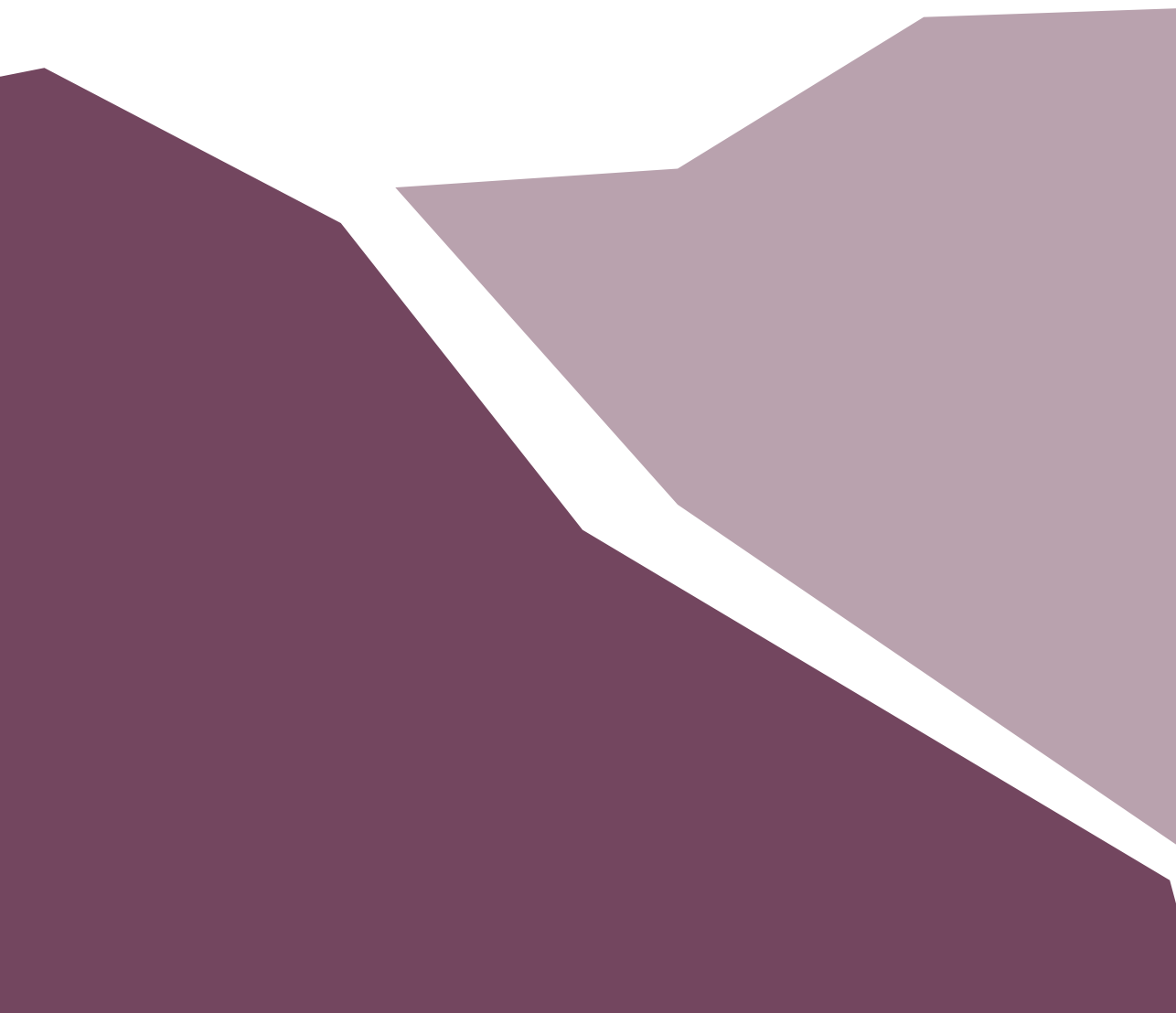
In this thesis we aim to connect several perspectives with regard to reducing research waste and overcoming the mismatch between the research priorities of researchers, patients and OHPs.
In part one of this thesis we aim to provide context for research programming by assessing how the oral health research field is currently composed. In **chapter 2** a bibliometric analysis was used to assess the current oral health research field over a 15-year period. In this study we determined if academic drift influences the oral health research portfolio by a drift towards basic science and away from research that serves oral health care. In **chapter 3** we estimated the expenditures of oral health care in the Netherlands for three years, based on claims data and data from an invoicing company. In **chapter 4**, the content of the Dutch Dental Journal (Nederland Tijdschrift voor Tandheelkunde – NTvT) over an 18-year period was analyzed. We analyzed which scientific knowledge – from different dental subfields - the Dutch OHPs are provided with through this journal. We also studied how this scientific knowledge from different dental subfields correlates to the oral health care expenditures from these subfields, as found in chapter 3.

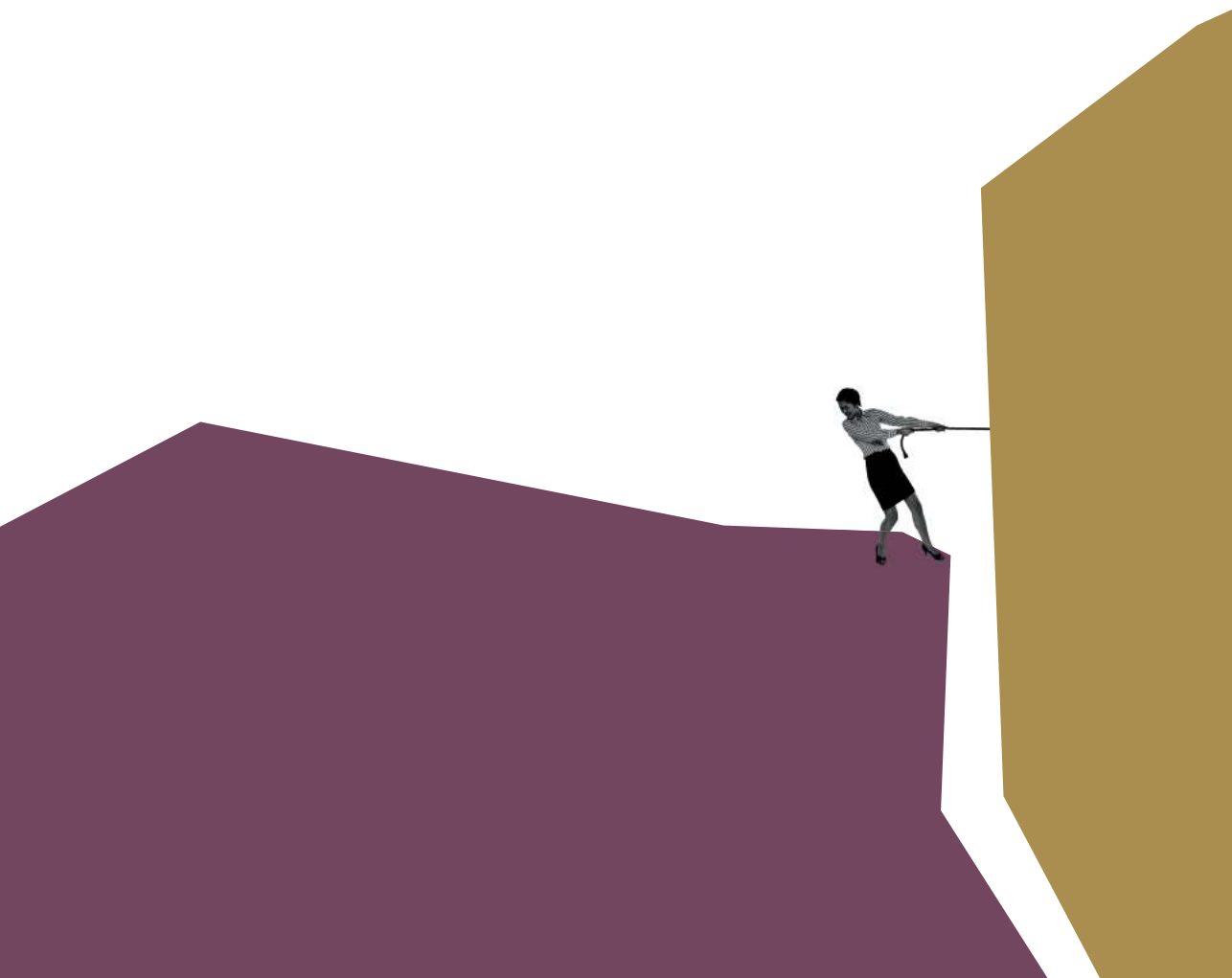
In part two of this thesis we describe the process of setting the research agenda for oral health for which the perspectives of OHPs and patients were included. In **chapter 5** the setting of research priorities from the OHPs' perspective, through a two-stage survey study is described. In **chapter 6** the setting of research priorities from the patients' perspective through focus group discussions and a survey is described. Also, the integration of these priorities with the priorities from OHPs from chapter 5, through a dialogue into joint priorities are found in chapter 6. In **chapter 7**, the research agenda setting process is reflected on from the perspective of a boundary object. It is shown how this research agenda setting process helped to overcome boundaries between different stakeholders.



Part one

Context for research programming
in oral health care





Chapter 2

Evidence and consequences of academic drift in the field of oral health research: A bibliometric analysis 2000-2015

Puck van der Wouden
Geert van der Heijden
Hagay Shemesh
Peter van den Besselaar

British Dental Journal Open (2022)8:3.

ABSTRACT

The mission of academic excellence has resulted in a science system that incentivises publications within high impact, often basic science journals, and less in application-oriented journals. For the dental research field this so-called academic drift can result in a research portfolio that moves away from research that serves oral health care. Therefore, we examined if and how academic drift has changed the dental research field.

Web of Science data were used to develop a network map for dental research containing journal clusters that show similar citation behavior. From the year 2000 up to 2015, we explored the intensity of knowledge exchange between the different clusters through citation relations. Next, we analyzed changes in research focus of dental research institutes in seven countries, in *dental research, clinical medicine research, basic science, public health research* and *other fields.*

Within the citation network, 85.5% of all references in dental journals concern references to other dental journals. The knowledge contribution of non-dental research fields to dental research was limited during the studied period. At the same time, the share of output of dental research institutes in dental research has declined. The research activity of the dental research institutes increased mainly in basic science while the knowledge input from basic science into dental research did not increase.

Our findings suggest that the dental research portfolio is influenced by academic drift. This academic drift has increased the disbalance towards basic science, and presents a challenge for the scientific progress in oral health care services.

INTRODUCTION

The science system functions as a reputation system, and researchers are inclined to choose research lines and publication strategies that may boost their reputation, which mainly is achieved through recognized contributions to science.[39] Thereby, researchers are amenable to choose research themes and publication strategies that may boost their reputation. The research systems of advanced countries stimulate the production of large volumes of high-quality publications in top journals.[40,41] For many research institutes, academic excellence and the science frontier is pivotal for their mission, their research policy and research portfolio.[8] Moreover, in the last decades, academic excellence has been a dominating feature of the performance evaluation of researchers and research groups. At the same time, the emphasis on academic excellence has been criticised, as it has resulted in a science system that is driven by incentives aiming at high citations and impact factor scores. It thereby disregards a major goal of science which is to respond to the needs and challenges of society, by creating relevant knowledge that brings benefit to society.[15–17,42]

In dental research*, according to the Dutch Health Council, the focus on 'excellence' has resulted in a changing dental research portfolio. That is, in 2010 already about half of the total output of the three Dutch academic dental institutes concerned research in the basic sciences - as opposed to applied research.[34] This seems to indicate that 'academic drift' occurs in dental research, notably, "*the process whereby knowledge which is intended to be useful gradually loses close ties to practice while becoming more tightly integrated with one or another body of scientific knowledge" (p.413)*.[43] Drift in this sense has been a common phenomenon in many domains of science, including agriculture, engineering, medicine, education and management. The emphasis on academic excellence has been translated in the medical (including dental) domains in an emphasis on publications in journals with high impact factors, the so-called 'top journals'. This most likely has affected research interests and the choice of research topics, as the majority of publications in those 'top journals' concern the basic sciences.[44,45] Applied sciences and in particular research addressing local or regional needs and practical challenges are considered outside of what is conceived as the frontier of science. Therefore, as a result of 'academic drift', a tendency to publish in high impact international basic research journals, and less in application oriented - often local or national – journals can be expected. As a consequence, the dental research field may partly move away from the more practical questions that emerge from everyday oral health care practices.[34]

* In this thesis, the term oral health research is used. In this chapter the term dental research is used, given the methodology. Please note that dental research is regarded as a synonym for oral health research.

The academic drift and the reputation system both harbor the risk of pursuing exclusively progress in science, thereby neglecting innovation and progress in society as a universal target. However, more recently the societal relevance of research has gained a more prominent place in evaluation and funding systems, which has resulted in a new paradigm of 'translational science'.[13,14,46] Because of the slow pace of the implementation of this paradigm shift, it remains to be seen whether it will reverse the impact of the reputation system and its impact in terms of the imbalances due to academic drift.

The purpose of this study is to provide insight in the occurrence of academic drift in the dental research field and whether and how this has impacted this field. Therefore, we address the following questions:

1. Is the balance between applied and basic research in the dental research field shifting away from applied research, which is oriented to oral health care practice?
2. What is the share of non-dental research within the portfolios of the dental research institutes, and what is the balance between dental and non-dental research?
3. Does non-dental research provide pertinent knowledge which is relevant for and of benefit for dental research?

In order to answer these questions, we use bibliometric methods to analyze trends in the dental research field from the year 2000 up to 2015 at a global level and for several important research countries. We use three approaches to operationalize academic drift.

As a first indicator of academic drift we use the change in research focus of *dental research institutes.* For this, we analyze whether research activities of dental research institutes in non-dental (and more basic) research fields increase at the expense of dental research. Therefore, we analyze changes in volumes of publications of dental research institutes in the dental and non-dental research fields.

Secondly, non-dental research may have relevance for dental research (basic science may inform applied science). Therefore, as a second indicator of academic drift, we analyze which non-dental research fields function as knowledge suppliers for dental research.

Thirdly, while many dental journals have an international orientation, readership and authorship, national journals may serve more locally and nationally oriented authors and readers, including OHPs. Hence, as third indicator of academic drift, we address the role of national journals, and study the changes in the volume of publications in the local dental journals.

MATERIAL & METHODS

How to analyze change in research fields?

The dynamics of science can be studied best at the macro level of the communication of research findings (publications), and not at the micro level of research activities.[47] Within most research disciplines, publication in scientific journals is the main vehicle of communication. This enabled us to study the change in a research domain by analyzing the dynamics of the journal structure.[48] In our study we initially define dental research as publications categorized in the Web of Science (WoS) category *Dentistry, Oral Surgery & Medicine.* WoS has a wide coverage of science and journals are categorized in WoS categories that correspond to research fields. Most importantly, WoS provides citation information, which allows us to study science dynamics. We derive the main dental research journals from the WoS category, and define dental research in terms of journal clusters, which enables us to map the structure of and knowledge streams within the dental research field and its environment. To identify research done within the dental research institutes we use the classification based on WoS categories, as this enables to analyze the changes in the topical focus of those institutes in relation to academic drift.

The changing place of dentistry in the scientific landscape

To analyze the structure and change of the dental research field from 2000 up to 2015, we first determined what the dental research field comprises. Therefore, we used the set of journals classified in the WoS category *Dentistry, Oral Surgery & Medicine* and indexed in the InCites Citation Reports with a Journal Impact Factor. Hereafter, we will refer to this set of dental journals as the "*core-set*".

In order to understand the changes in the research field of dentistry, we mapped the place of dentistry in the scientific landscape for the beginning, the middle and the end of the studied period: 2000, 2008, and 2015. This was done in the following way.[48] For each of these years, we selected the 27 journals with the highest impact factor from the *core-set*. (Annex A) These journals are related to each other and to other journals through citations. We then identified all journals that either cite (at least) one of the selected journals or are cited by (at least) one of the selected journals. These related journals are dental and non-dental journals as relevant research is not necessarily limited to exclusively dental journals. We restricted our analyses to related journals above a threshold of 0.5%[48] of the total number of citation relations with at least one of the selected journals (either citing or being cited). The lower numbers of citations are considered 'noise'.

Network analysis was used to identify clusters of journals that have similar citation behavior in the network. Journals with similar citation behavior belong to the same research field or subfield. As we started with our *core-set*, the network map is expected to show various dental research subfields, as well as other research fields that either are cited by these dental journals, or cite these dental journals themselves. The names of dental clusters were based on similarities in the journal titles, and corroborated by two authors who are field specialists (PvdW and HS). The names of non-dental journal clusters were based on the WoS category to which most journals of a cluster were assigned.

The network map shows the larger disciplinary landscape of and around dental research. This enables us to explore the structure and intensity of knowledge exchange (so-called knowledge streams) between the different clusters of journals using citation relations. The strength of the knowledge stream is determined by the number of times journals from one cluster are cited by journals from another cluster. Changes in citing behavior are an indicator of cognitive change[49], therefore we compare citation relations between journal clusters for the three years.

Analyzing the research focus of the dental research institutes

We compared the scientific output of identified dental research institutes between several countries in the WoS category *Dentistry, Oral Surgery & Medicine* with the output in other WoS categories. We included seven countries that have a well-developed research system and have contributed significantly to trends in the dental research field. Thus, we focused on countries that perform well in terms of quality and quantity of publications. In Annex-B it is described how these seven countries were selected. We expected dental research institutes to be the main source of publications in the dental research field, and therefore used the publications affiliated to dental research institutes as the source of publications for the selected countries. We tested if the dental research institutes are indeed the main source of dental publications by estimating the contribution of the dental research institutes to the total output in WoS category *Dentistry, Oral Surgery & Medicine*. The use of dental research institutes allows to determine ratios between dental and non-dental publications.

The dental research institutes, notably research institutes with one of the main dentistry concepts in their name, were identified using a dedicated query (see box 2.1). This query exploited two address fields within a WoS record. The field tag AD for address was used to identify relevant research institutes with one of the main dentistry concepts in their institute name. The field tag SG for Suborganization was used to identify relevant research suborganizations with one of the main dentistry concepts in their name. This

query was repeated per country. Publications affiliated with dental research institutes from multiple included countries were attributed to all included countries.

Box 2.1. WoS queries for dental research institutes

Per country:
(AD=((dent* NEAR/15 Country) OR (Cario* NEAR/15 Country) OR (Endodont* NEAR/15 Country) OR (Pedodont* NEAR/15 Country) OR (Periodont* NEAR/15 Country) OR ("Oral Biochemistry" NEAR/15 Country) OR ("Oral Cell Biology" NEAR/15 Country) OR (Implantol* NEAR/15 Country) OR (Prosthod* NEAR/15 Country) OR ("Oral Radiology" NEAR/15 Country) OR ("Oral Kinesiology" NEAR/15 Country) OR ("Oral Medicine" NEAR/15 Country) OR (Orthodont* NEAR/15 Country) OR (Maxillofac* NEAR/15 Country) OR (orofac* NEAR/15 Country)))
AND
(SG=(dent* OR Cario* OR Endodont* OR Pedodont* OR Periodont* OR "Oral Biochemistry" OR "Oral Cell Biology" OR Implantol* OR Prosthod* OR "Oral Radiology" OR "Oral Kinesiology" OR "Oral Medicine" OR Orthodont* OR Maxillofac* OR orofac*)) AND DOCUMENT TYPES: (Article OR Review)

World-wide:
(AD=((dent*) OR (Cario*) OR (Endodont*) OR (Pedodont*) OR (Periodont*) OR ("Oral Biochemistry") OR ("Oral Cell Biology") OR (Implantol*) OR (Prosthod*) OR ("Oral Radiology") OR ("Oral Kinesiology") OR ("Oral Medicine") OR (Orthodont*) OR (Maxillofac*) OR (orofac*))) *AND* **DOCUMENT TYPES:** (Article OR Review)

We then analyzed the changes in the publication activities of dental research institutes (aggregated on country level). First, the volume of research output by the dental research institutes in the *core-set* journals and the volume of total research output was determined. We analyzed growth in both volumes per country and worldwide. We calculated the share of research output in the *core-set* of the total research output for the periods 1998-2000 and 2014-2015.

Output by dental research institutes in the wider landscape

We analyzed in more detail to which WoS categories publications from dental research institutes were attributed. For each country, we calculated the share of publications by the dental research institutes per WoS category for the first period (1998-2000) and for the last period (2014-2015) to analyze (pattern of) changes in the importance of the research fields over time.

The changing focus on local journals

Based on the assumption that applied research has a tendency to be published in journals with a national or local orientation, we calculated the share of total output in local journals as indicator for applied research within the dental research field.[50–55] We considered journals related to international societies, like the *Journal of Dental Research* or the *International Dental Journal*, or targeting a particular dental specialism, like *Caries Research* or the *Journal of Clinical Periodontology,* to have an international orientation, when published in the English language. We categorized as local journals those either including a country name in their title, like *Swedish Journal of Dentistry*, or

when published in the national language. One may argue however that journals including British, American, Australian or New Zealand in their journal titles are not exclusively local because they are published in the English language. Therefore, we calculated the correlation between the countries' share in the *core-set* and the countries' share in journals that might be identified as local (based on the journal title). If this correlation was less than 0.5 the journal was identified as local. The journals in Annex-C are strongly dominated by publications from one or two countries, and were therefore classified as local.

Then we analyzed, per country, the share of total output of dental research institutes in the local journals, which may help to understand the national differences in the (application) orientation of dental research.

RESULTS

The place of dentistry in the scientific landscape

The resulting journal network for the year 2008 consists of about 250 journals, of which we used 187. We excluded 63 journals, as these are in the WoS database only as cited items. The network analysis of the 187 journals results in 31 clusters, each representing a research field or subfield. Some clusters obviously represent a dental research subfield, like dental materials and dental public health (see table 2.1: clusters 0, 2, 4, 5, 8, 10, 15, 16, 22) while other clusters represent a research field which is related to dentistry primarily through citation relations, like oncology and pain.

Table 2.1: Clusters within the dental journal network (2008)

	Journal cluster*				
0	General dentistry	12	Clinical microbiology	24	Biomechanics
1	Oncology	13	Pain	25	Laser
2	Operative dentistry & materials	14	Otorhinolaryngology	26	Public health USA
3	Public health / general medicine	15	Endodontology	27	Genetics
4	Implantology	16	Periodontology	28	Chemistry
5	Community dentistry	17	Pediatrics	29	Geriatrics
6	Plastic surgery	18	Neuroscience	30	Quality of life
7	Biochemistry	19	Immunology	31	Forensic science
8	Orthodontics	20	General medicine	32	Radiation
9	Microbiology	21	Anatomy	33	Anthropology
10	Oral surgery	22	TMD	34	Medical devices
11	Biomaterials	23	Kinesiology		

* Annex-D displays how the journals are distributed over these clusters

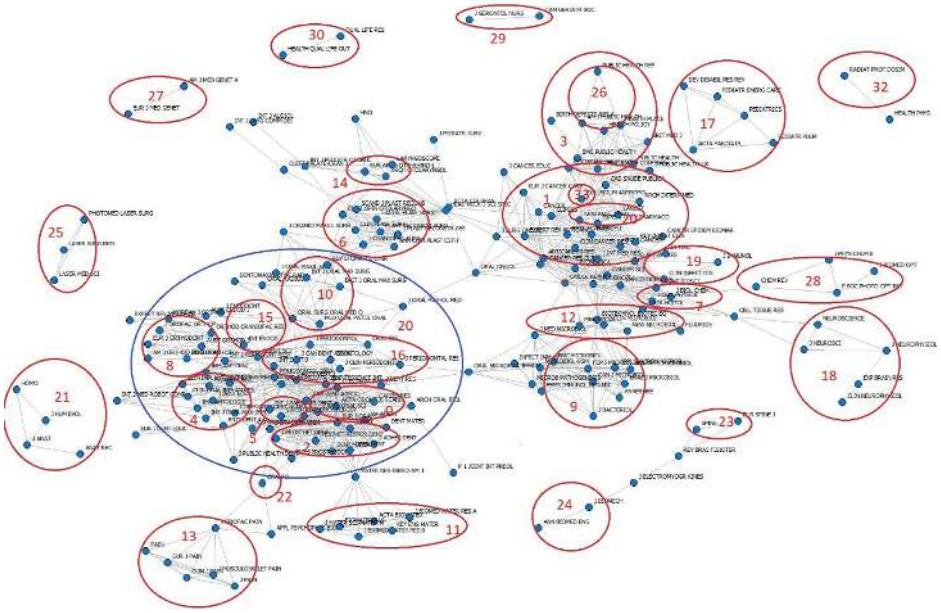


Figure 2.1: Map of the journal network of the dental research field (2008), with the main fields indicated
Figure 2.1 shows the map of dental research and the main neighboring fields. Each node represents a journal and all journal clusters are indicated on the map by a circle. In the large blue circle, the journal clusters representing dental research subfields are found. In Annex-D, an overview of all clusters including the journals belonging to them is found.

Quite a few of the non-dental clusters [7, 9, 11, 13, 18, 19, 21, 24, 27, 28, 33] seem to represent basic research that may be used within dental research. The remaining clinical [1, 6, 12, 14, 17, 20, 23, 29], public health related [3, 26, 30], instrumental and other [25, 31, 32, 34] fields may be used within dental research, or may be using dental research results. This can be visualized using a map that represents the knowledge streams between the clusters.

Figure 2.2 shows the knowledge streams between the main research fields for 2008. The map consists of the observed journal clusters, symbolized by a colored node, and these represent a research field. The citation relations between the fields are represented by the arrows between the clusters, and the direction of the arrow indicates the direction that the knowledge streams. The more citations of publications from journals in the cluster the arrow is pointing at, the thicker the point of the arrow is. We visualized only the stronger links. The streams can go in both directions, but that is not necessarily the case. In figure 2.2, the arrow from public health to community dentistry indicates that the community dentistry journals are citing the Public health journals but are hardly cited by public health journals.

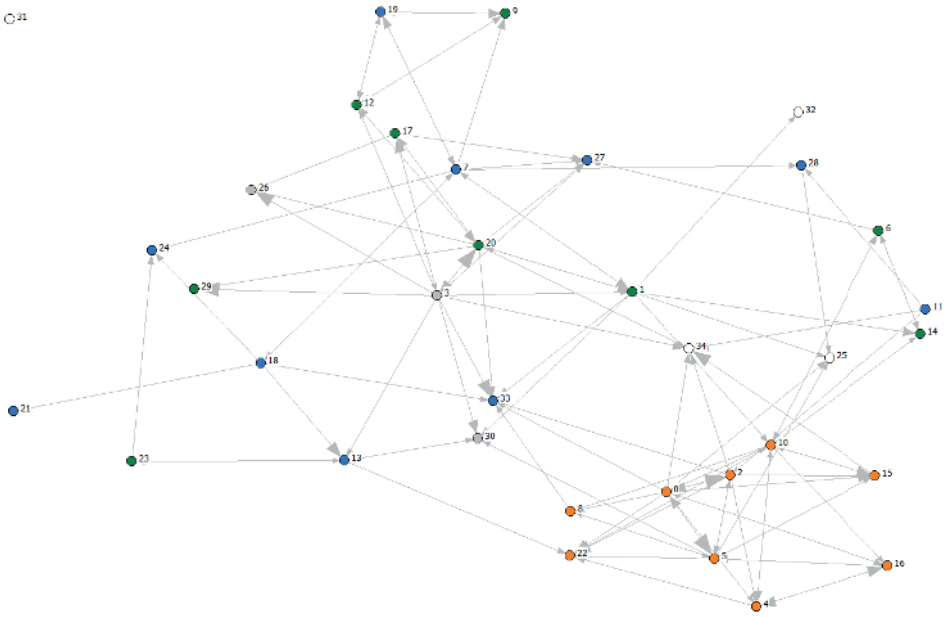


Figure 2.2: The knowledge streams around dental research 2008
The numbers refer to the research fields in table 2.1. The size of the arrows head indicates the strength of the knowledge streams. We only visualize the stronger links (larger than 3% of all references of the journals in a field).
Node colors: Orange = dental research clusters; Green = clinical medicine research clusters; Blue = basic science clusters; Grey = public health research clusters; White = other.

The dental clusters (orange nodes) are concentrated on the right part of the chart. Direct knowledge streams from non-dental clusters to dental clusters are limited. The following knowledge streams (represented by an arrow) to a dental cluster can be distinguished: The biomaterials cluster contributes knowledge to the dental materials and implantology clusters, the public health cluster contributes knowledge to community dentistry cluster, while the plastic surgery and oncology clusters contribute knowledge to the oral surgery cluster.

All other clusters at best indirectly contribute knowledge to the dental research clusters. For clarity we aggregated the knowledge streams for dental and non-dental clusters. Within the network, 85.5% of all references in dental journals concern citations of other dental journals, whereas 14.5% of the references in dental journals concern citations of the non-dental journals in the network. This shows that the non-dental fields contribute limited knowledge to dental research, indicating an inward orientation of dental research.

Comparing 2000, 2008 and 2015

The knowledge streams for the years 2000 and 2015 were analyzed as well. The network map of the scientific landscape of dental research changes between the years, but the main research fields and subfields are found in all three network maps (Annex-E). We aggregated the knowledge streams for the three years into streams between the five groups as found in figure 2.2: *dental research, clinical medicine research, basic science, public health research* and *other*. Table 2.2 shows the knowledge streams towards dental research clusters in the three years. In 2000, 80% of the references in the dental journals refer to other dental journals. The remaining 20% references were mainly to clinical medicine journals (11%), and basic science journals (8%). In 2008, the share of references to other dental journals was even higher (85%), while in 2015, the pattern was about the same as in 2000. Based on these findings we conclude that the dental research field mainly depends on knowledge produced within the dental research field. The knowledge streams from basic science into dental research have not increased much over the fifteen years period.

Table 2.2: Knowledge streams to dental research clusters, per group.

	Dental research 2000	Dental research 2008	Dental research 2015
Dental research	80 %	85 %	79 %
Clinical research	11 %	7 %	10 %
Basic science	8 %	6 %	9 %
Public Health research		1.4 %	0.9 %
Other	0.7 %	0.4 %	0.6 %

The research focus of the dental research institutes

In the previous section, we reported patterns in the dental research field at the global science level. In this section, we focus on the changing research portfolio of the dental research institutes in the seven selected countries (based on the largest dental research output in high impact factor dental journals) namely: USA, England, Germany, Italy, The Netherlands, Sweden, Switzerland.

Table 2.3 shows the dental output published by *non-dental research institutes* for the selected countries in the WoS category *Dentistry, Oral Surgery & Medicine*. In the first period, the share of total output by non-dental researchers in the *core-set* is between 10% and 23% and it declines to between 3% and 15%. Clearly, dental research institutes produced the overwhelming part of dental research output, and we consider the output of those institutes to be representative for the dental research field. Hence, we restricted the next analysis to these dental research institutes.

Table 2.3. Share of total output of non-dental research institutes within WoS category *Dentistry, Oral Surgery & Medicine*

	1998-2000	2014-2015
Sweden	23%	15%
Switzerland	11%	9%
Germany	17%	7%
England	10%	6%
USA	13%	6%
Italy	10%	5%
The Netherlands	13%	3%
Average	14%	7%

Publications by dental research institutes are not restricted to dental journals. We calculated the distribution of the publications over the WoS categories for the dental institutes from the seven countries. Based on figure 2.2, WoS categories were grouped into *dental research, clinical medicine research, basic science, public health research* and *other*. Annex-F displays to which group each WoS category was assigned. As displayed in table 2.4, the share of output in the *dental research* group is still the largest, but has declined from 61% to a 43%. Shares of output in all non-dental groups increased, with the share of *basic science* increasing from 33% in '98-'00 to 40% in '14-'15, and the group *other* increased from 5% to 8% over this period. The increase in this group is attributed to the WoS category *Multidisciplinary sciences* covering journals like Science, Nature and PNAS, journals that can be included under basic science. The more fine-grained changes at the level of individual WoS categories are found in Annex-F.

Table 2.4: Distribution of all output from dental research institutes, seven countries, over five groups 1998-2015

Group*	1998-2000	2014-2015
Dental research	61%	43%
Basic science	33%	40%
Clinical research	19%	20%
Other	5%	8%
Public Health research	2%	4%

* The total is higher than 100% as some journals are classified in more than one group

Table 2.5 shows an overview of the growth of research volume for dental research institutes worldwide and for the seven countries. We determined growth in output in the *core-set* as well as the growth in the total output.

Table 2.5: Changes in publication patterns, output of dental research institutes aggregated per country, 1998-2015*

	Growth output in *core-set* 1998-2015	Growth in total output 1998-2015	*Core-set*/Total 98-00	*Core-set*/Total 14-15
World	247	330	52%	39%
Italy	441	624	60%	43%
Switzerland	441	543	70%	57%
Germany	347	440	61%	48%
The Netherlands	209	356	64%	38%
England	129	224	45%	26%
USA	158	203	49%	38%
Sweden	125	180	74%	52%

* Index: 1998 = 100

During the studied period, the growth of publications in the *core-set* varied between 25% (Sweden) and 341% (Italy, Switzerland). In all countries, the increase in total publications (dental publications and publications outside of the dental journals, authored by dental research institutes) is larger than the increase in the number of dental research publications. This means that dental institutes publish relatively more in non-dental journals in the latter period. As a result, the share of dental output within the total output declines. In most countries, that percentage has fallen under 50%, and in England it is only 26%.

Based on the findings presented in table 2.2 and table 2.4, we conclude that the research activity of the dental research institutes diversified strongly, leading to an increased activity in basic science at the expense of dental research: the share of dental output declined. However, the knowledge streams from the basic science fields to dental research have not increased over the period. This suggests that dental research is not so much becoming more science based, but that the research activities of dental research institutes are showing academic drift.

The role of local journals

In the introduction we distinguished two pressures on the science system: (i) to increase excellence, resulting into academic drift, and (ii) to increase societal relevance. Above we showed that activities of dental research institutes increasingly move into non-dental research fields, where publications may have more impact. Next, we compared the role of local dental journals over time between the seven countries, as that may be used to illustrate the role of societal (oral health care related) relevance. In national research systems that demand knowledge transfer to 'end-users', researchers may be more inclined to publish also in local journals that may reach practitioners. Please note, if a German researcher publishes in a Swedish national journal, this is also counted as

'local' for the German researcher, as we assume that the type of publication, and not the country, is the pivotal difference between international and local journals.

To investigate the focus on societal relevance, we identified the local dental journals (Annex-C), and calculated for the dental research institutes in each of the countries the number of publications they have in these local journals. For each country, we then calculated the share of local publications of the total output. Table 2.6 shows the results for 2000 and 2015. The shares of local publications are very different between the countries in 2000: from 1% in Italy to 18% in Sweden. In 2015 these differences are much smaller: from 4% in the USA to 12% in Sweden. To quantify the decrease in differences, we calculated the coefficient of variance for 2000 and 2015 for the seven countries. The differences between the countries decline (the coefficient of variation decreases from 0.92 in 2000 to 0.30 in 2015). A possible explanation for this convergence is that in countries where the share of publications in local journals was high, the pressure on excellence has resulted in a declined focus on local publications. On the other hand, in countries where the share of publications in local journals was low, the increasing pressure on the science system for societal relevance may have caused an increase in local journal publications.

Take for example the Netherlands, where both pressures exist.[56] We see on the one hand an increase in publications in local journals (from 3% to 7% between 2000 and 2015), suggesting responsiveness of the research system to societal demand. On the other hand, the increase in publications in non-dental journals (from 36% to 62% between 2000 and 2015 – table 2.5) suggests an academic drift.

Table 2.6: Publications of dental research institutes aggregated per country in local journals, as share of all publications

	2000 Share in local	2015 Share in local
Sweden	18%	12%
England	16%	10%
Italy	1%	9%
Germany	5%	7%
Netherlands	2%	7%
Switzerland	3%	7%
USA	4%	4%
Coefficient of Variance	0,92	0,30

DISCUSSION

We reported an evaluation of the research dynamics within the dental research field through different approaches, and determined the place of dental research within the scientific landscape. Our analyses showed that dental journals have a distinct position on the journal network map, and the citation relations between the different dental research fields are much stronger than those with non-dental research fields. In addition, we have identified the rather limited knowledge streams from non-dental clusters to dental journal clusters, and these streams have not increased over time. These findings indicate that dental research constitutes a mono-disciplinary, and very likely even an insular research field.[57]

Due to academic drift the dental research portfolio has changed. The share of the dental research activities serving scientific progress in the basic sciences has grown the most in absolute and relative terms. Consequently, the balance in the dental research portfolio has further shifted towards basic research.

As shown, dental research institutes provide the overwhelming and increasing part of dental research. The focus of dental research institutes, however, has strongly shifted towards publications in non-dental research fields. For 5 of the 7 countries included in our analysis, less than half of the output of dental research institutes can be classified as research published in the *core-set* (table 2.5). Nowadays, dental research institutes particularly publish in basic sciences journals and clinical medicine journals, and the research activities (in terms of publications output) of dental research institutes show a drift away from dental research. At the same time, the knowledge streams from non-dental research to dental research are limited and rather stable. This suggests that the relevance of this non-dental research for dental research and practice may be limited. However, this raises the question whether dental research benefits from non-dental research through other mechanisms than citation relations, for example through research collaboration, through informal contacts, or through the use of medical instrumentalities.[58,59]

Through three different approaches our study showed how the dental research field is changing. The main contributors to dental research – the dental research institutes – shift their focus to non-dental research. However, the contribution of non-dental research to dental research seems to remain limited. This is a strong indicator for the occurrence and impact of academic drift in the dental research field.

How do our findings relate to those of others? A literature search (date 12th march 2020) resulted in 52 publications in WoS category *Dentistry, Oral Surgery & Medicine* that include a bibliometric analysis. Most of these publications focus on highly cited articles or on bibliometric indicators for a specific dental research field[60–62], a specific journal[63,64] or a specific country[65,66]. Only two publications approached the entire dental research field. Gil-Montoya et al[67] used a cross-sectional study design to quantitatively and qualitatively compare contributions from different countries to the dental research field. They concluded that a substantial part of the activities in the dental research field come from a limited number of countries. Pulgar et al[68] analyzed dental research including dental publications outside of WoS category *Dentistry, Oral Surgery & Medicine* per country using a topic search strategy. They found, similar to our findings, an increase of dental publications especially in WoS categories covering basic science.

To our knowledge only Skvoretz et al[69] analyzed in a cross-sectional study the knowledge exchange – in terms of citation patterns - between the dental research field and one non-dental research field, namely prenatal research. A keyword search was used to identify the dental and prenatal publications. Similar as in our study, they report that dental research (as well as prenatal research) shows 'inbreeding' tendencies in terms of citation behavior.

In our study we did not limit our analysis to knowledge exchange between a particular non-dental and dental field, but we used the publication output of dental research institutes, as this level of aggregation allowed us to not only move beyond analysis of citation relations with non-dental fields, but also to identify in which non-dental research fields dental research institutes publish: especially in surgery, in biomedical & tissue engineering, and in biomaterials (Annex F).

While Haslam and Lusher[57] found in general similar sparse citation relations between psychiatry and clinical psychology within the field of mental health research, in future research it remains to be shown whether our findings are typical for the dental research field or indicate a more general pattern in biomedical research or even in science.

A limitation of our study is the possible misclassification, notably publications from dental research institutes which cover dental research topics may have been classified as non-dental. Pulgar et al[68] reported that in the period of 2006-2008 approximately 15% of all dental publications (identified through a keyword search for dental topics) were published in a non-dental WoS category. Also, the opposite misclassification is possible, as publications within WoS category *Dentistry, Oral Surgery & Medicine* may cover basic science which eventually may not be related to dental research. Since we

did not use publication level for our analysis, it remains unclear how much publications were misclassified due to WoS categorization. However, dental research publications from dental research institutes in basic science journals would have been reflected in the gross-group citation patterns. As the share of publications of dental research institutes within non-dental journals has increased over time, the citation relations between non-dental and dental research have not increased. Therefore, we are convinced that a potential misclassification might only have limited impact on our findings and that our method is adequate for analyzing research dynamics of academic drift.

Furthermore, the share of publications from dental institutes in non-dental journals is much larger (57%) than the 15% through a topic search strategy found by Pulgar et al, which strengthens our findings that the largest part of publications in non-dental journals are classified as non-dental research correctly.

One might argue that the findings about academic drift and pressures towards societal relevance may be the effect of the selection of the countries. However, trends in a research field are foremost determined by countries with advanced research systems that contribute large volumes of publications, which justifies our selection of countries.[70]

As expected, dental research is for the largest part embedded within dental research institutes. A shift in the focus of these research institutes to other research fields holds important implications for the dental research field. The academic drift towards more basic science consequently has an effect on basic and applied dental research, which is covered by the *core-set* of dental journals. The major goal of science is to respond to the needs and challenges of society, by creating relevant knowledge that brings benefit to society. Hence, research policy makers within research institutes and on the national level, as well as research funders, hold an important responsibility for the focus of research activities.[6]

The increasing focus on non-dental research fields may result in a decline in research serving the oral health care services (OHPs and patients). We would argue that a balanced dental research portfolio is of importance for both policy in science and oral health care. Hence, when designing policy interventions in the research system, research policy makers should reflect on whether this will induce changes in the dental research field dynamics that are meeting their goals: will the interventions serve to stimulate research addressing oral health care and societal challenges in the oral health care field, or are they – unintended - stimulating further academic drift towards basic sciences?

CONCLUSION

Our findings suggest that academic drift has been influencing the research agenda in the dental research field. This is reflected in the changing focus of dental research institutes over the last decades towards an increasing share of publications in non-dental basic science journals and in clinical medical journals, and in the fairly limited and constant knowledge streams from basic science to dental research. An important task lies with the dental research community and research policy makers to establish a research portfolio that balances achieving scientific progress with serving oral health care.

ANNEX-A: SELECTING THE ENTRANCE JOURNALS.

For each of the three years, the journals from the WoS category *Dentistry, Oral Surgery & Medicine* with the highest impact factor were selected. The number of journals used as entrance journals depended on the number of journals that were related through citation relations to these entrance journals. This number was set at a maximum number of 250 journals in the map in order to keep the visualization readable. For 2000 and 2015, the number of entrance journals was 26, for 2008, it was 27 journals.

2000 (26 journals)	2008 (27 journals)	2015 (26 journals)
	Acta Odontol Scand	
	Am J Dent	
Am J Orthod Dentofac	Am J Orthod Dentofac	Am J Orthod Dentofac
Angle Orthod	Angle Orthod	Angle Orthod
Arch Oral Biol	Arch Oral Biol	Arch Oral Biol
Brit Dent J	Brit Dent J	Brit Dent J
Caries Res	Caries Res	Caries Res
Cleft Palate-Cran J	Cleft Palate-Cran J	Cleft Palate-Cran J
Clin Oral Implan Res	Clin Oral Implan Res	Clin Oral Implan Res
Community Dent Oral	Community Dent Oral	Community Dent Oral
Dent Mater	Dent Mater	Dent Mater
Int Endod J		Int Endod J
Int J Oral Max Impl	Int J Oral Max Impl	Int J Oral Max Impl
	Int J Periodont Rest	
Int J Oral Max Surg		Int J Oral Max Surg
J Am Dent Assoc	J Am Dent Assoc	J Am Dent Assoc
J Clin Periodontol	J Clin Periodontol	J Clin Periodontol
J Cranio Maxill Surg		J Cranio Maxill Surg
J Dent	J Dent	J Dent
J Dent Res	J Dent Res	J Dent Res
J Endodont	J Endodont	J Endodont
J Oral Maxil Surg	J Oral Maxil Surg	J Oral Maxil Surg
J Oral Pathol Med	J Oral Pathol Med	J Oral Pathol Med
J Oral Rehabil	J Oral Rehabil	J Oral Rehabil
J Periodontal Res	J Periodontal Res	J Periodontal Res
J Periodontol	J Periodontol	J Periodontol
J Prosthet Dent	J Prosthet Dent	J Prosthet Dent
Oral Microbiol Immun	Oral Microbiol Immun	
Oral Oncol	Oral Oncol	Oral Oncol
	Oral Surg Oral Med O	Oral Surg Oral Med O

ANNEX-B: SELECTING THE COUNTRIES

For between-country comparison we focused on the countries with the largest volume of publications in the most important journals (in terms of impact factor) of the dental research field from 1998 up to 2015. To overcome the differences per year in the list of top-10 impact factor journals we identified all journals that have been listed in the top-10 from 1998 up to 2016. For this we used the Journal Citation Reports for journal impact factors from 1998 up to 2016 for the category *Dentistry, Oral Surgery & Medicine*. The resulting 30 journals were ranked by their multiple-year impact factor, and the ten highest ranked, i.e. multiple-year top-10, were included for further analysis (table below).

Table Annex B: Ranking list of Top-10 Impact Factor Dental Journals between 1998 and 2016 based on rank sum.

	Journal Title	Ranksum	Average IF	No. times in IF top-10	No. years included since 1997
1	Journal of Dental Research	186	3,707	20	20
2	Periodontology 2000	122	2,738	16	20
3	Journal of Clinical Periodontology	114	2,652	19	20
4	Dental Materials	101	2,557	17	20
5	Clinical Oral Implants Research	95	2,507	17	20
6	Critical Reviews in Oral Biology Med.	92	3,300	10	10
7	Oral Oncology	88	2,425	16	20
8	Journal of Endodontics	46	2,099	10	20
9	Clinical Implant Dentistry and Related Research	39	3,027	8	10
10	Journal of Periodontology	36	2,102	8	20

To compose the ranking list, points were assigned to each position in the top 10 impact factor dental journals as follows: position 1=10 points, 2=9 points, 3=8 points, 4=7 points, 5=6 points, 6=5 points, 7=4 points, 8=3 points, 9=2 points, 10=1 point. The sum of assigned points is found in column 3.

We identified the ten countries that produced the most publications to the multiple-year top-10 journals. Seven countries, USA, England, Germany, Italy, The Netherlands, Sweden, Switzerland were used for further analysis. As earlier research[71] has shown that the research portfolio of upcoming countries is different from those of the more established countries, Brazil and China, as the upcoming countries during the studied period, were excluded from analysis. Japan was excluded from analysis as earlier research this country shows very different changes in the research portfolio.[72]

ANNEX-C: IDENTIFYING LOCAL JOURNALS

Journals were classified as local when its title included a country or a continent. Journals including British, American, Australian or New Zealand in their journal titles are not exclusively local because they are published in the English language. Therefore, we calculated the correlation between the countries share in the *core-set* of dental journals and the countries share in journals that might be identified as local. If this correlation was less than 0.5 the journal was identified as local.

The table below shows the journals that according to that criterion would be classified as local. For each of these journals we calculated which country dominates the journal (and in some cases which two countries dominate the journal). The second column shows that country, and the percentage of papers in the journals that are have an author of that country. For example, in *Acta Odontologica Scandinavica*, Norway and Sweden are good for more than 40% of all papers, which is much more than would be expected based on the share of those countries in the total world production of dental research papers. This the case for all journals in the list. As a second check, we show the share of the US publications in the journals, the largest producer of dental research papers. In the local US journals, the share of the US is much higher than expected, whereas in all other local journals, the share of the US is much lower than expected. Overall this suggests that our definition of local/national journals seems to be correct.

Journal	% Dominant	% US
Acta Odontologica Scandinavica	30% (Swe), 13% (Norw)	7%
Australian Dental Journal	70% (Australia)	4%
Australian Endodontic Journal	23% (Brazil), 17% (Aus)	7%
Australian Orthodontic Journal	21% (Aus), 14% (Swe)	8%
Brazilian Oral Research	91% (Brasil)	4%
British Dental Journal	83% (UK)	3%
British Journal Of Oral Maxillofacial Surgery	51% (UK)	13%
European Journal Of Dental Education	27% (UK), 13% (NL)	4%
European Journal Of Oral Implantology	55% (It), 43% (Swe)	6%
European Journal Of Orthodontics	15% (UK), 11% (Turkey)	3%
European Journal Of Paediatric Dentistry	47% (Italy)	3%
Journal Of Orofacial Orthopedics Fortschritte Der Kieferorthopadie	87% (Germany)	83%
Journal Of The American Dental Association	83% (US)	14%
Journal Of The Canadian Dental Association	58% (Canada)	9%
Korean Journal Of Orthodontics	7% (Korea)	3%
Medicina Oral Patologia Oral Y Cirugia Bucal	53% (Spain)	90%
Oral And Maxillofacial Surgery Clinics Of North America	90% (US)	1%
Revue De Stomatologie De Chirurgie Maxillo Faciale Et De Chirurgie Orale	70% (France)	1%
Revue De Stomatologie Et De Chirurgie Maxillo Faciale	75% (France)	2%
Swedish Dental Journal	94% (Sweden)	

ANNEX-D: CLUSTERS OF JOURNALS IN THE FIELD OF DENTAL RESEARCH IN 2008

0 General dentistry	**3. Public health / general medicine**	**7. Biochemistry**
j dent	j public health-uk	j biol chem
am j dent	bmc public health	j cell physiol
eur j oral sci	brit med j	j mol histol
j dent res	public health	front biosci
j am dent assoc	cad saude publica	Fluoride
int dent j	cochrane db syst rev	cell tissue res
j can dent assoc	cienc saude coletiva	Carcinogenesis
brit dent j	health policy	biotechnol biotec eq
j dent sci	lancet	j physiol pharmacol
oral dis	arch intern med	**8 Orthodontics**
swed dent j	j altern complem med	am j orthod dentofac
1 Oncology	int j lang comm dis	aust orthod j
j cancer res clin	int j circumpol heal	eur j orthodont
oncol rep	croat med j	angle orthod
anticancer res	j eur acad dermatol	j orofac orthop
brit j cancer	**4 Implantology**	korean j orthod
hum cell	implantologie	orthod craniofac res
int j cancer	int j oral max impl	**9 Microbiology**
expert rev anticanc	clin oral implan res	adv appl microbiol
clin cancer res	implant dent	fems microbiol let
int j oncol	clin implant dent r	appl environ microb
cancer sci	iti treatment guide	can j microbiol
cancer	int j periodont rest	microbiol-sgm
j surg oncol	periodontol 2000	Anaerobe
cancer epidem biomar	int j med robot comp	bmc microbiol
oral oncol	**5. Community dentistry**	j bacterial
in vivo	aust dent j	**10 Oral surgery**
eur j cancer care	community dent oral	brit j oral max surg
j int med res	community dent hlth	j oral maxil surg
j cancer educ	int j paediatr dent	oral radiol
	j public health dent	med oral patol oral
2 Operative dentistry & materials	j dent educ	int j oral max surg
j adhes dent	j clin pediatr dent	oral surg oral med o
oper dent	eur j dent educ	rev stomatol chir
dent mater j	acta odontol scand	dentomaxillofac rad
dent mater	pediatr dent	j cranio maxill surg
j esthet restor dent	caries res	j oral pathol med
j appl oral sci	**6 Plastic surgery**	**11. Biomaterials**
quintessence int	plast reconstr surg	acta biomater
mater res-ibero-am j	j plast reconstr aes	j biomed mater res a
j prosthet dent	ann chir plast esth	j mater sci-mater m
int j prosthodont	clin plast surg	Biomaterials
clin oral invest	scand j plast recons	key eng mater
gerodontology	facial plast surg	j biomed mater res b
arch oral biol	j craniofac surg	
	acta cir bras	
	cleft palate-cran j	
	clin anat	

ANNEX D – CONTINUED

12 Clinical microbiology	**18 Neuroscience**	**26 Public health (USA)**
new microbiol	j neurophysiol	am j public health
j clin microbiol	j neurosci	health place
med mycol	neuroscience	public health rep
j med microbiol	exp brain res	**27 Genetics**
biomedica	clin neurophysiol	am j med genet a
clin infect dis	**19 Immunology**	eur j med genet
braz j microbiol	infect immun	birth defects res a
antimicrob agents ch	microb pathogenesis	**28 Chemistry**
curr hiv res	fems immunol med mic	p soc photo-opt ins
13 Pain	oral microbiol immun	j phys chem b
eur j pain	j immunol	chem rev
j pain	**20 General medicine**	j phys d appl phys
clin j pain	clinics	j appl polym sci
pain	new engl j med	**29 Geriatrics**
j musculoskelet pain	expert opin pharmaco	j am geriatr soc
j orofac pain	**21 Anatomy**	j gerontol nurs
14 Otorhinolaryngology	j hum evol	**30 Quality of life**
eur arch oto-rhino-l	j anat	qual life res
laryngoscope	homo	health qual life out
arch otolaryngol	anat rec	**31 Forensic science**
int j pediatr otorhi	anthropol sci	forensic sci int
curr opin otolaryngo	integr comp biol	j forensic sci
head neck-j sci spec	j archaeol sci	**32 Radiation**
hno	**22 TMD**	radiat prot dosim
15 Endodontology	cranio	health phys
aust endod j	j oral rehabil	rofo-fortschr rontg
j endodont	appl psychophys biof	**33 Antropology**
int endod j	**23 Kinesiology**	collegium antropol
16 Periodontology	spine	**34 Medical devices**
j clin periodontol	eur spine j	expert rev med devic
j periodontol	**24 Biomechanics**	
j periodontal res	rev bras fisioter	
odontology	j electromyogr kines	
17 Pediatrics	j biomech	
pediatrics	ann biomed eng	
acta paediatr	int j sports med	
pediatr emerg care	bone	
dev disabil res rev	**25 Laser**	
pediatr pulm	laser surg med	
j pediatr surg	photomed laser surg	
pediatr anesth	laser med sci	
	j biomed opt	

ANNEX-E: COMPARING THE CLUSTER STRUCTURE OVER THE THREE YEARS

		2000	2008	2015
Dental research	General Dentistry	x	x	x
	Operative Dentistry / Dental Materials		x	x
	Oral rehabilitation	x		
	Endodontics	x	x	x
	Implantology	x	x	x
	Oral and Maxillofacial surgery	x	x	x
	Community dentistry	x	x	x
	Dental education			x
	Oral oncology			x
	TMD		x	x
	Orthodontics	x	x	x
	Periodontology	x	x	x
Public health	Public health (USA)		x	x
	Public health/General medicine		x	
	Quality of life research		x	x
Clinical medicine	General medicine	x	x	x
	Clinical microbiology	x	x	x
	Oncology	x	x	x
	Dermatology	x		x
	Pediatrics		x	x
	Neurosurgery	x		
	Plastic surgery	x	x	x
	Ophthalmology	x		
	Orthopedics	x		
	Geriatrics		x	
	Otorhinolaryngology	x	x	x
Basic science	Neurosciences		x	
	Virology	x		in interdisciplinary
	Microbiology		X	x
	Immunology	x	X	x
	Anatomy	x	X	scattered
	Biochemistry	x	X	x
	Chemistry		X	
	Biomaterials	x	X	x
	Material sciences	x		x
	Bone	x	Incl. biomechanics	x

ANNEX-E: COMPARING THE CLUSTER STRUCTURE OVER THE THREE YEARS (*CONTINUED*)

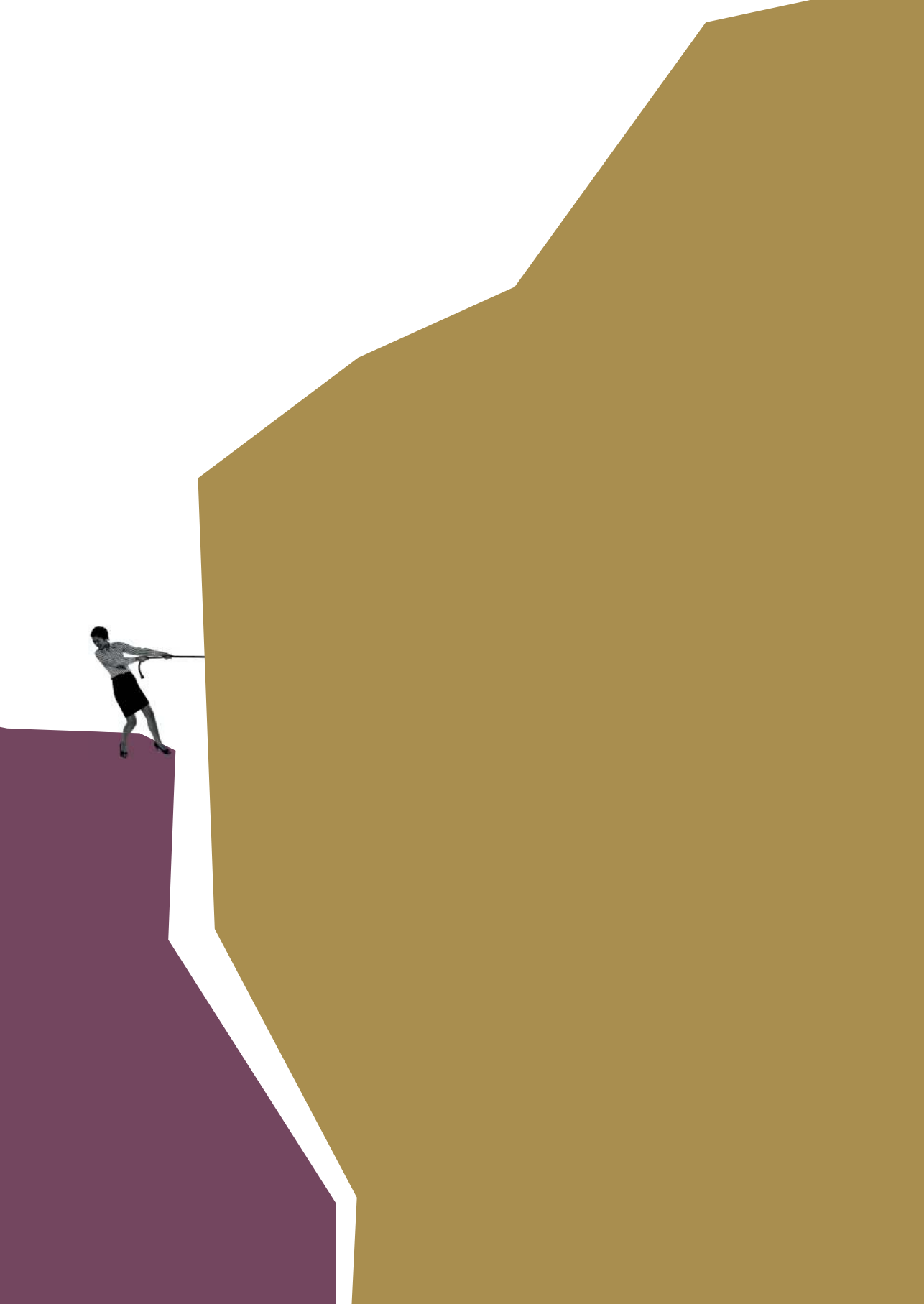
		2000	2008	2015
	Kinesiology		X	
	Genetics	x	X	x
	Anthropology	x	One journal	x
	Pain	x	X	
	Pathology	x		
	Speech	x		x
	Stem Cell transplantation	x		
	Develop biology			x
	Interdisciplinary			x
Other	Laser	x	X	x
	Forensics		X	x
	Radiology	x	X	
	Medical devices		One journal	x

ANNEX-F: DISTRIBUTION OF DENTAL RESEARCH INSTITUTES OUTPUT OVER WOS CATEGORIES

Discipline	Change*	Average share 98-00	Average share 14-15	Category**
Biomaterials / materials	up	4,8%	5,5%	b
Multidisciplinary sciences	up	1,2%	4,9%	o
Biochemistry molecular biology	up	3,2%	3,9%	b
Cell biology	up	2,6%	3,7%	b
Genetics heredity	up	2,1%	3,3%	b
Medicine research experimental	up	0,6%	3,0%	b
Clinical neurology	up	1,1%	2,7%	c
Medicine general internal	up	1,3%	2,6%	c
Endocrinology metabolism	up	1,6%	2,4%	b
Public environmental occupational health	up	2,0%	2,3%	p
Chemistry	up	0,9%	1,6%	b
Pediatrics	up	1,2%	1,5%	c
Health care / policy sciences	up	0,4%	1,4%	p
Surgery	equal	7,6%	7,8%	c
Engineering biomedical, tissue, ect	equal	7,1%	7,5%	b
Neurosciences	equal	2,7%	2,9%	b
Otorhinolaryngology	equal	1,2%	1,4%	c
Biochemical research methods	equal	0,7%	0,7%	b
Dentistry oral surgery medicine	down	60,5%	42,6%	d
Oncology	down	4,3%	3,1%	c
Immunology	down	3,1%	2,4%	b
Microbiology	down	2,5%	2,2%	b
Pharmacology pharmacy	down	2,1%	1,7%	o
Radiology nuclear medicine medical imaging	down	1,5%	1,3%	o
Pathology	down	1,8%	0,9%	c
Anatomy morphology	down	1,1%	0,4%	b

* change is based on the change in average share. Changes lower than 10% are considered as 'equal'.

** b= basic research, c= clinical research, d= dental research, o= other, p= public health & policy



Chapter 3

Financing and costs of oral health care

Original title: Kosten en financiering van de mondzorg

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Nederlands Tijdschrift voor Tandheelkunde 2019; 126: 335-340

ABSTRACT

In the Netherlands, oral disorders rank third based on health care expenditures. This ranking is based on macro data and does not provide insight in the content of the oral health care provided. Claims data give more insight in the content oral health care, but due to limitations in reimbursement of oral health care these data represent only a part of the expenditures in oral health care. In this study an estimation of oral health care costs on a more detailed level is made. This estimation includes expenditures that are self-paid, based on the ratio between claims data from insurances and data from a large invoicing company for the years 2011, 2013 and 2014. Based on this estimation can be concluded that between 21% and 32% concern out-of-pocket expenditures in oral health care. Moreover, the structure of the current financial system of oral health care in the Netherlands impedes transparency on consumed oral health care.

INTRODUCTION

Oral health care accounts for a large share of the Dutch health care system, both in volume and costs. Approximately 80% of the Dutch population visits a dentist at least once a year.[73] In 2011, 4% of the total costs of health care (3.6 billion out of 89.4 billion euro) could be attributed to health care for oral disorders, according to the Dutch Institute for Public Health and Environment.[74] When ranked by health care costs, oral disorders ranked in third place, after intellectual disabilities and dementia. For the age groups 0 to 15-year-olds and 15- to 65-year-olds the costs of oral disorders ranked second (after intellectual disabilities) and for the population of 65 years and older oral disorders ranked tenth. Worldwide, oral diseases, particularly untreated caries, are identified as some of the most prevalent disorders.[75] Next to untreated caries, edentulousness and periodontitis affect billions of people, and the costs of oral health care (direct and indirect) result in a high economic burden.[76,77]

Insight in how the expenditures of oral health care are distributed among different areas of oral health care informs OHPs and policy makers which areas to focus on when optimizing the effectiveness of oral health care for individuals and the population.

In this study, we provide insight into the distribution of expenditures of oral health care. In addition, we will discuss how the current financing system provides only limited insight into the costs of oral health care.

Financing of oral health care

For a large part of the population the costs of oral health care are self-paid. This hampers the determination of the total expenditures of oral health care, and their distribution among different areas of oral health care. We will first briefly describe the financing system for oral health care in the Netherlands.

Purchasing basic health care insurance is compulsory for all individuals living or working in the Netherlands. The health insurance for adults is paid for 50% by a community-rated premium and the other 50% via an income-dependent premium. For children up to the age of 18 the health insurance is covered through a government contribution from taxes. Under the Health care Insurance Act, insurance companies have to accept every individual for the standard basic health care insurance benefits package. As a result, 99.7% of the Dutch population is insured for health care. Rare exceptions are, for example, individuals who refuse insurance on religious grounds.

The standard basic health care insurance benefits package covers oral healthcare for up to the age of 18, and for adults in some instances. In 2014, 20.5% (3.5 out of 17.2 million persons) of the total population was under 18 years of age and therefore eligible for oral health care under the national health care insurance. In addition, complete dentures (on dental implants if necessary) are reimbursed for a substantial part. Oral surgery

treatments are fully reimbursed under the basic health care insurance and individual entitlement of reimbursements for special needs dentistry is possible.
The expenditures of oral health care that are not reimbursed under the basic health care insurance are self-paid. These can be paid out-of-pocket or via voluntary additional insurance for oral health care. A variety of voluntary additional oral health care insurances is available. As managed competition between insurance companies is allowed, the coverage of the costs of oral health care varies per company, while the reimbursement of the costs of oral health care is limited. As a consequence, a substantial part of oral health care is self-paid. When purchasing a voluntary additional oral health care insurance, it is often unknown which care will be needed when. This complicates the choice for the most suitable additional insurance.
Oral health care for people in an institution is mainly covered through the Long-term Sickness Benefits Act (WLZ). Since 2015, the WLZ has replaced the Exceptional Medical Expenses Act (AWBZ).

INSIGHT INTO THE COSTS OF ORAL HEALTH CARE: AN ESTIMATION

A national database that comprises all oral health care data, notably on compulsory basic and voluntary additional insurance and out-of-pocket payments, is not available. Statistics Netherlands (CBS) estimated that the turnover by dental practices in 2010 amounted to approximately € 2.6 billion. Adding the turnover from dental hygienists, dental technicians and oral health care in institutions (special needs dentistry, pediatric dental health care centers) the total expenditures for all primary oral health care is amounted over € 3.1 billion. The total expenditures for oral health care are over € 3.4 billion when the costs of oral health care by oral surgeons and orthodontists is added. RIVM estimated the total costs for oral disorders in 2011 to be about € 3.6 billion.

These macro data are based on data from the tax authorities and only provide insight in the total expenditures of oral health care. There is no publicly available information on how the expenditures are distributed over different areas of oral health care. Claims data do provide this information, but these do not comprehensively cover all the expenditures of oral health care. Hence, in this study we estimate the out-of-pocket expenses; the part that is not included in the claims data. In addition, we estimate the expenditures distributed over different domains of oral health care. For this, we used a number of sources, which we will briefly describe below.

Vektis database

Vektis is the organization that administers data from health care insurers. Vektis collects, manages and analyses data on health care claims and reimbursement by insurance companies. The Vektis database covers 98% of all claims for oral health care under the standard basic health care insurance benefits package. Additionally, it covers a part of the claims for oral health care under the voluntary additional oral health care insurance. According to Vektis 88% (14.8 out of 16.9 million) of the population had an additional insurance for oral health care in 2011. In subsequent years, this percentage decreased slightly to 85% (14.6 out of 17.2 million people) in 2014.

Data on the expenditures of oral health care in the Vektis database are not complete, but it is unknown which proportion of the total oral health care costs is covered in the Vektis database. There are a number of explanations why not all oral health care cost data are included in the Vektis database. Firstly, costs of oral health care which are paid out-of-pocket are not included. Secondly, costs of oral health care that are excluded from the voluntary additional oral health care insurance, are not included in the Vektis database. Thirdly, when the maximum reimbursement of the voluntary additional oral health care insurance is reached, there is no entitlement to reimbursement of a subsequent invoice, and it should be paid directly by the insured. There are however no uniform procedures how insurance companies handle these invoices. If such invoices are submitted as a claim with the insurance company, it is unclear whether and which part of these are included in the database.

For this study all oral health care claims from the Vektis database for the years 2011, 2013 and 2014 were requested. These are all claims submitted to an insurance company, regardless of reimbursement. As a temporary claim system reform for oral health care applied to 2012, we excluded this year from our analysis.

Treatment fees in Dutch oral health care system are based on UPT codes. These UPT codes and their fees are determined by the National Health Authority. For our analysis, data from the Vektis database that were clustered at the level of UPT code were available. The UPT codes are categorized in areas of oral health care, for example fillings, preventative treatments or dentures. The clustered data were split into age categories (0-17, 18-45, 46-65 and 65+ years). For the age category up to 18 years of age, the Vektis database contains 100% of the expenditures for oral health care since reimbursement for this age category is covered by the national health care insurance.

Famed database

Famed is a company specialized in the administration, invoicing and collection of claims in health care. It is one of the largest invoicing companies for oral health care in the Netherlands and handles the acquisition of claims of costs for oral health care clinics.

All oral health care data from the Famed database for the years 2011, 2013 and 2014 were included in the current study. Similar to the Vektis data, the Famed data were clustered at the level of UPT code and could be split into age categories (0-17, 18-45, 46-65 and 65+ years).
The clients of Famed are oral health care clinics. The Famed database covers all of their invoiced oral health care. It includes all expenditures for oral health care provided under the standard basic health care insurance benefits package and voluntary additional oral health care insurance. These data provide insight into oral health care that is self-paid, and so includes the part that is not comprehensively covered by the Vektis database.

CAK

The CAK manages oral health care expenditures claimed under the Exceptional Medical Expenses Act (the AWBZ), the predecessor of the current Long-term Health care Act (Wlz). The entitlement to oral health care under the AWBZ applies to people in an institution. All costs for oral health care (e.g. costs for dental assistance and equipment) are included in the budget of the institution, except for the fee of the oral health care provider and dental technician costs. These costs are invoiced to the CAK by the oral health care provider. Costs for technique and fees for oral health care provided under the AWBZ for the years 2011, 2013 and 2014 have been obtained via the CAK.

The data from Vektis, Famed and CAK could not be traced back to individuals (patients or OHPs).

Estimating total oral health care costs - method

To estimate the costs of oral health care not covered under the standard basic health care insurance benefits package, we used the ratio between data in the Vektis and Famed database for the age category under 18. Since the Vektis data for this age category is considered complete, the ratio between Vektis and Famed data could be used for extrapolating the proportion of the costs for oral health care that remain as not covered.
For 2014, the Famed database contains invoiced oral health care costs of M€211 in the age group under 18 years. That is 33% of the M€645 claims data for the age group under 18 in the Vektis database of 2014. The Famed database contains in 2011, 2013 and 2014 respectively 28%, 30% and 33% of the Vektis claims for oral health care for the age group under 18 years. We use the ratios to estimate the oral health care expenditures for persons aged 18 or older for 14 UPT categories. For these 14 UPT categories, we multiplied the oral health care expenditures for oral health care provided for persons aged 18 or older from the Famed database for 2011, 2013 and 2014 with respectively 3.57 (1/0.28), 3.33 (1/0.30) and 3.03 (1/0.33). The 14 UPT categories can be found in figures 1 to 5. The U (hourly rate) category and the category for special needs groups are reimbursed

almost entirely through the standard basic health care insurance package. We therefore considered the Vektis data for these clusters complete.
Then, the total expenditures of oral health care were calculated by adding all claims for persons under the age of 18 from the Vektis database (reimbursed under the standard basic health care insurance benefits package) to the estimated oral health care expenditures for persons aged 18 and over. Subsequently, the claims for oral surgery, claims filed under hourly rate (U-category), oral health care for special need groups and oral health care filed under AWBZ for all age categories were added.

RESULTS

Table 3.1 below displays the result of the estimated total expenditures in oral health care. For 2011 the estimated total expenditures in oral health care was a total of M€ 3.023, for 2013 M€ 3.494 and for 2014 M€ 3.499. The percentage of expenditures not filed under the standard basic health care insurance varies between 21% and 32%. Therefore, the Vektis database contains between 68% and 79% of the total expenditures of oral health care. Figures 3.1 to 3.5 show how the costs are distributed over 14 UPT clusters. A distinction between the persons over 18 years of age and up to 18 years of age was made. In appendix 1 the data as shown in figures 3.1 to 3.5 are presented.

Table 3.1: Estimation of total expenditures in oral health care for the years 2011, 2013 and 2014

Expressed in millions of euros	2011	2013	2014
Estimated expenditures for oral health care 18+	2.213,5	2.620,8	2.622,4
0-17 VEKTIS claims data	517,9	579,0	633,7
Oral surgery	250,7	231,4	172,3
U (hourly rate)	3,5	3,3	3,7
Special needs groups	19,2	35,0	37,9
AWBZ	18,8	24,8	29,1
Total	**3.023,6**	**3.494,3**	**3.499,1**

Dental treatments from the UPT category V (fillings) accounted for 20% of oral health care costs. The categories for fillings, consultation, and prevention accounted for over 40% of oral health care costs. Costs attributed to the UPT category M (prevention) ranged from 11% in 2011 to 14% of the total in 2014. The Vektis data included relatively few claims from the UPT categories F (orthodontics), R (fixed prosthetics), G (TMD) and B (sedation), respectively 46%, 63%, 67% and 32% in 2014. The R-cluster (fixed prosthetics) is consistently the fourth largest cluster, although its share of the total costs is decreasing.

The costs for the UPT categories orthodontics, fixed prosthetics, TMD and sedation mainly concern out-of-pocket expenditures. As the insurance coverage for these UPT categories is limited, their estimated expenditures are the least accurate.

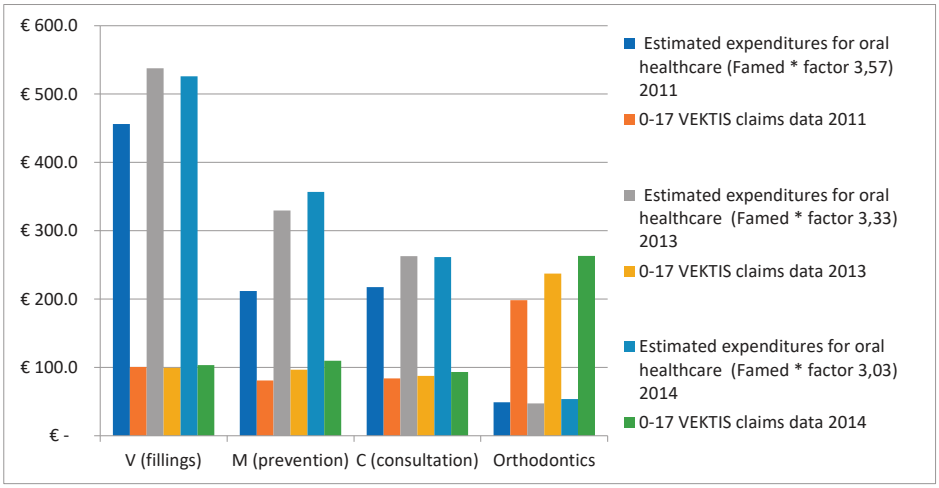

Figure 3.1: Expenditures in oral health care for UPT categories V, M, C and F*, expressed in millions of euros

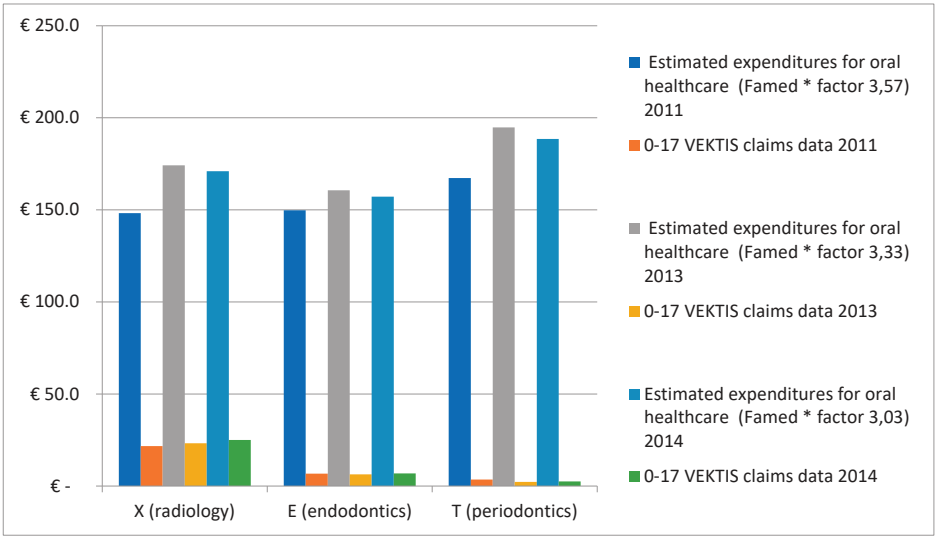

Figure 3.2: Expenditures in oral health care for UPT categories X, E and T*, expressed in millions of euros

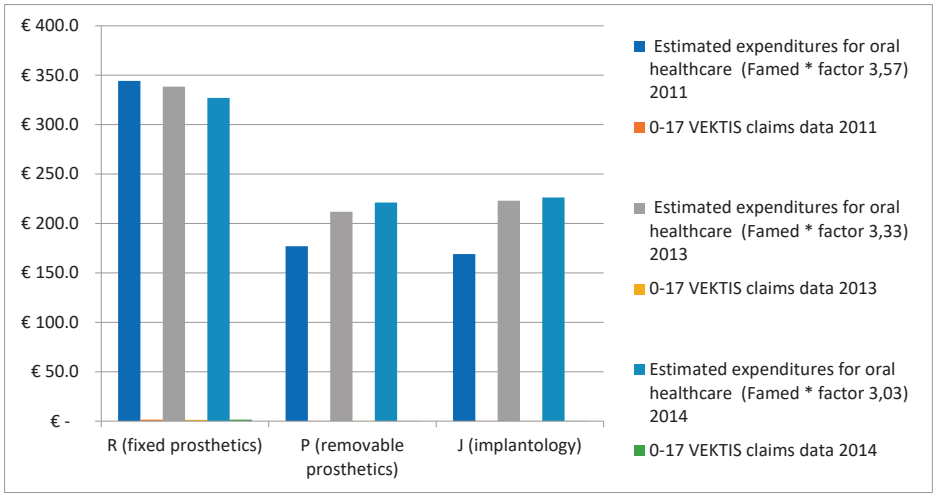

Figure 3.3: Expenditures in oral health care for UPT categories R, P and J*, expressed in millions of euros

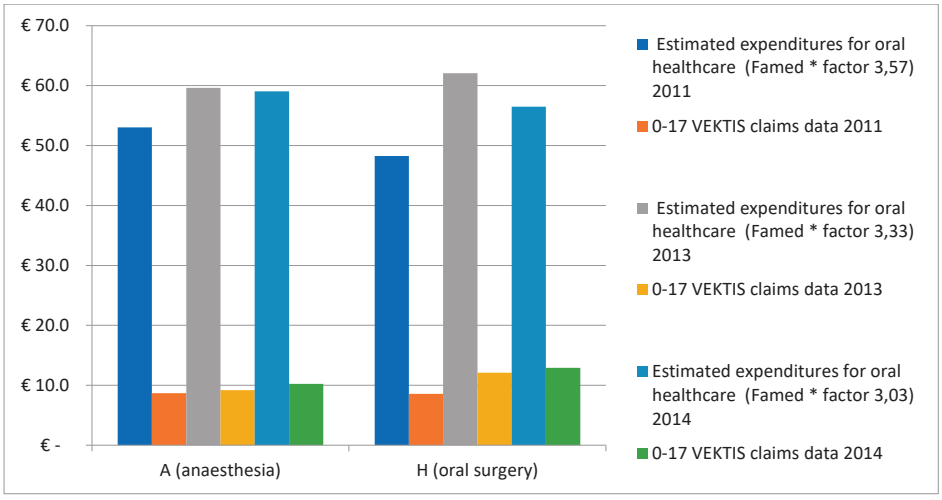

Figure 3.4: Expenditures in oral health care for UPT categories A and H*, expressed in millions of euros

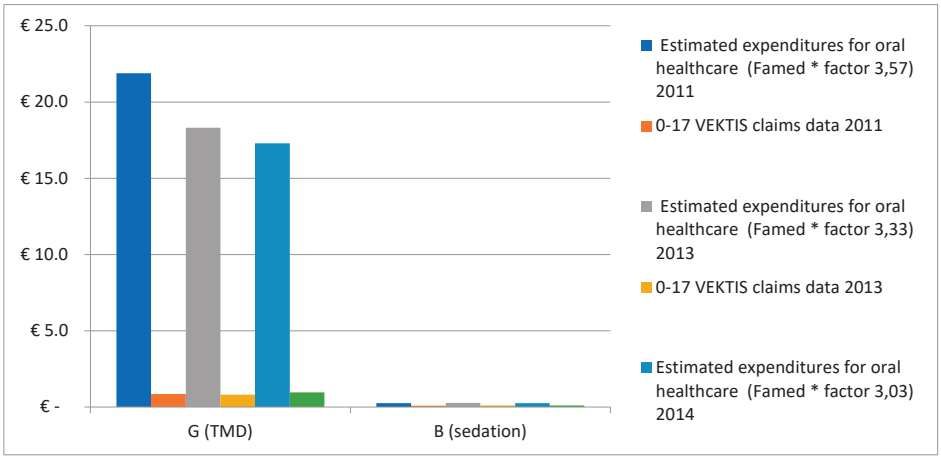

Figure 3.5: Expenditures in oral health care for UPT categories G and B*, expressed in millions of euros

CONCLUSIONS AND DISCUSSION

This study describes how the data from an invoicing company were used to estimate the costs of oral health care in the Netherlands. The described method of combining data from Famed and Vektis is innovative. Until now, estimations of the total costs of oral health care were based on data from CBS and the tax authorities, or out-of-pocket expenditures were not included in calculations. To our knowledge, this study is the first to describe the expenditures of oral health care at the level of UPT categories. For policymakers and OHPs, this may provide new insights.

Our analysis shows that the current financial system is complex. Comprehensive accurate data sources which provide more accurate estimates for the total expenditures are currently lacking. This impedes transparency on the content of the oral health care provided. Despite the combined data sources, it remains difficult to make accurate estimates of the content and costs of oral health care. The Famed database for the age group under 18 comprises approximately one-third of the claims of oral health care for the age group under 18 (based on the Vektis database). This ratio was used for extrapolation to estimate oral health care expenditure for 18 years and up. Based upon this finding we estimate that between 21% and 32% of the total costs of oral health care concern out-of-pocket expenditures. However, it is unclear whether the oral health care practices affiliated with Famed are a fair representation of oral health care practices in the Netherlands. Therefore, the presented estimated expenditures of oral health care per UPT category, to some extent, remain uncertain.

The various policy documents use the same source for reporting oral health care expenditures which is CBS macro data.[34,74] CBS uses data from the tax authorities to estimate oral health care consumption. For the period 2010-2013, CBS reported more detailed data on oral health care which is based on the CBS health survey using a sample of 15,000 people. These concern self-reported oral health care data on the frequency and reason of dental visits, but still provides limited information on the content of oral health care. The Royal Dutch Dentist Association (KNMT) reported data on volumes and expenditures of oral health care.[78] In addition to the data from Vektis and CBS, the KNMT uses claims data from a sample of dental practices. However, data from this sample reflect only a small part of the oral health care data used in our study from Vektis and Famed.

Obviously, the estimates in this study do not represent data on the incidence, prevalence or severity of oral diseases among the Dutch population or the oral health care provided. Moreover, the presented data cannot be used to analyze the effectiveness or outcomes of oral health care. Furthermore, the data used in our study are from a three-year period. These data do not allow identification of patterns in the content or expenditures of oral health care or trends or shifts thereof resulting from policy measures (e.g. changes in financing structure).
Insight in the expenditures of oral health care is important for policymaking as this provides a firm basis for determining the contribution of oral health care to the health of the Dutch population. In order to make a comprehensive assessment of the balance between the costs of oral health care and its contribution to the health of the Dutch population, a systematic and continuous monitoring system is required. Such monitoring provides a framework for evaluating policy changes and the efficacy of oral health care.[34,79]

APPENDIX 1 DISTRIBUTION OF ORAL HEALTH CARE EXPENDITURES OVER UPT CLUSTERS

Expressed in millions of euros	2011			2013			2014	
UPT category	Estimated oral health care expenditures (Famed * factor 3.57)	Claims data for age group <18 Vektis	Estimated oral health care expenditures + Claims data for age group <18 (% of total declarations)	Estimated oral health care expenditures (Famed * factor 3.33)	Claims data for age group <18 Vektis	Estimated oral health care expenditures + Claims data for age group <18 (% of total declarations)	Estimated oral health care expenditures (Famed * factor 3.03)	Claims data for age group <18 Vektis	Estimated oral health care expenditures + Claims data for age group <18 (% of total declarations)
V (fillings)	456,2	100,5	**556,7 (20,4)**	537,6	99,3	**636,9 (19,9)**	526,0	103,3	**629,4 (19,3)**
C (consultation)	217,4	84,1	**301,5 (11,0)**	262,9	87,5	**350,4 (11,0)**	261,5	93,3	**354,8 (10,9)**
M (prevention)	211,9	81,0	**292,9 (10,7)**	329,7	96,7	**426,3 (13,3)**	356,9	109,6	**466,5 (14,3)**
R (fixed prosthetics)	344,3	1,4	**345,7 (12,7)**	338,5	1,4	**339,8 (10,6)**	327,0	1,5	**328,5 (10,1)**
P (removable prosthetics)	176,9	0,1	**177,1 (6,5)**	212,0	0,1	**212,1 (6,6)**	221,1	0,1	**221,2 (6,8)**
F (orthodontics)	49,1	198,2	**247,3 (9,1)**	47,2	237,2	**284,4 (8,9)**	53,9	263,3	**317,1 (9,8)**
J (implantology)	169,0	0,2	**169,3 (6,2)**	223,0	0,2	**223,2 (7,0)**	226,3	0,2	**226,5 (7,0)**
X (radiology)	148,2	21,6	**169,9 (6,2)**	174,2	23,3	**197,5 (6,2)**	171,0	25,1	**196,1 (6,0)**
E (endodontics)	149,8	6,8	**156,6 (5,7)**	160,7	6,4	**167,0 (5,2)**	157,2	6,9	**164,1 (5,0)**
T (periodontics)	167,3	3,5	**170,9 (6,3)**	194,7	2,2	**197,0 (6,2)**	188,5	2,5	**191,0 (5,9)**
A (anaesthesia)	53,0	8,7	**61,7 (2,3)**	59,6	9,2	**68,8 (2,2)**	59,0	10,2	**69,3 (2,1)**
H (oral surgery)	48,2	8,6	**56,8 (2,1)**	62,1	12,1	**74,2 (2,3)**	56,5	12,9	**69,4 (2,1)**
G (TMD)	21,9	0,9	**22,7 (0,8)**	18,3	0,8	**19,1 (0,6)**	17,3	1,0	**18,2 (0,6)**
B (sedation)	0,3	0,1	**0,4 (0,01)**	0,3	0,1	**0,4 (0,01)**	0,3	0,1	**0,4 (0,01)**
Total	**2.213,5**	**515,8**	**2.729,4 (100)**	**2.620,8**	**576,4**	**3.197,2 (100)**	**2.622,4**	**630,2**	**3.252,5 (100)**

Chapter 4

Publications in the Dutch Journal of Dentistry - an analysis for the period 2000 - 2018

Original title: De inhoud van publicaties in het Nederlands Tijdschrift voor Tandheelkunde. Een patroonanalyse over de tijd.

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Hagay Shemesh
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Nederlands Tijdschrift voor Tandheelkunde 2019; 126: 91-100.

ABSTRACT

In 2018 the Dutch Journal of Dentistry (NTvT) celebrated its 125th anniversary. Publications in NTvT since 2000 were systematically mapped to determine the research topics addressed. These research topics were compared with dental publications written by authors with a Dutch affiliation in the international literature and with expenditures in subfields of oral health care. This analysis showed that the number of publications covering topics such as *social dentistry* topics has increased during the evaluated 18-year period, while other topics (e.g. basic science topics) received less attention in NTvT. For some dental subfields a large share of publications was published in international journals, compared to the share of publications in NTvT. In addition, there appeared to be a limited correlation between subfields with the highest share of oral health care expenditures (e.g. cariology and prevention) and the share of publications in these subfields. This applied to both Dutch and international publications.

INTRODUCTION†

The Netherlands is among the ten best performing countries in oral health research, both measured in numbers of publications and in terms of scientific impact.‡ However, access to knowledge from these publications is limited for Dutch oral health care practitioners (OHPs) for a number of reasons. First, many journals charge a high fee, for individuals not related to an academic institution. Second, scientific publications are not always easy to read or interpret for the clinician. Third, reading a few publications is not enough to get acquainted with research, while health care professionals lack time to digest large volumes of publications.[24]

Journals like the Dutch Journal of Dentistry (*Nederlands Tijdschrift voor Tandheelkunde (NTvT)* are regarded as media that disseminate knowledge from oral health research to OHPs. NTvT is one of the few journals focused on the Dutch and Belgian oral health care field. With a circulation of almost 5,000 copies in the year 2019, it informs a substantial part of OHPs about scientific knowledge in the field of oral health care.

The readers of publications in NTvT are mostly Dutch and Belgian OHPs. The role of local journals, like NTvT, is not only to distribute scientific knowledge from international research to the local field, but also to disseminate application-oriented knowledge.[50,51]

On the occasion of 125th anniversary of NTvT, we systematically mapped topics that NTvT addressed over the past 18 years through a network analysis. This provides insight into the research subfields that are emphasized within oral health research in the Netherlands. In addition, we aimed to determine changes over time in the distribution of research topics over subfields of oral health research. This analysis of changes within the field of oral health research allows for reflection on future developments in the field of oral health (care).

We discuss the content of NTvT from two angles, restricted to oral health research originating from the Netherlands. Firstly, we determined to what extent the content of NTvT represents international publications from authors with a Dutch affiliation. Secondly, we compare the content of NTvT with the demand for oral health care as expressed in terms of costs of oral health care provided, to determine if the areas of oral health care are represented in publications in NTvT reflect the pattern in oral health care expen-

† The authors thank Prof. Dr. M.A.J. Eijkman and Dr. M.D. Lagerweij for their help in interpreting the findings. The editors of NTvT provided the data.

‡ Using bibliometric indicators linked to these publications (R. Cartes-Velásquez and C. Manterola Delgado, 2014; Y. Gingras, 2016).[80,81]

ditures. A recent article in the Dutch Journal of Medicine (Nederlands Tijdschrift voor Geneeskunde NTVG) related the shares of Dutch publications in different biomedical research fields to the shares of expenditures for various fields of health care.[82] From their analysis can be concluded that intellectual disability, dementia and oral diseases account for large proportion of the health care costs, but relatively little research is conducted in these fields (Figure 4.1). In this study we perform a similar analysis for oral health research.

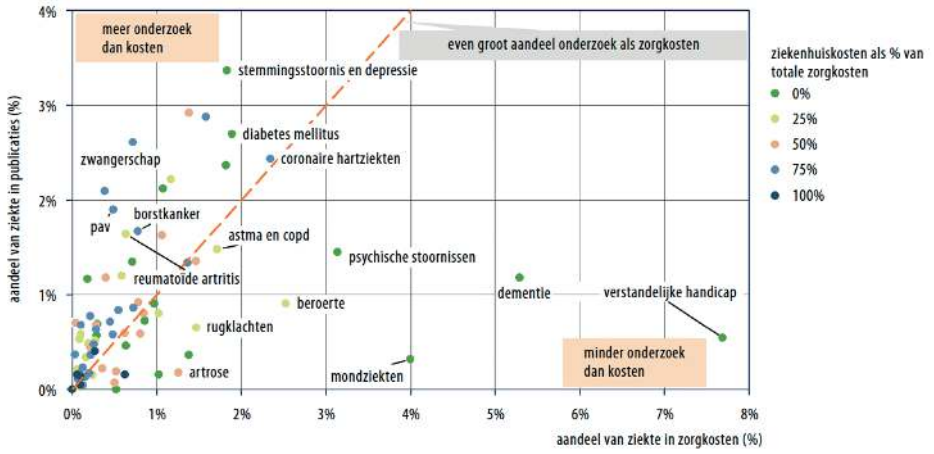


Figure 4.1
Specific diseases and conditions as the topic of scientific publications from the Netherlands, related to the health care expenditures that these conditions accounted for in 2011. The health care expenditures are based on the RIVM report *Kosten van ziekten* (Costs of Diseases). The share of specific diseases and disorders in publications was calculated as the percentage of publications on a specific disease out of the total of all disease-specific publications from the Netherlands in 2012 in Web of Science (taken from T.M. de Kruif et al 2017 with permission).

MATERIAL & METHODS

Mapping the publications of NTvT

For this study we used publications (in PDF format) published in NTvT for the period 2000-2017. A total of 1,439 publications were analyzed, and the numbers per year varied between approximately 60 and 100 publications. The following procedure was used to perform network analysis on the research topics.

The publications were divided into six overlapping four-year periods: 2000-2003; 2003-2006; 2006-2009; 2009-2012; 2012-2015; 2015-2018. We used periods of four years to ensure that topics were represented by a sufficient number of publications. The overlap of periods was used to prevent distortion, for example, because a small cluster of publi-

cations is split up into two even smaller cluster (and is therefore excluded from analysis) due to yearly cut offs.

All PDF files were converted into text (TXT) files. All the words in the publications were extracted and listed using the program CorTexT. From this list, all terms that are relevant for dentistry and oral health care - research and practice - were selected independently by two of the authors (PW and PB). The results were compared, discrepancies were discussed and resolved, and the final list was achieved. All publications were indexed based on the terms on this list.

For each of the six periods, the terms listed were clustered using co-word analysis.[83,84] This analysis is based on the principle that publications cover one or more topics, and that topics are characterized by a set of terms. If terms often occur together in publications it is likely they are used to describe a certain topic. A set of publications that contain the same terms are called a cluster. This cluster of publications represents a dental research topic. This co-word analysis for clustering was done with the program CorTexT.

For each of the six periods a clustering map has been made in which clusters are shown as a circle, each with a different color. The size of the cluster in each map indicates how many publications were included in the cluster. Each triangle within a cluster represents a term, and the larger the triangle is, the more often the term appears in the set of publications.

Finally, the clustering was examined by three experts. They determined the topic of each cluster by its set of terms. Based on their topics, the clusters were then categorized in dental subfields. Clusters with only one or two terms were ignored.

For example, on the map 2006-2009 there is a cluster (no. 15 in Figure 4.2) consisting of the following terms: bisphosphonates, osteonecrosis, necrosis, face, swelling. This cluster has been identified as the topic ‘bisphosphonates and osteonecrosis’ and has been categorized in the subfield ‘Oral Medicine’.

Comparing publications in NTvT and international journals

For this analysis we used the clusters of the NTvT publications categorized into dental subfields. For each dental subfield we calculated the share of publications in that subfield as a percentage of all publications in NTvT. We compared the distribution of publications in NTvT with the distribution in international journals written by authors with a Dutch affiliation over dental subfields. For the international publications, we limited the analysis to publications (referred to as ‘article’, ‘review’ or ‘proceedings paper’) included

in the Web of Science (WoS) category *Dentistry, Oral Surgery & Medicine*. We categorized the journals in WoS, based on journal titles into dental subfields. All international publications were distributed over the dental subfields, except publications that were published in general dental journals, as these cover multiple dental subfields. For each dental subfield we calculated the share of publications in that subfield as a percentage of all publications in WoS category *Dentistry, Oral Surgery & Medicine.*

The costs of oral health care and NTvT publications

We compared research topics covered in publications in NTvT with expenditures in oral health care. We used claims data in the Netherlands from 2014 for oral health care from VEKTIS. VEKTIS is the organization that administers data from health care insurers. Claims data are classified according to dental subfields as represented in UPT categories. The UPT categories are clusters of treatment codes, and each code represents a treatment fee. These codes and UPT categories are established by the Dutch Health care Authority (NZA). We matched the UPT categories to dental subfields by which NTvT publications were classified. Only disease specific subfields or dental subfields that focus on specific treatment for which an UPT category exists were included. This excluded analysis of, for example, topics covering social dentistry, or research subfields that focus on a certain patient group (e.g. children). Also, UPT categories C (consult) and A (anesthesia) were not included in this analysis, since these categories were so generic it was not possible to match these with a specific research subfield. In addition to the claims data from VEKTIS, the costs of oral health care filed under the Exceptional Medical Expenses Act (AWBZ) were included in the analysis. In table 4.2 these data are presented.

RESULTS

In figures 4.2 and 4.3 the maps of clusters of NTvT publications are presented for respectively the period 2006 up to 2009 and the period 2012 up to 2015. Comparison of the maps shows over-time changes in topics. Compared to the map for 2006 up to 2009, the map for 2012 up to 2015 displays relatively few clusters covering topics on *prosthetic dentistry* or topics on *Temporomandibular Disease (TMD)*, while clusters covering topics on *sedation* and *quality policy and continuing education* emerge. In the period 2012-2015 almost one third of clusters cover a medical topic, as the number of clusters in the domain of *Oral, Maxillofacial and Facial Surgery (OMFS)* and *Oral Medicine* double from 4 to 8 clusters.

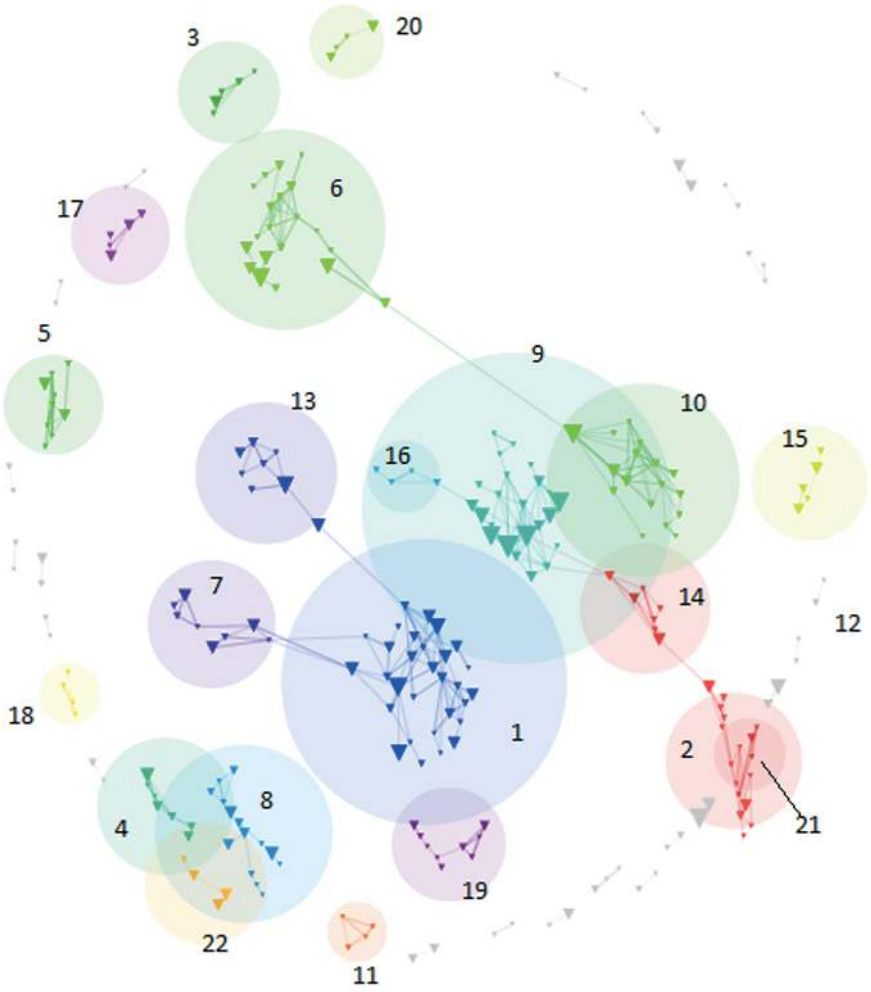


Figure 4.2: Map of NTvT publications 2006-2009
1: Orthodontics; 2: Prevention in vulnerable populations; 3: Nutrition and erosion; 4: Dental anxiety and treatment; 5: Gnathology; 6: Facial pain; 7: Removable prosthetics; 8: Periodontology and medical conditions; 9: Laws and regulations; 10: Head and neck oncology; 11: Endodontic surgery; 12: Dental materials; 13: Orthognatic Surgery; 14: Health care system and Education; 15: Bisphosphonates and Osteonecrosis; 16: Oral health care for disabled; 17: Removable dentures II; 18: Implantology; 19; Various OMFS; 20: Lifestyle Interventions; 21: TMD; 22: Basic Science.

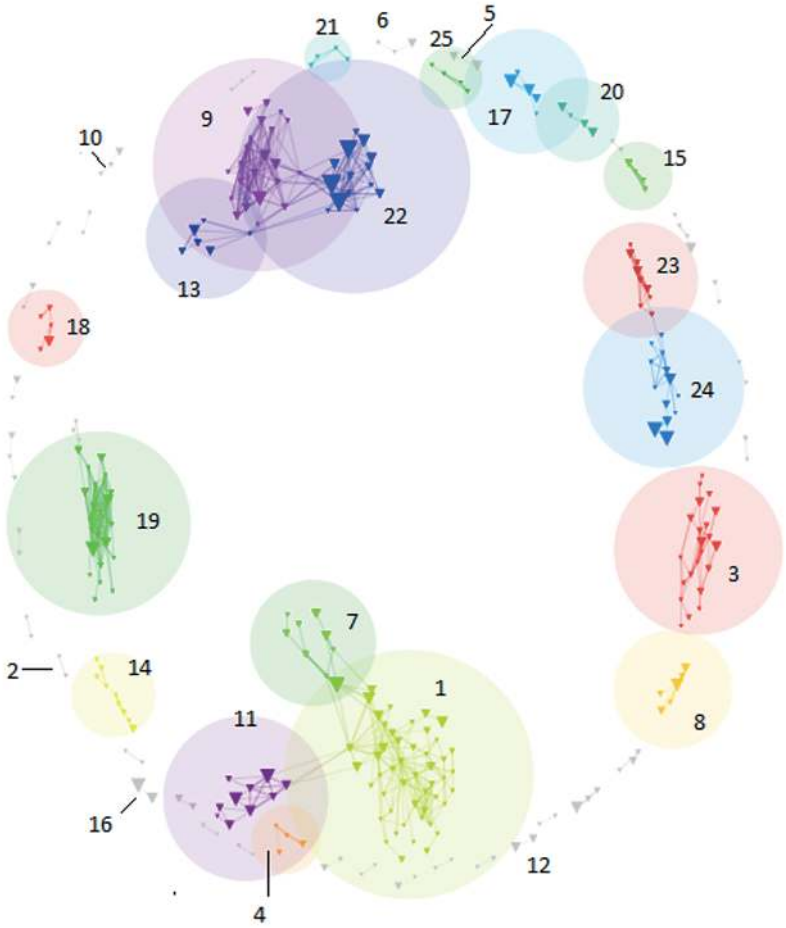


Figure 4.3 Map of NTVT publications 2012-2015
1: Orthodontics; 2: Pediatric Dentistry; 3: Nutrition and Erosion; 4: Dental Anxiety and Treatment; 5: Gnathology; 6: Facial Pain; 7: Removable prosthetics; 8: Periodontology and Medical Conditions; 9: Laws and Regulations; 10: Endodontology; 11: Dental Materials; 12: Medical and dental interactions; 13: Health care system and education; 14: Dento-alveolar surgery; 15: Sedation; 16: Bisphosphonates and osteonecrosis; 17: Gerodontology; 18: Surgery (cysts); 19: Cosmetic facial surgery; 20: Oral medicine; 21: Implantology; 22: Policy on Quality of care and Professional Education; 23: Oral medicine; 24: Miscellaneous OMFS; 25: Scoliosis.

We present the over-time changes in detail in table 4.3 (appendix) since not all maps are displayed here. The number of topics per dental subfield varied during the three periods. Some topics were present in all periods, and some topics occurred only in one period. Table 4.1 summarizes the number of clusters grouped by dental subfield for all six periods.

When we ranked dental subfields by the number of clusters we observed that the ranking is consistent over time. During the studied period most clusters concern *OMFS* topics, especially topics concerning oral surgery. Next are clusters concerning *community dentistry*, followed by *special needs dentistry* and *oral medicine*. The number of clusters changed over time for some subfields while the subfields *implantology* and *pediatric dentistry* emerged. The subfields *basic science* and *cariology* were hardly covered in publications in NTvT. For both these topics in some periods no clusters were found, and if clusters were found they appeared small with little thematic variation.

Table 4.1: Number of clusters per dental subfield for 6 subsequent 4-year periods

	2000-2003	2003-2006	2006-2009	2009-2012	2012-2015	2015-2017	Total
Oral, Maxillofacial and Facial Surgery (OMFS)	4	6	3	4	4	4	25
Community dentistry	2	2	3	3	3	4	17
Special needs dentistry	2	2	2	2	3	3	14
Oral Medicine	1	1	1	2	4	1	10
Prosthetic dentistry	2	1	2	2	1	1	9
Orofacial Pain and Dysfunction	1	1	2	1	1	2	7
Multidisciplinary	1	1	1	1	1	2	7
Periodontology	1	2	1	1	1	1	7
Orthodontics	1	1	1	1	1	1	6
Prevention	1	1	1	1	1	1	6
Endodontology	0	1	1	1	1	1	5
Materials sciences	1	0	1	1	1	1	5
Cariology	1	1	0	0	0	1	3
Implantology	0	0	1	0	1	1	3
Pediatric dentistry	0	0	0	0	1	1	2
Basic science	0	1	1	0	0	0	2
Imaging	0	1	0	0	0	1	2
Miscellaneous	0	0	1	0	0	1	2
General medicine	0	0	0	0	1	0	1
Total number of clusters per map	18	22	22	20	25	27	

Table 4.2 presents an overview how expenditures in oral health care (both UPT categories and AWBZ data) are linked to dental research subfields.

Table 4.2: Categories of oral health care expenditures UPT and the matching research subfields

Oral health care expenditures (UPT categories)	Research subfields
V (fillings)	Cariology
M (prevention)	Prevention
C (consultation)	Not included in the analysis
Orthodontics	Orthodontics
P (removable prosthetics)	Prosthetic dentistry
R (fixed prosthetics)	Dental Materials
J (implantology)	Implantology
X (X-ray)	Radiology
T (periodontology)	Periodontology
E (endodontology)	Endodontology
H (oral surgery)	Oral and maxillofacial surgery
A (anaesthesia)	Not included in the analysis
G (TMD)	TMD
AWBZ	Special needs dentistry
X special needs groups	Special needs dentistry
U (hourly rate)	Special needs dentistry
B (sedation)	Special needs dentistry

In figure 4.4 the shares of publications distributed over the research subfields both in NTvT and in international journals are presented. The shares of publications are correlated to the expenditures in oral health care as displayed in table 4.2.

In some subfields the share of international publications exceeds the share in NTvT (if the red square is higher than the blue dot – e.g. for the subfield *periodontology*), while in other fields the opposite is observed (e.g. for the subfield *prosthetic dentistry*). The *OMFS* subfield is a clear outlier. Its share of publications in especially international journals by authors with a Dutch affiliation was large compared to that from other research fields. Also, when related to expenditures for oral health care its share of publications is large.

The authors with a Dutch affiliation in the dental subfields *implantology, dental materials* and *periodontology* show a strong international orientation, while publications in the dental subfields *prosthetic dentistry* and *special needs dentistry* relatively often are published in NTvT. For other dental subfields, the share of publications in NTvT and the share of international publications is similar.

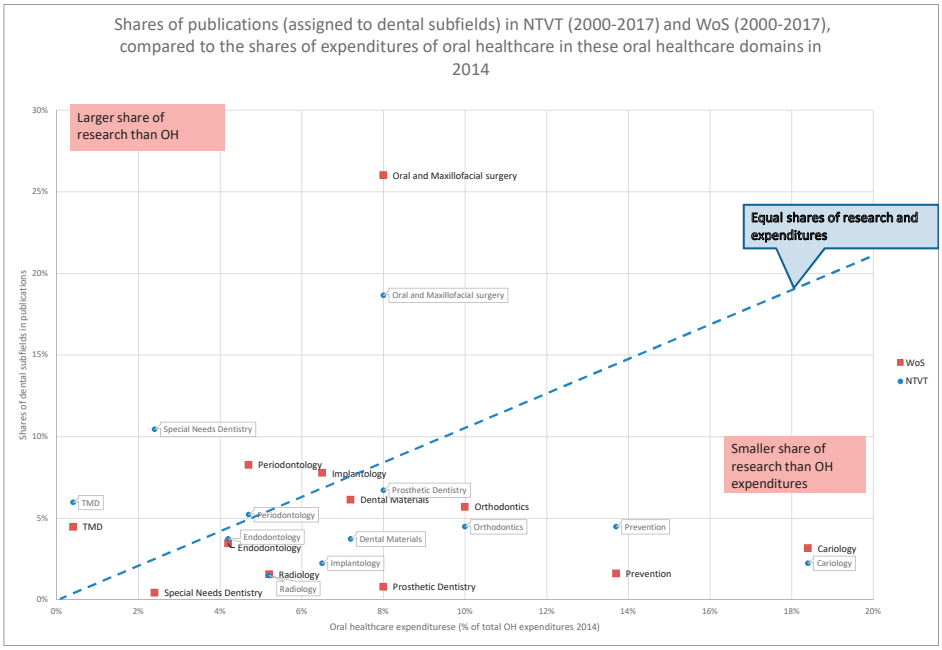


Figure 4.4:
Specific subfields within dentistry as the topic of scientific publications from the Netherlands (period 2000-2018) both in WoS and NTvT, compared to the costs of oral health care in 2014, as categorized in Table 4.2.

Although the subfields *cariology* and *prevention* account for the largest share of oral health care costs, only a relatively small amount of publications on these topics are published in NTvT and international journals.

DISCUSSION

In this study, we analyzed which topics in oral health research have been covered in publications in NTvT over the past 18 years. We compared the topics of publications in NTvT with publications from authors with Dutch affiliation in international journals. Per dental subfield we compared the share of NTvT publications and international publications with the share in costs of oral health care. Our study provides insight for the work field into which topics have been discussed, emerged or disappeared during this period and thereby may provide information for policy and planning for research and editors.

Research from the *OMFS* subfield comprises the largest share of Dutch oral health research. This conclusion applies both to publications in NTvT and to international publications affiliated to Dutch authors. This can be explained by the fact that OMFS pro-

fessionals work in a research environment of academic medical centers, in which there are established networks which stimulate collaboration and participation in research. In addition, research is quite common as part of the OMFS postgraduate professional training program, either before enrolment or as PhD after enrolment in the program. For the dentistry training program this incentive does not apply. Another explanation can be found in the relatively high number of 17 OMFS-specific international journals among the 117 dental journals in WoS. These specialized journals provide a substantial platform for publishing, and therefore Dutch researchers in the *OMFS* subfield may be less likely to publish outside their subfield in for example journals with an interdisciplinary character or non-dental journals.

For the subfield *special needs dentistry*, the opposite applies. The share of international publications from this subfield was the smallest of all subfields. Only two specialized journals were available during the studied period. These two journals allow only a limited number of publications. In order to publish publications on *special needs dentistry,* researchers are therefore compelled to publish in interdisciplinary dental journals or non-dental journals (e.g. journals on anesthesiology or care for the disabled). Publications on *special needs dentistry* in these journals are missed in our analysis.

We compared the share in expenditures of oral health care per subfield to the share of NTvT publications for each research subfield, and found OMFS to be a clear outlier. While there were some limitations in using UPT categories of claims data (e.g. some dental research subfields could not be linked with a UTP category) our approach provides a general picture of the correlation between the pattern of oral health research with the pattern of expenditures in oral health care.

An important limitation of our study is the exclusion of international publications with a Dutch affiliation published in non-dental journals. We calculated the ratio between publications in dental journals and non-dental journals for one dental research institute to estimate the impact for this decision. For the period 2000 up to 2018, 4,277 publications had a Dutch affiliation in WoS. Of these, 1,564 (37%) publications were affiliated with the Academic Center for Dentistry Amsterdam (ACTA). According to ACTA's 2016 Annual Research Report 149 of the 253 (59%) publications affiliated with ACTA were published in non-dental journals.[85] It however is unclear whether these concern publications on dental topics in non-dental journals, which eventually may have been missed in our analysis, or publications on non-dental topics which were rightly excluded from our analysis. To date, the ratio of publications on dental and non-dental topics for other dental research institutes remains unknown.

Relatively few publications in NTvT cover topics of basic science. NTvT mainly focuses on the OHPs and the work field, for whom findings from basic science might be of limited relevance and applicability. The Health Council of the Netherlands reported in *Perspectives on oral health care* (*De Mondzorg van Morgen)* that almost 50% of the Dutch publications covered basic science, while the proportion of applied research was relatively low.[34] Since such a large proportion of Dutch dental research publications cover basic science, publishing in NTvT seems to be unattractive for a substantial part of the researchers in oral health research. It is, however, unclear whether basic science researchers are either not willing or not able to address the priorities of the Dutch OHPs.[86]

An important question, as posed in the Health Council report, is whether the oral health research field meets the information needs of the users of oral health research. A recent research project called *Research Agenda for Oral Health (Kennisagenda Mondgezondheid*) has identified and prioritized the information needs of the OHPs, as principle end-users of oral health research.[34,87] For the Research Agenda for Oral Health, OHPs prioritized behavior and lifestyle-related topics. In addition, there appears to be a need for knowledge on cariology and preventative topics. According to our analysis, these topics are underrepresented in Dutch oral health research, while these subfields account for the vast majority of oral health care expenditures. When programming future research, the priorities of OHPs should be taken into account. Consequently, a targeted research portfolio can be established which may contribute an increase in the societal value of oral health research.

ANNEX-A TABLE: DENTAL TOPICS AND SUBFIELDS FOR SIX PERIODS

	2000-03	2003-06	2006-09	2009-12	2012-15	2015-18
Special needs dentistry						
Dental anxiety and treatment						
Sedation						
Oral health care for disabled						
Gerodontology						
Cariology						
Cariology						
Preventive dentistry/cariology						
Endodontology						
Endodontology						
Endodontology and restorative dentistry						
Endodontic surgery						
Implantology						
Implantology			1			
Materials science						
Materials Science						
Oral and maxillofacial surgery						
Head and neck oncology						
Orthognatic surgery						
Dento-alveolar surgery						
Surgery for cysts						
Cosmetic facial surgery						
Mucosal anomaly						
Various OMFS						
Various OMFS						
Multidisciplinary						
Facial pain						
Cleft lip and palate						
Orofacial Pain and Dysfunction						
Gnathology						
TMD						
Oral Medicine						
Medical and dental interaction						
Bisphosphonates and osteonecrosis						
Oral Medicine						
Oral Medicine						
Orthodontics						
Orthodontics						2

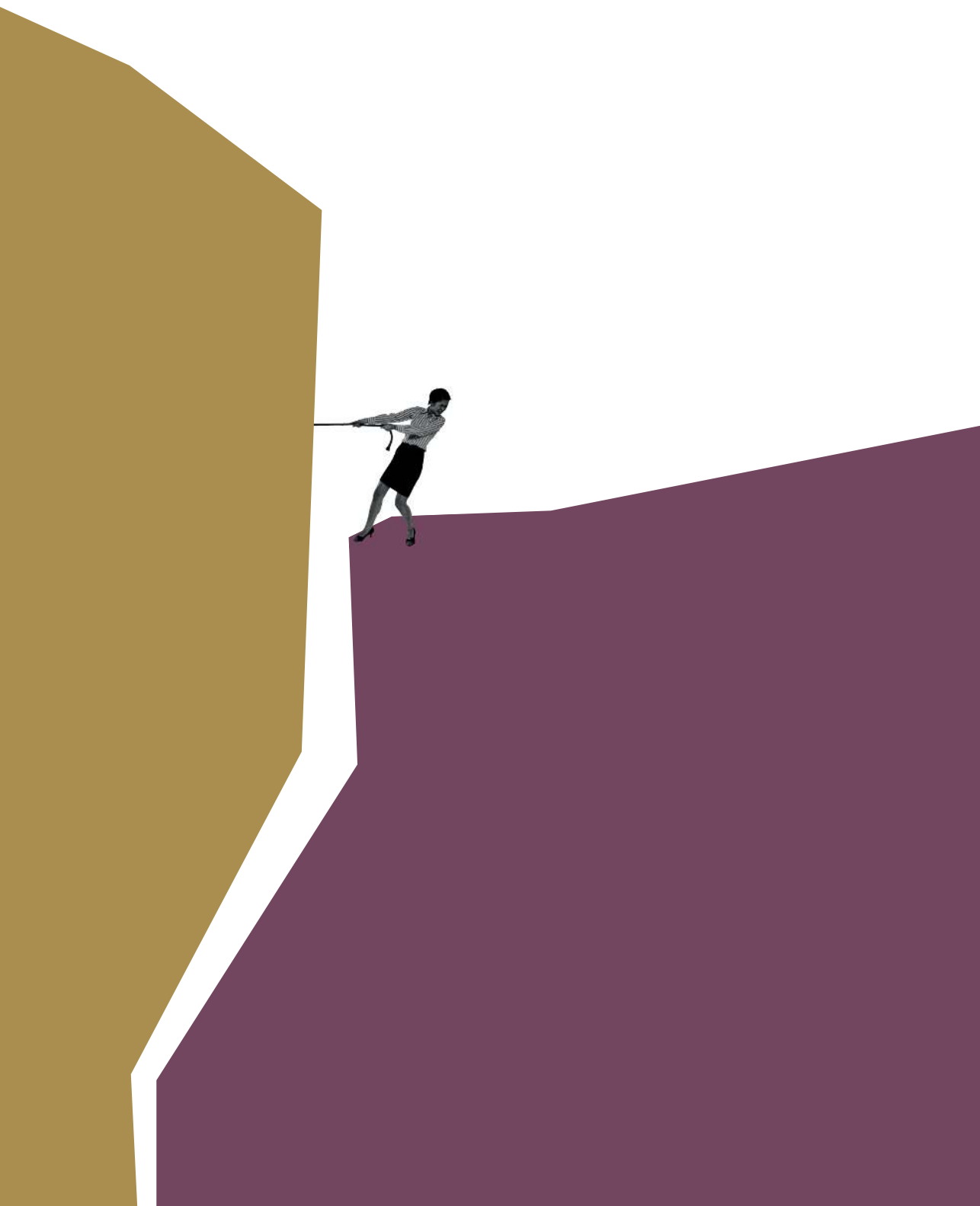
ANNEX-A TABLE: DENTAL TOPICS AND SUBFIELDS FOR SIX PERIODS (*CONTINUED*)

	2000-03	2003-06	2006-09	2009-12	2012-15	2015-18
Periodontology						
Periodontology				3		
Juvenile periodontitis						
Periodontology and medical conditions						
Preventive dentistry						
Nutrition and erosion				4	4	
Prosthetic dentistry						
Dentures						
Dentures II				5		
Dental Public Health						
Prevention in vulnerable populations			6	6		
Laws and regulations		7	8	9	8	9
Health care system and Education			9		9	
Dental Public Health						
Policy on quality of care and professional education						
Pediatric dentistry						
Pediatric dentistry						
Imaging						
Radiology						
Basic science						
Basic science		10	11			
Medicine						
Scoliosis						
other						
Lifestyle interventions						
Prosthodontic dentistry						

If there is a very specific subject in a cluster, this is indicated by a number. The cipher legend below shows which specific topics are involved.

1: including bone remodeling; 2: including auto transplantation; 3: including peri-implantitis; 4: including saliva; 5: including QoL; 6: emphasis on youth; 7: including education; 8: including care organization; 9: including professionalism and ethics; 10: oral cell biology; 11: oral biochemistry

In the first column all identified topics, ordered by subfield, are presented. In the next columns the distribution of topics per period is presented.



Part two

Agenda-setting for research in oral health care

Chapter 5

Research priorities for Oral Health care - Agenda setting from the practitioners' perspective

Puck van der Wouden
Hagay Shemesh
Geert van der Heijden

Acta Odontologica Scandinavica. 2021; 79: 451-457.

ABSTRACT

Objectives: The aim of this study was to develop a research agenda based on the most important information needs concerning the effects and outcomes of oral health care provided by OHPs.

Methods: A two-stage survey study was used to identify and prioritize topics for future research. The first survey generated topics based on information needs by OHPs. Topics were clustered thematically and overlapping topics were merged in 84 research topics. In the second survey respondents selected their top-5 from the 84 research topics. Topics were sorted by the rank number based on rank sum.

Results: In the first survey 937 topics were suggested. Almost half (*n=430*, 46%) were identified as topics related to endodontology, cariology, oral medicine/surgery or tooth restoration. Topics were grouped in 84 research topics, covering 10 research themes. These were prioritised by 235 OHPs. *Behaviour change for oral health* and *oral health care for geriatric patients* ranked as most important.

Conclusions: Consultation of OHPs has resulted in a research agenda, which can be used to inform programming future oral health research. The highest prioritized research topics have an interdisciplinary nature, mainly concern oral disease prevention and are underrepresented in the current oral health research portfolio.

INTRODUCTION

Since the 1980's global oral health has improved, but the impact of scientific research on the delivery of oral health care is limited.[35,37,38] In general, research addressing technical and scientific challenges dominates the current output of oral health research.[34] The limited impact of such research can be explained by different barriers for implementing evidence based oral health care. For example, the accessibility to information sources, the attitude towards changes due to research findings or a mismatch between research and the information needs in daily clinical practice.[88,89] While the current reward system of academic excellence and funding opportunities drive research output from academic groups, research priorities are foremost defined by individual interests and expertise of principal investigators.

For different fields of health care mismatches have been reported between research output and research priorities as perceived by the principal consumers of the research output.[26,28] The interests, information needs and challenges of patients and practitioners are rarely considered in research programs. In the field of oral health, OHPs have sporadically been consulted on their information needs and challenges to identify priorities for a research agenda.[90–92] Considering the information needs of OHPS for future research can increase the relevance of research for oral health care practice. Moreover, such a research agenda may help to align the challenges and information needs from OHPs with the perspectives of researchers, and is therefore considered essential to overcome the mismatch between research and practice. Involving OHPs in the programming of research will also enable to address contemporary societal challenges for oral health care and dental practice.[6] Examples of such societal challenges are, on the one hand, the limited information on the health outcomes and (cost-) effectiveness, and on the other hand, the need for patient-centred care, transparency on quality of care, evidence based oral health care and evidence informed policy.

As such, the priorities of OHPs can inform researchers, policymakers and funders and can be used for programming future oral health research.[6,93] Therefore, the aim of this study was to develop a research agenda based on the most important information needs concerning the effects and outcomes of oral health care encountered by OHPs in their daily oral health care practice.

MATERIAL & METHODS

In this agenda-setting project, we used a systematic and transparent methodology to identify the top-ten research topics from the perspective of OHPs.[94,95] For this a two-stage online survey was used to identify and prioritize topics for oral health (care)

research.[96] This approach provides a process to reduce the range of responses in a group during subsequent rounds. Using such an iterative process, participants were able to use the group response of the previous round to reach a consensus. Such methodology was shown to be effective for collating different perspectives into collective judgments among stakeholders with diverse backgrounds, and has been used before to establish research priorities in many areas of health and health care.[97,98]

All phases of the project, notably project design, collection and analyses of data and reporting, were closely guided and monitored by a project steering group. This steering group included representatives of relevant scientific and professional organisations, societies and associations of OHPs, and convened for consultation and advice in several meetings. During these meetings stakeholders and experts were consulted on the project design and for interpreting the findings of the project. Figure 5.1 is a schematic overview of the project, and clarifies when these meetings took place.

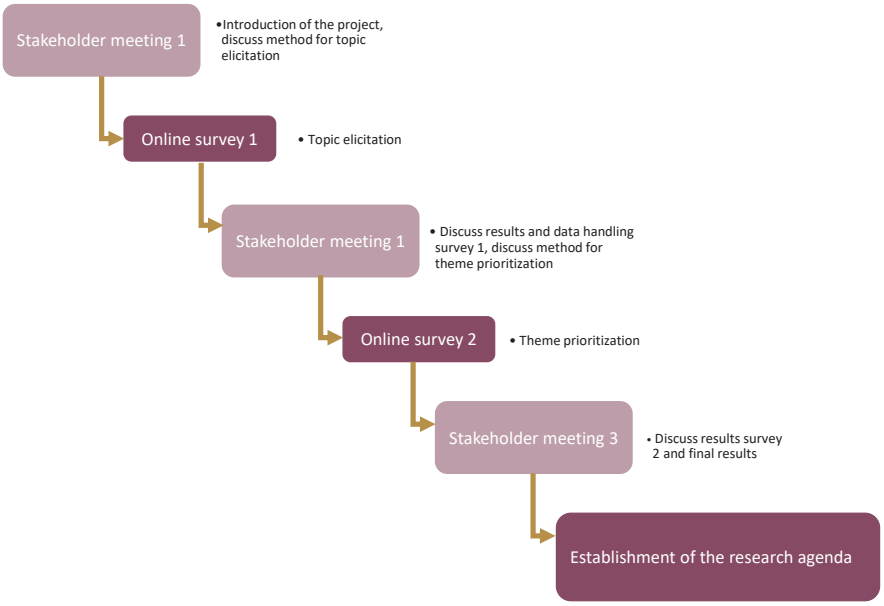


Figure 5.1: Schematic presentation of the phases and structure of the study

Ethical considerations

All participants were informed through the introductory text of the calls to participate in the surveys. This contained information on the background, aims and the design of the project. In line with General Data Protection Regulation on data safety and privacy protection, tracing back responses to individuals was not possible. A project website (www.mondzorg2020.nl) was developed containing all information about the aims, design and results of the project.

Participants and outreach

The OHPs, notably, general dentists, specialized dentists, oral surgeons, orthodontists, dental hygienists, and prosthetic dental technicians, working in the Netherlands, were targeted as participants for this project. To engage these OHPs in the surveys, open calls for participation were published in printed and online media and newsletters from relevant scientific and professional organisations, societies and associations of OHPs.

Survey 1 – Identification of topics

The first online survey was used to generate a long list of topics. OHPs were asked to suggest at least three topics relating to their uncertainties and information needs about patient management [99–102], which they consider relevant for future research. Survey 1 is displayed in supplement A. Additionally, respondents were asked to provide demographic data, notably, age, gender, year of graduation, profession, and occupational situation. Prior to distribution, five OHPs tested the text, structure and length of the survey. Based on their feedback the text of the survey was adjusted. This online survey was available between 15th March 2016 and 31st December 2016.

Survey 1- Data Analysis

All suggested topics were evaluated according to the aim of this project: to identify information needs of OHPs concerning the effects and outcomes of oral health care. Topics beyond this scope (e.g. organizational issues) were excluded.

The first author (PvdW) analysed the data using a directed content analysis approach.[103–105] All topics suggested were coded, according to a list of predefined oral health research areas (based on *disease, treatment* or *oral health specialization*). This list was open for additions when required. Topics were sorted and clustered thematically, and those strongly associated or overlapping were merged. This resulted in 84 research topics. The topic coding and their thematic grouping was checked by two independent researchers. Discussion with the first author resolved all initial disagreements and consensus was reached on topic coding and their thematic grouping. Thereafter, the research topics were logically grouped, so that related topics presented specific research themes.

Survey 2 - Ranking research topics

The objective of the second survey was to prioritize the 84 research topics that were derived from Survey 1. Participants were asked to select their two most important topics from each of the 10 specific research themes. The full list of 84 research topics divided over the 10 specific research themes is found in supplement B. Subsequently, the list of 20 topics they selected was presented. The respondents were asked to select and rank their top-5 from these 20 topics. This stepwise approach ensured that participants would

also prioritize topics beyond their personal interests and individual focus. Respondents were asked to provide demographic data, notably, age, gender, year of graduation, profession and occupational situation. The survey's text, structure and length were tested by three OHPs, which showed that adjustments were not required. This online survey was available between 25th August 2017 and 21st December 2017.

Survey 2 – Data Analysis

Only submitted surveys with complete data were included for further analysis. The research topics were sorted by their priority as reflected from the rank number based on rank sum. The rank sum of the research topics was calculated as a product of the frequency of endorsement and weight for the ranking position. This weight was calculated as 5-(r-1) (r=ranking position). For example, the rank sum for a research topic ranked as #1 was calculated as 5-(1-1)=5 points, and the rank sum of a research topic ranked as #5 was calculated as 5-(5-1)=1 point.

Stakeholder meetings

Stakeholder meetings formed a structural and vital part of the project. The goal of these meetings was to engage opinion leaders from different stakeholder groups in the field of oral health care. Their involvement and support were crucial for the project as it facilitated outreach of the project and allowed embedding it in their network.

Prior to each survey round a meeting was organized to inform stakeholders about the different stages of the project and to discuss the design of the research agenda setting process. After the second survey a final meeting was held to discuss and validate the results from the surveys with the stakeholders.

These meetings were structured according to the World Café method.[106] The World Café method is an easy-to-use approach for connecting multiple perspectives and different ideas between diverse stakeholder groups. It is designed to create a safe, welcoming environment for engaging participants in several discussion rounds. The use of this approach facilitated structured conversation and collaborative dialogue in small groups to explore the structure and process of research agenda setting.

RESULTS

Survey 1 - Identification of research topics

In total, 210 OHPs suggested 1,103 topics for future research. Of these, 937 topics qualified for further analyses. Topics excluded for the analysis mainly concerned organizational issues in oral health care. The first column of table 5.1 displays how the 937 suggested topics were distributed over 16 areas of oral health care.

Table 5.1: Distribution of data in each stage of the research agenda setting process

Topics suggested in survey 1, grouped by research area			*Research topics derived from topics; grouped by research themes*			*Result from survey 2*
Research areas	**Number of topics**	**(%)**	**Research themes**	**Number of research topics**	**%**	**Research topics in top-10**
Prevention	68	7	Prevention and lifestyle	9	11	#1 and #4 and #6
Diagnostics	19	2				
Patient factors	21	2				
Special needs groups	49	5	Special needs groups	5	6	#2
Anaesthesia*	12	1				
Oral medicine/surgery	100	11	Oral medicine/surgery	11	13	#3 and #9
TMD	50	5	TMD	7	8	#5
Cariology	103	11	Cariology	7	8	#7 and #10
Periodontology	68	7	Periodontology	6	7	#8
Orthodontics	73	8	Orthodontics	9	11	
Pain	69	7	Pain	6	7	
Tooth replacement	18	2	Tooth replacement / restoration	13	15	
Tooth restoration	93	10				
Implantology	20	2				
Removable prosthetics	40	4				
Endodontology	134	14	Endodontology	11	13	
Total	**937**	**100**	**Total**	**84**	**100**	

* 8 of the topics in Anesthetics were grouped into research topics in the domain of special needs groups (general anesthesia), 4 were grouped into a research topic in oral medicine/surgery (local anesthesia)
The first column shows the distribution of topics from the first survey over the research areas. The second column shows how the research areas were grouped into research themes and how the research topics were distributed over these themes. The third column shows from which research themes the top-10 topics originate.

On verification of topic coding and their thematic grouping, initial disagreement on 107 topics (10%) existed. These initial disagreements were resolved during a consensus discussion by those involved in coding and thematic grouping. Disagreements were mainly due to variability in topic allocation to the predetermined areas of oral health care research, based on slightly different topic interpretation. Inductive coding for additional areas was therefore required in some cases. Almost half (*n=430,* 46%) of the topics were identified as disease or treatment in specific disciplines, namely endodontology, cariology, oral medicine/surgery or restoration of an element.
Table 5.2 provides examples on how research topics were derived from topics, and how these topics were then logically grouped in a research topic. The grouping of topics into research topics ensured all suggested topics were represented, while it resulted in a manageable number of topics for the prioritization survey. This method firstly avoided

too many very specific questions, and secondly the risk that a research topic would be diluted across multiple questions.
The second column of table 5.1 summarises the distribution of the 84 research topics over 10 research themes.

Table 5.2: Illustration of data handling

Topic	Research Area	Merged into research topic	Research theme
"What is the effect of dental education for the individual? Would it be better to spend that time differently?"	Prevention	What is the effectiveness of various preventive treatments? (dental education, fissure sealing, scaling and polish, fluoride application)	Prevention & Lifestyle
"My colleague advises fissure sealants while I see no indication for it."	Prevention		
"It is difficult to achieve behavioral change in patients."	Patient factors	What is the most effective method for behavioral change?	Prevention & Lifestyle
"How to deal with stubborn patients who don't follow up advice?"	Patient factors		

Research topics derived from suggested topics, and logically grouping of the research topics in research themes.

Survey 1 - Respondents

In total, 210 OHPs participated and returned a complete survey. All (sub)specialties of OHPs, were represented in this survey except oral surgeons. Most respondents were general dental practitioners (n=99, 47%). More than half of the respondents (*n=113*, 54%) were between 40 and 60 years old. Table 5.3 presents the distribution of respondents in the first survey over the OHP disciplines and the age categories.

Survey 2 – Ranking research topics

Table 5.4 presents the top-10 research topics sorted by their rank-sum. The third column of table 5.4 presents the research theme these research topics originate from.
Research topics on behaviour change for oral health, oral health care for geriatric patients and the relation between chronic diseases and oral health were chosen as most important research topics. In supplement A the rank number for the 84 research topics can be found. All 84 research topics were selected as an individual top-5 at least twice (ranging from 2 to 69 times as a top-5 topic).

Table 5.3: Distribution of respondents' OHP disciplines and age categories

	Respondents of Online survey 1 Topic Elicitation n (%)	Respondents of Online survey 2 Theme Prioritization n (%)	Dutch OHP population n (%)
Discipline			
Dentist	99 (47)	77 (33)	8,024 (60)
Dental Hygienist	46 (22)	57 (24)	4,052 (30)
Orthodontist	19 (9)	24 (10)	615 (6)
Specialized dentist	20 (10)	50 (21)	770 (5)
Total*	***184 (88)***	***208 (89)***	***13,461***
Age			
20 – 29 years	13 (6)	33 (14)	2,380 (18)
30 – 39 years	39 (19)	59 (26)	3,445 (26)
40 – 49 years	46 (22)	38 (17)	2,881 (21)
50 – 59 years	67 (32)	67 (29)	3,071 (23)
60 – 69 years	39 (19)	29 (13)	1,684 (12)
70+ years	4 (2)	3 (1)	Not available
Total*	***208 (99)***	***229 (97)***	***13,461***

* Not all respondents completed the demographic data

Survey 2 – Respondents

In total, 235 OHPs participated and returned a complete survey. Similar to survey 1, all (sub)specialties of OHPs were represented except oral surgeons. Most respondents were general dental practitioners (*n=77,* 33%), though their contribution was lower than in survey 1. On average the age of OHPs participating in this survey (mean age=45, SD=12,8) was lower than those participating in the first survey (mean 49, SD=12,2). Table 5.3 presents the distribution of respondents in the second survey over the OHP disciplines and the age categories.

Stakeholder Meetings

A diverse group of stakeholders including OHPs, patient representatives, researchers, medical professionals, policy makers, representatives from dental industry and research funders attended the stakeholder meetings.

During the first meeting consensus was reached on the method to be used for topic identification during the first online survey. The importance of addressing and engaging the full range of OHPs throughout the whole project, notably, general dentists, oral surgeons, orthodontists, dental hygienists and prosthetic dental technicians was endorsed.

Table 5.4: Top-10 research topics for future oral health care research prioritised by OHPs

Research topics	n	Rank sum	Research theme
What's the most effective method to change behaviour to improve oral health?	69	250	Prevention and lifestyle
Oral health care for the geriatric patient: What are the implications for the treatment plan and treatment?	54	152	Special Needs Groups
What is the relation between (chronic) illnesses and oral health?	41	143	Oral medicine/ surgery
What is the effect of preventive interventions? (dental education, sealants, supragingival calculus and / or professional removal of dental plaque, fluoride application)	36	122	Prevention and lifestyle
Tooth wear: When should it be treated, and what is the best treatment (method)?	38	107	TMJ
What is the relation between nutrition/diet and oral health?	33	104	Prevention and lifestyle
When has dental caries progressed so much that invasive treatment (drilling and filling) is required? What defines this treatment decision?	22	81	Cariology
What is the most effective supportive periodontal therapy (SPT) (method and frequency)?	22	81	Periodontology
What is the effect of (foreign) material use in the mouth on general health?	23	76	Oral medicine/ surgery
Can we predict (the development of) caries based on the current knowledge?	24	75	Cariology

n: number of times the research topic was among an individual top-5
Rank sum was calculated as a product of n and weight. Weight was calculated as 5-(r-1) (r=ranking position)

During the second meeting the approach used for grouping the 937 suggested topics in 84 research topics and subsequently into 10 themes was endorsed, and consensus was reached on the method to be used for topic prioritisation during the second online survey.
During the third meeting participants unanimously endorsed the ten highest prioritized research topics and thereby the final research agenda was established.

DISCUSSION

This is the first study to establish an agenda for oral health research for which a wide variety of OHP disciplines was engaged as principle stakeholders and survey participants in all phases of the project. As a result, the priorities for future oral health research surpass the interests of one specific OHP discipline.
Most of the top-10 research topics prioritized by OHPs are of an interdisciplinary nature and mainly concern oral disease prevention. OHPs prioritised *behavior change* and *oral*

health care for geriatric patients as respectively priority research topic #1 and #2. Only two topics concern a specific dental treatment, notably priority research theme #7: *"When has dental caries progressed so much that invasive treatment (drilling and filling) is required? What defines this treatment decision?*" and priority research theme #8: *"What is the most effective supportive periodontal therapy (SPT) (method and frequency)?"*
This oral health research agenda may help to legitimately decide which research should be conducted, while reflecting the relevance for oral health care practice. It may help to overcome the disconnect between the communities of researchers and practitioners and thereby prevent a mismatch of future research output. By using this research agenda as a basis for programming new research, the value of research increases, the number of (treatment) uncertainties can be reduced and the quality of oral health care will therefore improve.[6]

Since this was the first project to establish a research agenda for oral health care in the Netherlands, the Dutch OHPs were unfamiliar with research agenda setting. Therefore, the collection of topics took more time than anticipated, and the first survey was available online for nearly eight months. Using open-ended questions provided an opportunity for participants to identify information needs and treatment uncertainties that so far were unnoticed, and thereby reveal a-priori challenges for new areas of research. Still, some respondents indicated that they found it difficult to suggest topics and to see the long-term benefits of such a research agenda. But given the large number of topics suggested (*n=1,103*) this did not apply to most respondents. This large number of topics indicates that OHPs encounter treatment uncertainties and experience information needs during their work in daily practice. This adds to the strength of our approach of participant recruitment and topic elicitation. Moreover, the number of topics we have identified is comparable to that of a recent priority setting partnership (PSP) project for oral health in the UK[91], but exceeds the number of topics identified in many similar other research agenda setting projects.[107,108]

Compared to other research agenda setting projects for oral health care research, we used a different approach, as we exclusively engaged OHPs and included a broad range of OHP disciplines.[91,92,109–111] In Canada, general dentists were only asked to prioritize oral health care research topics restricted to the priorities predefined and listed by researchers. The resulting topic list concerned evaluation of either effectiveness of specific treatment or the development of new materials.[92] In the UK PSP project, a top-10 of research themes for oral health shared by both patients and OHPs was identified.[112] Similar to our project, the PSP research priorities concern prevention and oral health care for special needs groups. But in the PSP, the inclusion of patient's perspective resulted in both the accessibility and organisation of the (oral) healthcare system as priorities.[110,113]

To establish a broadly supported research agenda we valued the representation of variety of OHPs highly important. Therefore, we reached out to all Dutch OHPs to increase ownership of the project. We sought to recruit as many OHPs as possible in both surveys and intended to involve OHPs who would otherwise not have participated. Both surveys were open for all OHPs and no specific restrictions to participation were applied, e.g. no research expertise was required. Via a mix of professional media, we invited OHPs to share their information needs and contribute to the identification and prioritization of topics for future research.

As a result, we have succeeded to engage a broad selection of OHPs as respondents in both surveys. While a considerable number of OHPs has responded to and completed both surveys, due to responder anonymity it remains unclear how many have participated in both surveys.
Compared to the distribution of Dutch OHPs, in both surveys a majority of OHPs was 50 years of age or older, but in terms of occupation, participants in both surveys form a fair representation of the Dutch OHP population. Table 5.3 displays the distribution of respondents over the OHP disciplines and the age categories compared to the Dutch OHP population. A considerable number of respondents in both surveys were OHPs affiliated with an academic institution with a specific interest in research. Of these, several additionally worked in private practice.

The first survey resulted in a large number and a wide variety of topics addressing all fields of oral health care practice and research. Understandably not all OHPs hold the same views on research priorities. Therefore, the approach of research topic prioritization in the second survey was designed to ensure ranking of topics across all oral health subfields. This way, we challenged respondents to venture beyond their own area of specialism, invested interests or expert opinions.
Participant self-selection may introduce responder bias, i.e. the information needs from those motivated to participate may differ from those that did not participate. Although the majority of suggested topics in the first survey concerned technical aspects of treatment decisions in daily practice, in the second survey OHPs gave higher priority to societal engaged research topics. It is therefore unlikely that we have on the one hand disregarded substantive information needs and on the other hand overweighed specific fields of research and practice. Moreover, the rank-sum for the top-10 priorities show convergence and stability of opinions and preferences among the respondents.

CONCLUSION

In this study we developed a research agenda for oral health care from the perspective of OHPs, which has resulted in a research agenda addressing their challenges and information needs in daily practice. Many of these topics are underrepresented in the current oral health research portfolio. Researchers, policymakers, and research funding agencies can use this research agenda for programming future research seeking to answer the highest prioritized questions. As in most other research agendas, the research topics we have prioritised, are broadly defined and obviously need further detailing, notably specification of research questions and elaboration of study designs. To effectively target research that meets the needs of OHPs, we advise to involve OHPs in this specification and elaboration.

SUPPLEMENT A

Design Survey 1 – Identification of topics

1 *Example 1: You treat a disorder in a certain way, while your colleague uses a different treatment strategy.*

Example 2: On course A you are told that a treatment/material is superior (supported by scientific literature), while on course B you will be advised a different treatment/material (also supported by scientific literature).

Can you describe cases where conflicting insights lead to treatment uncertainty or confusion?

2 Example: You usually prefer a certain treatment (e.g. (in-)direct pulp capping instead of an endodontic treatment in case of a deep caries lesion). However, in some cases you wonder whether this 'routine' is the best choice.

Can you describe one or more cases where you questioned your treatment decision?

3 We would like to hear what questions you think should be included in the *Research agenda for Oral health care*. What research topics concerning oral health and oral health care would you like to be researched?

SUPPLEMENT B

Research topics over 10 research themes

	Special Needs Groups	**n=5**	Rank sum
1	When is general anesthesia for dental treatment of patients with dental anxiety indicated?		12
2	When is general anesthesia for dental treatment of children indicated? What are the long-term negative effects of treatment with general anesthesia?		35
3	What is the optimal approach to mentally disabled people in oral health care?		25
4	Oral health care for the geriatric patient: What are the implications for the treatment plan and treatment?		152
5	What is the influence of patient-specific psychological factors on oral health and oral health care?		65
	Caries	n=7	
6	When has dental caries progressed so much that invasive treatment (drilling and filling) is required? What factors can guide this treatment decision?		81
7	What is the preferred method of caries treatment for the individual patient?		45
8	To what extent should caries be removed and which method is preferred?		71
9	What is the best treatment for caries profunda?		39
10	What is the best treatment when the prognosis of an element affected by dental caries is poor? Is this choice different for deciduous teeth?		22
11	Can we predict (the development of) caries based on the current knowledge?		75
12	What is the best treatment for caries in deciduous teeth?		35
	Tooth replacement/restoration	n=13	
13	Which materials and methods are the best to restore elements? Do these materials have harmful effects?		48
14	What is the indication for an indirect restoration (crown)?		44
15	What is the indication for replacement of a restoration?		37
16	What is the indication and best method of replacement of (a) missing element (s)?		15
17	What is the indication for complete dentures?		12
18	What is the best method to make dentures?		17
19	When are removable dentures preferred over preservation of dentition in a mutilated dentition?		36
20	Replacement of dentures: What are the clinical criteria and what are the criteria from patient perspective for indication?		27
21	What instructions are important for maintenance and durability of dentures?		14
22	What is the indication for a dental implant?		9
23	What is the best method to create sufficient bone height and volume for a dental implant?		9
24	Which method of implantation and with which type of dental implant leads to the best results?		9

SUPPLEMENT B (*CONTINUED*)

Research topics over 10 research themes		
25	How can problems with (acceptance of) a new prosthesis be prevented and / or cured?	13
Endodontology		n=11
26	What is the success rate of the direct pulp capping therapy? And is this the best treatment in the case of exposed pulp?	13
27	What are the treatment options for pain at an endodontically treated element?	9
28	What is the best approach of a periapical lucency to an element without clinical symptoms (with or without endodontic treatment)?	49
29	What is the success of treatment aimed at preservation of elements affected by dental trauma?	14
30	How is the condition of the pulp and the ability to recover from a pulpitis assessed? When is endodontic treatment indicated in case of pulpitis?	54
31	How can fractures (root / cracked tooth) accurately/reliably diagnosed?	53
32	What is the effectiveness of calcium hydroxide dressing during endodontic treatment?	5
33	What is the optimal working length for the endodontic treatment? How is the length of the root canal reliably assessed?	8
34	What are the best (file) systems and materials for endodontic treatment?	23
35	When treatment of a perforation beneficial? What is the best treatment method?	6
36	What is the best coronal seal/restoration after root canal treatment? Is placing a post after endodontic treatment beneficial?	25
TMD		n=7
37	How can TMD pain and dental related pain be distinguished?	24
38	What is the cause of orofacial pain? How to diagnose and treat orofacial pain?	31
39	What is the best treatment for symptoms due to oral parafunctions?	35
40	When is treatment of tooth wear indicated and what is the best treatment (method)?	107
41	What is the added value of canine guidance in case of tooth wear?	66
42	What is the cause of orofacial pain?	17
43	What is the best treatment strategy for orofacial pain?	28
Oral Medicine and oral surgery		n=11
44	What is the best (treatment)approach to oral lesions or mucosal abnormalities/lesions?	24
45	What is the relation between (chronic) illnesses and oral health?	143
46	What is the effect of using (foreign) materials in the mouth on general health?	76
47	What is the indication for antibiotic prophylaxis?	42
48	What is the best approach to patients on anticoagulant therapy?	33
49	What is the effect of medication use on the oral health?	66
50	What is the indication for (preventive) extraction of the third molar?	34
51	What is the effect (harm) of retained root fragments after extraction?	16
52	What is the optimal postoperative care after an extraction?	2

SUPPLEMENT B (*CONTINUED*)

Research topics over 10 research themes			
53	What is the optimal local anaesthics and has the least adverse effects (both local and systemic)?		39
54	What is the effectiveness of assessing and eliminating odontogenic foci?		55
Orthodontics		n=9	
55	What type of retention after orthodontic treatment is preferred?		36
56	What is the best method to create space in patients with space deficiency in the dental arch?		20
57	What is the best approach for patients with one or more missing teeth (agenesis)?		28
58	When is the best timing to start/initiate orthodontic treatment?		31
59	Relapse of anterior open bite after orthodontic treatment: What is the cause and how can it be prevented?		30
60	Is rinsing with fluoride mouthwash during orthodontic treatment with fixed appliances effective in preventing (white spot lesions) caries around brackets?		23
61	For which malocclusion is which orthodontic treatment most effective?		12
62	Class II relation: Which orthodontic and/or surgical treatment is indicated?		4
63	Class III relation: Which orthodontic and/or surgical treatment is indicated?		13
Periodontology		n=6	
64	When is periodontal treatment more effective (and efficient) than regular oral hygiene treatment?		63
65	What are the most effective methods and agents for the treatment of periodontitis?		75
66	What is the indication for periodontal surgery?		22
67	What is the best treatment when the prognosis of an element affected by periodontitis is poor? Is extraction or treatment aimed at preserving an element better?		70
68	What is the effectiveness of antibiotics as part of periodontal treatment?		45
69	What is the most effective supportive periodontal therapy (frequency and method)?		81
Pain		n=6	
70	What is the indication for antibiotics in case of dental pain?		11
71	What is the best method to diagnose pain originating from the orofacial region?		54
72	What is the influence of pain perception and the individual pain threshold on the treatment decision in case of orofacial pain?		28
73	What causes pain after restoration of a tooth?		11
74	What is the best approach when the cause of the pain cannot be determined?		71
75	What is the best approach in case of pain after restoration?		12
Prevention and lifestyle		n=9	
76	Which oral selfcare products are most effective to improve oral health?		20
77	What is the relation between nutrition and oral health?		104
78	What is the most effective method for behavioral change?		250

SUPPLEMENT B (*CONTINUED*)

Research topics over 10 research themes		
79	What is the most effective treatment for sensitive teeth and/or exposed cervical dentin?	32
80	What is the effectiveness of various preventive treatments? (dental education, fissure sealing, scaling and polish, fluoride application)	122
81	What is the indication for taking an X-ray? What are the harmful effects of exposure to X-rays? Same for CBCT.	28
82	What is the optimal interval for routine oral examination?	55
83	What are the adverse effects of using oral care products?	18
84	What are the adverse effects of exposure to X-rays?	7

Chapter 6

Establishing the research agenda for oral health care using the Dialogue Model – patient involvement in a joint research agenda with practitioners

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European Journal of Oral Sciences. 2021 Dec 22;130(1)

ABSTRACT

Engagement of patients in research programming, for example through composition of a research agenda, is essential to reduce the gap between research and practice and thereby generate more impact. The aim of this study was to establish a research agenda for oral health care. Experienced challenges and needs with oral health (care) of OHPs and patients formed input for the research agenda. We describe the identification of research priorities of patients and the integration of these with previously identified research priorities of OHPs, using a participatory multi-phase approach for research agenda setting (Dialogue method). Via focus group discussions, 32 research topics were generated. Next, 1.495 patients prioritized these topics in an online survey. The prioritized topics of patients and the prioritized topics of OHPs were discussed in a consensus meeting, to establish a joint research agenda. A top-8 of research topics was agreed upon. The research agenda covers a wide range of topics that for a large part were contributed by patients, but were prioritized by both stakeholder groups. The most important topics concerned behavior change and the relation between general and oral health. This research agenda provides new directions for future research, as many topics are currently underrepresented in oral health research.

INTRODUCTION

In many medical research fields, a mismatch between research and practice has been reported. This mismatch in particular concerns a gap between current research topics and the research needs of end-users of research.[26,28] Traditionally, research topics in the oral health care field have mainly been based on the established interests from academic research groups, funding agencies or dental industry.[114] As a result, research addressing technical and scientific challenges dominates the current oral health care research while research on the effects of prevention, patient reported outcomes of care and the quality and organization of oral health care remains scarce.[34] The engagement of end-users of oral health research, mainly OHPs and patients, in research planning and programming, for example through the composition of a research agenda which reflects their research needs, is essential to reduce this gap.[6,115]

Addressing the needs of the OHPs and patients in research on oral health and oral health care increases its societal relevance.[6] While OHPs encounter treatment uncertainties and knowledge gaps in daily practice, patients experience oral health (care) problems in their daily life that can have functional and psychosocial impact on many aspects of life.[116] Thereby, their unique perspective complements the perspectives of OHPs. Next to the argument of a unique perspective, the involvement of patients and their perspectives adds to the legitimacy of research, since patients may benefit from the results thereof.[117] Another important argument to involve patients has a normative ground: the outcomes of research will impact the health and wellbeing of patients. Therefore, it is their right to have a voice in research decision-making.[118,119] Both stakeholder groups provide unique and important perspectives. When these perspectives are aligned in a set of joint priorities, these may serve to inform and shape future oral health research.

The overall aim of the current study was to establish a research agenda with the most important topics for future research on oral health and oral health care from the perspective of health and wellbeing. The information needs of the users of oral health research – OHPs and patients – form the basis of the research topics on the agenda. The aim of this paper is two-fold: we first aim to reflect on the establishment of the research priorities of patients. Next, we reflect on the integration of the patient research priorities with the previously established research priorities of OHPs by means of a dialogue meeting. The research priorities of OHPs are published elsewhere.[120] The COREQ checklist has been followed in the reporting of this research.[121,122]

MATERIAL AND METHODS

Methodology

This research agenda setting project was initiated by the department of Oral Public Health of the Academic Centre for Dentistry Amsterdam (ACTA). The principle investigators with a background in epidemiological and dental research, collaborated with researchers from the Athena Institute of the VU, who have elaborate experience in patient involvement in health research.

To develop a joint research agenda, we followed the methodology of the Dialogue Model.[115] The Dialogue Model involves a participatory research approach, which facilitates needs articulation and knowledge co-creation of relevant stakeholders. It is based on a responsive methodology and the Interactive Learning and Action Approach. The approach rests on the premise that after articulating stakeholders' perspectives, integration of the perspectives can take place.[123] The use of the Dialogue Model is guided by six principles: (1) active involvement of end-users (including OHPs and patients), (2) adaptation to social conditions, (3) respect for experiential knowledge of end-users, (4) dialogue and partnership, (5) emergent and flexible design, and (6) independent facilitation. The Dialogue Model is designed to follow six phases: exploration, consultation, prioritization, integration, programming and implementation. In the project reported here, we applied the first four phases. (Table 6.1)

Staged approach

To allow sufficient opportunity to sensitize OHPs towards the experiential knowledge of patients in the project, patient involvement was gradually introduced. Therefore, the research priorities of OHPs were established first. In the exploration phase an introduction meeting to engage opinion leaders from different stakeholder groups was organized to create support for the project. A project steering group to provide feedback and advise the project team was composed. In the consultation phase OHPs were asked to share their treatment uncertainties and suggestions for future research topics in an online survey. In total, 937 topics were suggested by 210 OHPs. Through direct content analysis the suggested topics were translated into 84 research topics. These were categorized in 10 research themes.

Next, in the prioritization phase, the 84 research topics were prioritized in an online survey: Per research theme 2 topics were chosen. The 20 chosen topics were presented and respondents were asked to rank a top-5. 235 OHPs filled in this online survey. These research topics were sorted by their priority as reflected from the rank number based on rank sum. This is described in detail elsewhere.[120]

Table 6.1. Dialogue Method – Description of the phases used in the project

Phase	Aim	Actions
1**. Exploration**	Create good social conditions for the dialogical process and to gain a first understanding of the stakeholder issues.	The project team identifies and contacts patient and professional organizations, and informs and motivates potential participants about the project.
2. **Consultation**	Establish the research priorities of each stakeholder group.	Consulting each group separately since asymmetries between stakeholders can prevent meaningful interaction right from the start; professionals need to be sensitized to respect the experiential knowledge of patients while patients first need to go through a process of empowerment to prepare them for a more equal interaction with professionals.
3. **Prioritization**	Prioritize the research topics per stakeholder group.	A questionnaire is an appropriate method to identify the priorities of larger groups, while a Delphi study is more suitable for smaller groups.
4**. Integration**	Integrate the prioritized topics of all stakeholder groups via dialogue.	A Dialogue meeting with representatives of all relevant parties is organized to foster a negotiation about the research agendas. Given the asymmetries between stakeholders the dialogue should be carefully prepared to give each stakeholder group a 'say'. An equal number of patients and professionals, selection of participants with an open mind and the use of non-technical language help to create a fair and meaningful process.

Adapted from Abma, T. A., & Broerse, J. E. W. Patient participation as dialogue: setting research agendas. *Health Expectations*, *13*(2), 160-173.

In this paper we focus on the research priority setting of patients and the integration with the priorities of OHPs via a Dialogue meeting. During the prioritization phase of OHPs, the research priority setting process of patients was commenced (Figure 6.1).

Data collection

Data were collected from April 2018 to January 2019 in the Netherlands.

Exploration: Patient involvement in this project was not obvious. The oral health care patient does not exist as such, and the patient group is not clearly defined. This impeded targeting and approaching a specific patient group. To facilitate patient involvement in this project we targeted patients with chronic diseases in the consultation phase, namely people suffering from diabetes mellitus (DM), cardiovascular diseases, depression, rheumatic disorders, or lung diseases. We based the selection of chronic diseases on one hand on the increased risk for oral health (care) problems, and on the other hand on the high prevalence and burden of disease.[124–129]

The Netherlands Patient Federation (NPF), that represents over 200 patient organizations, supported the project and assisted by the approach of relevant patient organizations that are affiliated with their federation.[130] Additionally, a bottom-up approach

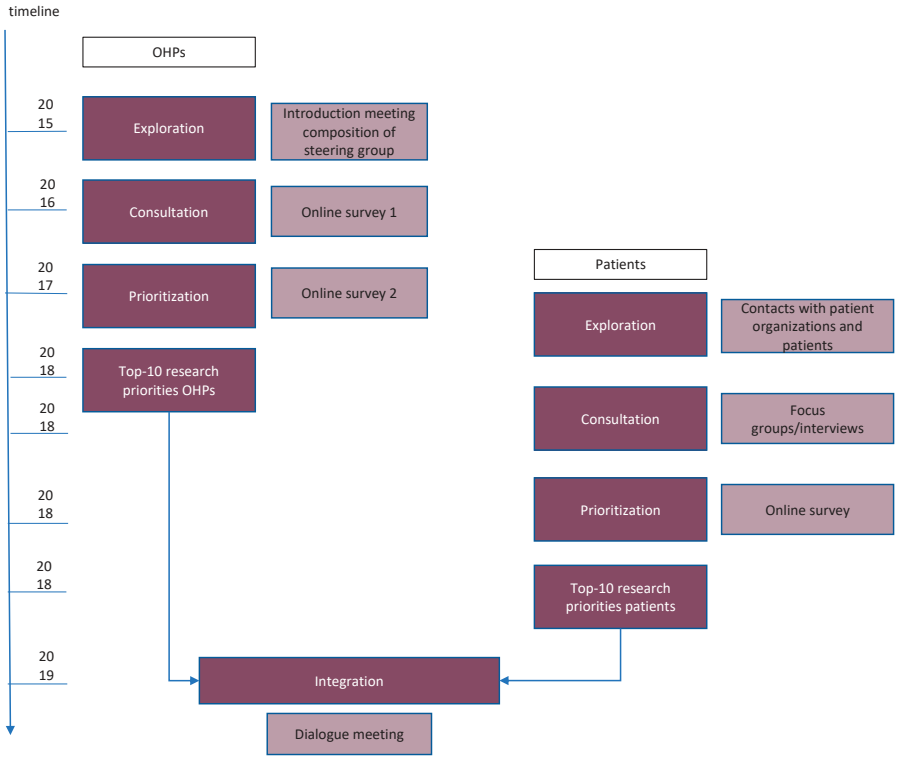

Figure 6.1: Schematic presentation of the phases and structure of the study

through social media and patient meetings, was used to recruit a sufficient number of participants for the consultation of all targeted patient groups.

Consultation: In the consultation phase the problems that patients experience in their daily lives regarding oral health (care) were mapped during 4 focus group discussions (FGDs). A moderator, assisted by research team members, chaired the FGDs. We expected recognition of problems amongst patients suffering from the same disease to stimulate discussion and create a safe environment. Therefore, we organized an FGD for each patient group separately. At the start of the FGD, each participant was asked to list the problems they encountered with oral health (care). These were then discussed within the group. The moderator and research team members grouped the listed problems and informally translated their underlying narratives to create a list of topics. Topics were inductively categorized and thematically labelled. Confirmation for the listed topics was sought from FDG participants. If relevant topics were missed, they were added to the list.

For people with depression we did not manage to organize an FGD. For this patient group we collected data through three semi-structured interviews. Patients were asked about their problems with oral health (care) and were asked if common oral health (care) problems as described in the literature applied to their situation. After each FGD and the three interviews, a summary of the findings was sent to all participants for respondent validation.

In total, 30 patients volunteered to participate in the FGDs and interviews. In table 6.2 an overview is found of the number of participants and demographics per patient group.

Table 6.2: Characteristics of participants of the consultation phase

Patient group	Number	Gender (female/male, n)	Mean age (years)
Depression	3	3/0	39
Diabetes Mellitus (DM)	7	3/4	66
Heart disease	6	1/5	79
Lung disease	6	4/2	64
Rheumatic disorders	8	7/1	64
Total	30	18/12	65

Prioritization: In this phase the research topics collected in the consultation phase were prioritized through a survey study among a larger sample of patients. The survey was distributed amongst the panel of NPF. This panel consists of over 20.000 volunteers with a diverse medical background. All panel members received a general newsletter in which the survey was announced. If panel members indicated that they were interested to participate, they received a subsequent invitation to the survey in a separate mail distributed by NPF. Approximately 3.000 panel members positively replied to this announcement. In addition, patient platforms on social media were used to recruit respondents. Therefore, not only patients suffering from chronic diseases as targeted for the FGD and interviews, but patients in general (irrespective of the presence of a disease) were targeted for this survey.

The outcomes of the consultation were translated into research topics categorized in five research themes and presented in the survey as such. We used Qualtrics software (Version 2018, Qualtrics, Provo, UT) for the survey. Participants were asked to select their two most important topics for each of the five research themes. Subsequently, participants selected and ranked their top-3 from the list of 10 selected topics. At the end of the survey, patients were asked to suggest research topics they had missed in the survey. Data was collected on demographic characteristics, notably age and gender, as well as on presence of any disease. If respondents were interested to participate in a

meeting to establish a joint research agenda together with OHPs, they were requested to provide their e-mail address. Based on the survey data a top-10 research topics list of patients was determined.

Integration: To establish the joint research agenda, a Dialogue meeting was organized for patients and OHPs. The aim of this meeting was to integrate the prioritized research topics of OHPs with the prioritized research topics of patients. A total of 11 patients and patient representatives and 10 OHPs attended the Dialogue meeting. We aimed for an equal distribution of participants from both patients and professionals. The participating patients had a diverse background in terms of diseases. The ten participating OHPs represented a variety of OHPs, notably general dentists, specialized dentists, dental hygienists and a dental technician. In table 6.3 the characteristics of each participant is described. Five of the participating OHPs had attended previous meetings during the project to establish the top-10 of OHPs.

Table 6.3: Characteristics of each participant of the integration phase

Patients		OHPs	
Gender	**Condition**	**Gender**	**Profession**
F	High blood pressure	F	Dentist for patients with special needs
F	Rheumatic Disorder, DMII	F	Periodontologist
M	Psoriasis	F	Dental hygienist
M	Morbid Obesity	M	General dental practitioner
F	Fibromyalgia and Myalgic Encephalomyelitis	F	General dental practitioner
M	ADHD and PTSD	M	Dental technician
F	Myalgic Encephalomyelitis	M	Endodontologist
M	None	F	General dental practitioner
F	Bechterew's disease	F	Periodontologist
F	Patient representative Rheumatic disorders	M	Implantologist and Geriatric Dentist
F	Patient representative Diabetes Mellitus		

We invited patients based on two criteria. Firstly, at least two out of three prioritized topics of the participant had to be included in the patients' top-10. By this, we ensured the topics of the participant were represented at the meeting. Secondly, we aimed for a patient group that represented a broad variety in terms of medical background and invited participants accordingly.
An independent moderator facilitated an open and safe climate to ensure equal dialogue.[131] After explaining the aim of the meeting, the top-10 research topic list of OHPs and the top-10 research topic list of patients with diseases were presented. We stratified the results of the prioritization survey for respondents without chronic disease. There were 4 topics prioritized by this group that were not found in the top-10 of all patients.

These topics were added as a starting point for the consensus meeting, since these topics could be of importance for the public at large. The resulting list with the 24 most important topics formed the basis of the dialogue.

The participants were assigned to four smaller discussion groups (Dialog meeting groups; DMG), in which professionals and patients were evenly distributed. The aim of the DMGs was to discuss the priorities in-depth in a smaller setting. This increased mutual learning of other perspectives and stimulated reflection on one's own priorities. Each DMG was chaired by a moderator to ensure an equal contribution in the dialogue for both patients and professionals.
The DMG started with each participant naming his or her top-3 of most important topics of the 24 topics presented. These topics were not restricted to the stakeholder group they represented, that is, patients were allowed to prioritize topics from OHPs and OHPs were allowed to prioritize topics from patients. All participants explained their choices to provide other DMG participants insight into each other's perspective. Next, each DMG was asked to establish an integrated top-10 by means of a constructive dialogue. During this dialogue flexibility for rephrasing and adding topics was allowed if thereby consensus could be obtained. The results of each DMG were presented and discussed during a final plenary session. After this plenary session, each participant was again asked to select his or her individual top-3. Based thereupon, an integrated topics list shared by patients and OHPs was determined. The design of the meeting ensured room for individual choice and consideration while mutual appreciation and understanding for other opinions or perspectives was encouraged.

Data analysis

Consultation: All FGDs and interviews were audio recorded and transcribed verbatim in Dutch. Transcripts were analyzed and evaluated to identify problems in oral health (care) using a directed content analysis approach in Dedoose software (version 8.0.36, 2018, SocioCultural Research Consultants, LLC). Topics that were collected on sight during the FGDs formed the basis of the coding tree. New topics were added to the list based on transcript analysis when required. Problems mentioned by participants during the FGDs that overlapped or were strongly related were merged into research topics. The research topics were grouped into 5 overarching research themes after all FGDs and interviews were completed. This was done by PW and regularly discussed and checked by FH. PW and FH discussed the coding tree, and the coding of the first FGD was discussed in depth.

Prioritization: Survey data were analyzed by SPSS version 26.0 (2019, IBM). Selected research topics were sorted by their priority as reflected from the rank number based on

rank sum. The rank sum was calculated as a product of frequency of endorsement and weight for the ranking position.

Integration: The moderators of the DMGs clarified and discussed the results of their integrated top-10 topic list with each other and the project team. Specifically, topics that, according to the participants of the DMG, required rephrasing or merging were discussed and interpreted. The research topics prioritized by the DMGs were used for individual voting. The individual top-3 topics that were selected at the end of the dialogue meeting were used to determine the integrated top-10 topics list shared by patients and OHPs. Topics were ranked to establish the joint research agenda, including those chosen most frequently.

Ethical considerations

This project concerns Health Services Research which has been approved by the Ethics Committee of the Academic Centre for Dentistry (document number 2018009 dd 15th February 2018). Under the Medical Research Involving Human Subjects Act (WMO), Health Services Research projects is not considered as medical-scientific research.[132] As such, neither ethics clearance from a Medical Ethics Research Board, nor individual consent of volunteering participants of focus groups or surveys is required.

All participants in the consultation phase received written and verbal information beforehand. Participation was voluntary and all were informed that they could withdraw at any time. With prior verbal permission of participants, the interviews and FGDs were recorded and the transcripts were anonymized. Thereafter recordings were deleted.

The introductory text of the survey in the prioritization phase contained information on the background, the aims of the study and the voluntary basis of participation. In line with General Data Protection Regulation on data safety and privacy protection, tracing back responses to individuals participating in the survey for the prioritization phase was not possible.[133]

RESULTS

To establish a joint research agenda, the perspectives of OHPs and patients on research priorities were integrated. The research priorities of OHPs were established first and reported elsewhere.[120] In this section, we first describe the oral health (care) problems of patients that were identified in the consultation phase, and how these were translated into research topics. Next, we present the results of the survey in which patients priori-

tized research topics. Last, the results of the integration phase, the Dialogue meeting, are described.

Consultation phase

FGD participants provided disease-specific as well as more general problems concerning their oral health (care). When these were thematically grouped and listed as research topics five main themes emerged, notably: (1) *oral symptoms, (2) Lack of information on oral health (care), (3) problems in daily life, (4) organization and design of (oral) health care, and (5) the role of (oral) health care professionals.*

In this section we present the oral health (care) problems mentioned by patients per research theme. These problems were translated into 32 topics and presented per theme in the prioritization survey (table 6.4). All topics in this section are indicated by a number that refers to the topic number in the survey as found in table 6.4.

Table 6.4: Research topics per theme

Oral symptoms
1. Oral fungus
2. Problems with my jaws (pain, limited opening of my mouth, stuck)
3. Dry mouth
4. Inflammation of the gums
5. Caries/dental cavities
6. Periodontitis
7. Problems with dental implants
8. Sleep apnea
Lack of information on oral health(care)
1. Providing information on oral health regarding my medical condition
2. How patients can participate in decisions on their oral health care treatments
3. What medical information should I provide to my OHP, and how should it be provided
4. Where do I find reliable information about my chronic condition and oral health
5. Exchanging experiences and information with other people suffering from similar conditions
6. How patients can participate in scientific oral health research
Impact of oral health (care) problems on daily life
1. How to cope with problems concerning oral health, for which no solution is (yet) available
2. Effective Products for oral (self)care
3. Oral care products that I can use, despite my physical disability
4. How to motivate myself to take care of my oral health
5. How to motivate myself to visit my OHP
Organization and design of (oral) health care
1. How my oral health care professional can improve interaction with my medical professionals
2. The possibility to include oral health care to the basic insurance system
3. How access of oral health care practices can be improved for people with a physical disability.

Table 6.4: Research topics per theme (*continued*)

Organization and design of (oral) health care
4. Adjusting the time between consecutive (dental) appointments in order to optimally adjust them to my situation
5. Oral health care that is attuned to my condition.
The role of (oral) health care professionals
1. Increasing the knowledge of other health care professionals about the effect of my condition on oral health.
2 Increasing the knowledge of oral health care professionals about the effect of my condition on oral health.
3. Expanding knowledge of OHPs beyond their own field of expertise
4. Improve communication between OHPs and other health care professionals about my oral health problems
5. Improve communication between me and my OHP about my oral health problems and my chronic condition
6. Improve creation and updating my medical file by my OHP
7. Improve access to OHPs (e.g. Finding a new dentist after moving, or finding an OHP specialized in treatment of patients with my medical condition

Oral symptoms

In total, 8 topics concerning oral symptoms were mentioned during the FGDs and interviews. Some of these were unique for certain patient groups, such as oral fungus (1) for lung disease patients and painful jaws (2) for patients with rheumatic disorders. Other oral symptoms were mentioned in different FGDs. For example, problems due to a dry mouth (3) (DM, depression, lung disease) and inflammation of the gums (4) (rheumatic disorders, DM). Next to these, dental caries (5), periodontitis (6) problems with dental implants (7) and sleep apnea (8) were mentioned.

Lack of information on oral health (care)

Patients almost unanimously stated that they lack information concerning their oral health (care). The six identified research topics within this theme apply to multiple aspects of oral health (care). For example, some participants felt they needed more information from their OHP about the relation between oral health and a chronic condition (1).

Participant 3 from the DM FGD stated *"I think it is very important that the OHP actually discusses: Do you suffer from this and use that medication? It is important to take that into account (in your dental treatment plan)".*

Some patients felt they miss crucial information to make decisions about (future) oral health care treatments (2). Participant 3 from the heart disease FGD: *"Sometimes you have to make treatment decisions, and I think OHPs are often reluctant to give sufficient information".*

In the FGD of patients with lung disease there was discussion on which medical information should be shared with your OHPs (3). Some participants stated that as a patient you should provide all information on the first visit, others doubted the importance of such information to the OHP.

Another topic concerns sources of reliable information for patients about their chronic condition and oral health (4). As participant 5 of the heart FGD stated: *"I feel like the internet is like a fallen bookcase. You are just not sure the right books are on top.".*

Many FGD participants expressed they value the exchange of experiences and information with other people suffering from similar conditions, but are unaware of possibilities regarding this (5).

Some participants also missed information on how they could contribute to scientific oral health care research (6). *"As far as research is concerned, researchers may be working on all sorts of things. I wonder if there is research in the field of oral care, to which I can contribute in some way?" (Participant 5, DM FGD)*

Impact of oral health (care) problems on daily life
Six topics were identified that covered (the coping with) oral health (care) problems in daily life. Many participants searched for solutions to cope with these problems and limit the impact. For example, participant 4 of the DM FGD had brought his charcoal toothpaste, which he had purchased after a thorough internet search on how to reduce his gum problems. Other participants chose adaption to their situation as their coping strategy. This more general observation was translated in the topic: *How to cope with problems concerning oral health, for which no solution is (yet) available*. (1)
Many participants experiencing oral symptoms tried to find effective oral care products (2). In the FGD of patients with rheumatic disorders participant 5 stated that for her dry mouth "..*the gel just doesn't work. Neither does the spray. They all ended up at the back of a cabinet."* Other participants of the FGD for patients with rheumatic disorders reported problems with use of oral care products, e.g. a toothbrush that is too heavy, toothpaste tubes they are unable to open. This resulted in the topic: *Oral care products that I can use, despite my physical disability.* (3)

Other problems that patients encountered were a lack of motivation to take care of their oral health. For some, this applied to daily care (4); *"(...) because of the diabetes I am so tired and I don't have the energy to do anything anymore in the evening. Yes, then I neglect my oral care." (participant 6, DM)*
While others encountered a lack of motivation to visit an OHP (5); *"Of course, it is a form of self-care that you have to grant yourself and if you're feeling down you might make less of an effort". (participant 3, Depression)*

Organization and design of (oral) health care

Many participants encountered problems with the oral health care system, mostly because they experience it as an insular system with limited connection to other health care domains. Furthermore, many found oral health care to follow a one-size-fits-all principle with little attention for an individual situation. Four topics mentioned by the participants reflect this. First, some participants observed a lack of exchange of important information between OHPs and other health care providers as there is little integration between oral health care and other health care fields (1). Participant 6 in the FGD of patients with rheumatic disorders noticed: *"One of the advantages is that in recent years .., all those doctors discuss your case together. I don't understand why the dentist is still not part of that."*

Second, the (Dutch) dental insurance system does not consider the presence of a (chronic) condition as a reason of additional expenses required for maintaining oral health (2). Third, for some participants the one-size-fits-all experience in oral health care was reflected in the fact that some oral health care practices are not adequately designed for people with chronic conditions (3). Participant 4 from the FGD of lung diseases stated; *"The dental hygienist is upstairs. So, you have to climb up the stairs if I go for a check-up and then I am completely out of breath".*

Next to the physical design of the practice, participants also missed tailored recalls (4). A quote of participant 3 of the FGD of rheumatic disorders clarifies: *"I had to persuade the dentist to allow me to visit three times a year instead of twice a year."* Moreover, some participants wondered why oral health care and dental treatments are not tailored to their specific situation (6). As participant 1 from the lung disease FGD pointed out: *"The problem with dentists is that they obstruct my nose during the treatment with all kind of instruments devices they use".*

The role of (oral) health care professionals

The seven topics in this theme all concern the role and responsibility of OHPs and other health care professionals. For most part, these topics reflect lack of knowledge and communication issues. Participants encountered ignorance on different occasions and levels. Some found their OHP as well as their other health care providers ignorant to the effect of their condition on their oral health as reflected in the topics *Increasing the knowledge of other health care professionals about the effect of my condition on oral health* (1) and *Increasing the knowledge of oral health care professionals about the effect of my condition on oral health* (2). As participant 7 of the FGD of rheumatic disorders stated:

"What I notice is that the rheumatologist didn't say anything at all about the connection between my disease and the mouth. Also, from the rheumatology nurse, I've never heard

anything about it. Uh, my old dentist didn't say anything about that either. I think they just don't know"

Participants found the knowledge of OHPs limited and felt OHPs should expand their knowledge (3). *"An oral surgeon only covers one part of the body, just like a dentist, they never take the rest of the body into account. That's something that bothers me."* (Participant 4, DM)

Moreover, participants experienced problems in communication between professionals. Only limited information exchange on oral health problems between OHPs with other health care providers takes place (4). Another topic concerned the need to improve communication between the OHP and the patient (5): *"Well, that downplaying of the oral problems by my dentist makes me feel like I am not being taken serious and that I'm not getting the right information*". (Participant 5, Rheumatic disorders)

A recurrent subject in each FGD was how OHPs create and update their medical files (6). Some participants were not aware that OHPs are obliged to ask their patients about their medical status. On the other hand, some participants do not want to inform their OHP every visit. *"Because you don't really want to talk about your condition all the time. After a few visits you don't need your OHP to talk about your condition again".* (Participant 4, Lung disease)

Finally, the role of OHPs in the improvement of accessibility to oral health care was discussed (7). A participant stated "*I would like to have access to a list of specialized OHPs for my rheumatic disorder.*" (Participant 4, Rheumatic disorders)

Prioritization phase

The 32 topics in table 6.4 were presented for prioritization in an online survey. In total - so via the patient panel of NPCF and social media - 1.495 patients participated and returned a complete survey. Characteristics of the participants of the survey are displayed in table 6.5. Of the respondents, 321 had no (chronic) disease. 666 respondents indicated they (also) had other diseases than DM, cardiovascular diseases, depression, rheumatic disorders, or lung diseases. Diseases that were often mentioned were cancer, physical disabilities, multiple sclerosis, different types of bowl diseases and mental illnesses.

Table 6.5: Respondents of the survey in the prioritization phase

Demographics		
Gender	Male	588
	Female	897
	Total*	1485
Age	Mean (sd)	61 (12)
Level of education	Low	125
	Middle	501
	High	852
	Total*	1478
Condition	Rheumatic disorder	452
	Heart disease	270
	Diabetes I/II	225
	Depression	125
	Lung Disease	308
	Other	666
	Total**	2046
	None	321
Visit OHP	Yes	1389
	No/missing	106
	Total	1495

* Not all respondents completed the demographic data
** Multiple answers were allowed

Table 6.6 presents the top-10 research topics sorted by the product of their frequency of endorsement and priority. With the rank of each topic the theme they originated from is given.

Topics concerning oral symptoms (#3 and #4) and (financial) access to oral health care were highly prioritized. The most important topic for patients was the possibility to add oral health care to the standard basic health care insurance benefits package for people with chronic diseases. In total, 667 respondents chose this particular topic among their top-3 priorities, of which 304 respondents as #1. The topic that ranked as second most important was *effective products for oral health self-care*, which was chosen among the top-3 by 375 respondents of which 108 respondents as #1.
When we stratified the results of respondents with one of the beforehand selected chronic disease, we saw substantial differences between the prioritized topics. Only the topics #1 and #2 of the patients top-10 were found in the top-10 for each patient group. The other eight topics varied for each patient group, and this variation was mainly explained by disease specific topics in the top-10 of a specific patient category. For

Table 6.6: Top-10 research topics of patients

Research topic		Research theme	Ranksum
I would like to see research done into:			
1.	The possibility to include oral health care in the basic insurance system	Organization and design of (oral) health care	1469
2.	Effective Products for oral (self)care	Impact of oral health (care) problems on daily life	709
3.	Problems with my gums, related to my disease or medication	Oral symptoms	438
4.	Dry mouth, related to my disease or medication	Oral symptoms	411
5.	Oral health care that is attuned to my condition.	Impact of oral health (care) problems on daily life	388
6.	Expanding the knowledge of (oral) health care professionals beyond their own expertise.	The role of (oral) health care professionals	352
7.	How patients can participate in decisions on their oral health care treatments.	Information on oral health supplied to patients	319
8.	How access of oral health care practices can be improved for people with a physical disability.	Organization and design of (oral) health care	307
9.	How my oral health care professional can improve interaction with my medical professionals	Organization and design of (oral) health care	299
10.	Increasing the knowledge of oral health care professionals about the effect of my condition on oral health.	The role of (oral) health care professionals	282

patients with rheumatic diseases, problems and pain in the jaws was highly prioritized, for heart disease this was sleep apnea, for DM motivation for selfcare and for depression motivation to visit an OHP. In the top-10 of lung disease patients, problems with implants was prioritized.
Topics that were suggested by respondents and were not included in the survey covered privacy issues in oral health care, oral health care for patients with dental anxiety and oral health care for elderly patients.

Patients without a chronic disease prioritized four topics that were not found in the top-10 of patients with chronic disease(s) namely: *How to motivate myself to take care of my oral health*; *How patients can participate in scientific oral health care research*; *To improve access to oral health care professionals* and *Adjusting the time between consecutive (dental) appointments optimally to my personal situation*. These four topics were added to the list of priorities of patients for the integration phase, to broaden the scope of their research topics.

Integration phase

The goal of the Dialogue meeting was to establish a joint research agenda that reflects both OHPs and patient perspectives, and is supported by both groups. To do this, participants simultaneously prioritized the 10 research topics of the OHPs (Table 6.7) and the 14 topics of patients.

Table 6.7: The top-10 research topics of OHPs

1.	What's the most effective method to change behavior to improve oral health?
2.	Oral health care for the geriatric patient: What are the implications for the treatment plan and treatment?
3.	What is the relation between (chronic) illnesses and oral health?
4.	What is the effect of preventive interventions? (dental education, sealants, supragingival calculus and / or professional removal of dental plaque, fluoride application)
5.	Tooth wear: When should it be treated, and what is the best treatment (method)?
6.	What is the relation between nutrition/diet and oral health?
7.	When has dental caries progressed so much that invasive treatment (drilling and filling) is required? What defines this treatment decision?
8.	What is the most effective supportive periodontal therapy (SPT) (method and frequency)?
9.	What is the effect of (foreign) material use in the mouth on general health?
10.	Can we predict (the development of) caries based on the current knowledge?

Dialogue Meeting Groups

All 4 DMGs succeeded in reaching consensus over a list of prioritized topics. Among the 4 groups the discussions resulted in considerable variability on the topics prioritized. Some topics were merged since the participants agreed they overlapped. For example, the topic on *behavior change* (originating from the top-10 of OHPs) was merged with the topic on *the effect of prevention* in DMG 2 and with the topic *how to motivate myself to take good care of my oral health* in DMG 3. The participants of DMG 4 merged the topic on *behavior change* with the topic on *prevention* and *nutrition.* Thereafter, the top-10 priorities of the 4 discussion groups together included 17 topics (Table 6.8). Four topics were not found in the list of 17 topics as they were merged into one of these topics, namely: *the effect of preventative interventions (*in the topic on *behavior change), the relation between nutrition and oral health (*in the topic on *behavior change),* and *how the time between OHP appointments should be adjusted to provide adequate care (*in the topic *How patients can participate in decisions on their oral health care treatments).* The topic on *adjusting time between appointments* was merged with the topic on *participating in decisions on oral health care*. The other three topics that were dismissed as of lesser importance concerned: *treatment of tooth wear, supportive periodontal treatment* and *effective products for oral self-care*. Most of the topics that needed rephrasing or merging, according to the participants, originated from the top-10 of OHPs.

Plenary reflection

During the plenary discussion every participant was asked to select three topics. For 8 topics there was strong support from participants from both stakeholder groups while there was limited support for the remaining 8. One topic, notably *Problems with my gums, related to my disease or medication*, was selected by none of the participants. Hence a top-8 rather than a top-10 of research topics was established and agreed upon by both OHPs and patients and therefore qualified for the shared research agenda for oral health care. (Table 6.8)

Of the 8 highest prioritized topics, 5 topics originate from the top-10 of patients and 3 topics from the top-10 of OHPs. Strikingly, these topics originated from #5 downwards in the patients top-10, except for the topic on including oral health care in the basic health care insurance. The final votes of OHPs showed clear convergence: topic #1, #2 and #3 received 9, 8 and 4 votes from OHPs respectively. The other 5 topics of the 8 highest prioritized topics received only one or two votes from OHPs. The voting of patients was much more differentiated. All 8 highest prioritized topics received between 2 and 4 votes, and no single topic could be designated as most important for this stakeholder group.

Strikingly, only one and no votes respectively were attributed to topics concerning oral symptoms during the final voting, while these topics were highly prioritized in the prioritization survey. In two of the four DMGs, topics concerning oral symptoms were implied in the topic *What is the relation between (chronic) illnesses and oral health?.* Possibly, the merging of specific oral symptoms into a broader topic has stimulated participants to strategically vote for this broader topic in which more perspectives are represented.

In table 6.8 the 17 research topics used for prioritization during the Dialogue meeting are displayed.

Consensus through the dialogue resulted in topics that were found important to both patients and professionals. These were not self-evident the highest ranked topics from a particular stakeholder group. For example, the topic on effective products for oral self-care was #2 priority in the top-10 of patients but in the Dialogue meeting was not selected for the final research agenda, while the topic *How my oral health care professional can improve interaction with my other medical professionals* ranked #9 in the top-10 of patients but was ranked #3 in the joint research agenda.

Table 6.8: The 17 research topics, as ranked during the Dialogue meeting

	Joint research agenda	# Votes (patients / OHPs)
1	What is the most effective method to change behavior in order to improve oral health?	13 (4 / 9)
2	What is the relation between (chronic) illnesses and oral health?	12 (4 / 8)
3	How my oral health care professional can improve interaction with my medical professionals	6 (2 / 4)
4	Oral health care that is attuned to my condition.	5 (4 / 1)
5	The possibility to add oral health care to the basic insurance system	5 (4 / 1)
6	Oral health care for the geriatric patient: What are the implications for the treatment plan and treatment?	4 (2 / 2)
7	Expanding the knowledge of (oral) health care professionals beyond their own expertise.	4 (3 / 1)
8*	How patients can participate in decisions on their oral health care treatments.	4 (3 / 1)
9	Can we predict (the development of) caries based on the current knowledge?	3 (1 / 2)
10	Increasing the knowledge of oral health care professionals about the influence of my condition on my oral health.	2 (1 / 1)
11	To improve access to oral health care professionals	2 (2 / 0)
12	How patients can participate in scientific oral health care research	2 (2 / 0)
13	When has dental caries progressed so much that invasive treatment (drilling and filling) is required? What defines this treatment decision?	1 (0 / 1)
14	What is the effect of (foreign) material use in the mouth on general health?	1 (1 / 0)
15	Tailoring the design of an oral health care practice to people with a physical disability.	1 (1 / 0)
16	Dry mouth, related to my disease or medication	1 (1 / 0)
17	Problems with my gums, related to my disease or medication	0 (0 / 0)

* A top-8 of research topics was agreed upon as the joint research agenda for oral health care

DISCUSSION

In this study we have described the establishment of the research priorities of patients and how these were integrated with the priorities of OHPs into a research agenda for oral health care. It represents a list of topics that, through consensus, was prioritized by OHPs and patients and was established through a systematic and transparent methodology. The research agenda covers a wide range of topics from prevention and treatment of oral disorders to health system research and personalized (oral) health care. Some of the topics on the research agenda represent existing knowledge gaps regarding oral health care as still many issues about treatment, prevention and oral health care services remain unanswered.[35,37,38]

Since oral health is a public priority, research to provide information on the prevention and treatment of oral disorders is essential. The burden of oral disorders for the individual as well as socio-economic burden is high due to its high prevalence - dental

caries and periodontitis rank among the most prevalent diseases worldwide.[134] However, the people suffering from and treating oral disorders, to whom the results from research often apply, are rarely consulted in research agenda setting. In our study, the problems of patients and treatment uncertainties from daily practice by OHPs have provided important insights in the knowledge gaps that are important for the end-users of research, and thus exceed the researchers and policy makers perspective. The results of the research agenda indicate that according to patients and OHPs not only prevention and treatment are priorities for future research. Topics that cover affordability and accessibility as well as health system research and organizational issues were prioritized. By considering different perspectives, this research agenda has uncovered directions for future research that go beyond many evident research topics and include less obvious research topics.[26,135]

To uncover these topics, it was essential to consult OHPs as well as patients. Previously, OHPs have been consulted to identify research priorities in the field of oral health care, but these concerned priorities that were classified as a priori defined topics, notably on oral diseases, conditions, symptoms, or medical specialization.[90,92] Projects in which OHPs and patients are both consulted are rare.[136]

Interestingly, simultaneously as the research agenda project was running in the Netherlands, a Priority Setting Partnership (PSP) was executed in the UK.[91] The goal of this project was similar to our project, but the approach differed. The consultation in the PSP for patients was via an online survey while we used FGDs. The results of both projects are quite similar. Many topics showed substantial overlap on *prevention of caries*, *accessibility* and *cooperation with other health professionals*. The most important difference was the prioritization of topics that concerned personalized care (#4 and #8 in our research agenda) in our research agenda, while the PSP does not contain such topics. Possibly, the consultation via FGDs allowed for more in-depth topic analysis than an online survey, which has resulted in the inclusion of these topics in the top-10 of patients. Also, the Dialogue meeting was designed not only to reach consensus on a research agenda, but to stimulate mutual learning from other perspectives. The prioritized topics of personalized care predominantly reflect the perspective of patients. We believe this is a strong indication that by our methodology, we succeeded not only to establish a joint agenda, but that through the dialogue the experiential knowledge of patients was acknowledged as of high importance by both patients and OHPs.

Strengths and limitations

There are a number of strengths to this study. An important strength was the inclusive and widespread consultation, where everyone of interest had been offered the opportunity to contribute. As a result, we have established a research agenda that represents the research priorities of a large patient group and a wide diversity of OHPs.[120]

The involvement of patients and OHPs in the field of oral health care was not self-evident.[135] Especially the engagement of patients in our project appeared a challenge, as the patient group is difficult to define; everyone qualifies as an oral health care patient. This bared the risk that people do not feel addressed, with low engagement as a possible result. However, through our approach of targeting specific patient groups (based on (chronic) diseases) and a survey thereafter, this barrier was bypassed.
We applied a methodology (the Dialogue method) which facilitated the equal use of the input of both patients and OHPs. As we consulted both groups individually we used this phase in the process to stimulate sensitizing the professionals and empowering patients. This process prior to the Dialogue meeting, the design of the Dialogue meeting as well as the use of sensitive moderators have encouraged equality and respect for other perspectives, which is required to reach consensus and establishment of the research agenda.[131]
Through our approach we have consulted a fragmented group of patients, which has resulted in many topics identified in the FGDs of patients that at first glance seemed very disease specific. Through thematic analysis we defined broader research topics based on common denominators. The results of the prioritization phase of patients were therefore surprising. There was clear conversion for the two highest ranked topics (*The possibility to add oral health care to the basic insurance system* and *Products for oral (self)care that are effective*). For the other eight topics the prioritization was much more heterogenic, as could be expected based on the heterogeneity of the patient group.
This heterogeneity is also found in the final research agenda as the prioritization of patients was far from unanimous. However, the method of using the ranking of both patients and OHPs revealed a clear top-8 of research topics, that diluted the effect of the heterogeneity. In the final voting, 5 out of 8 topics originated from the top-10 of patients and were included in the final research agenda. As these were prioritized by both patients and OHPs, we conclude that through our methodology the effect of fragmentation was largely overturned.

The main limitation in this study is the restricted inclusion of patients with chronic diseases in the consultation phase, as this possibly has had an effect on the generalizability to a larger public. However, in the prioritization phase there were no restrictions for participants, in which 21% of the respondents indicated they had no disease. To further counterbalance the effect of our patient selection in the consultation phase, we used four topics prioritized in the survey by patients without chronic disease in the dialogue meeting as these topics could be of interest for a larger public. Two of these four topics (*access to oral health care* and *participate in scientific research*) were prioritized in the final dialogue. However, since we did not include patients without chronic diseases in the consultation phase, we might have missed important topics.

During some FGDs and the Dialogue meeting, it was stressed that through our approach, the perspective of children and adolescents was underrepresented. Some topics that were prioritized might be applicable to patients of all age groups, for example the topic on *behavior change* and *the prediction of caries*. However, it is important that the research priorities for this patient group are identified and we therefore urge researchers in the field of pediatric dentistry to develop a research agenda for this specific group as well.

Another limitation is that many of the topics on the research agenda are broadly formulated. Researchers should therefore define research questions based on the research agenda, in conjunction with both patients and OHPs, when targeting a specific research area. By giving both patients and OHPs the main voice in this research agenda setting process, and include their perspectives in the following phase of designing new research, the usability of research results and therefore the impact and value of research will increase.[6]

The reported research agenda concerns the research priorities shared by patients and OHPs regarding oral health (care) from the perspective of health and wellbeing. It covers a wide range of topics that for a large part were contributed by patients, but were prioritized by both stakeholder groups. The topics of the research agenda indicate that researchers should not only focus on the prevention and treatment of oral diseases. Research topics on affordability and accessibility as well as health system research and organizational issues were highly prioritized in this study. To respond to the needs of both patients and OHPs, an important task lies with researchers, research policy makers and research funders to design new research based on the topics on the research agenda, many of which are currently underrepresented in the portfolio of oral health research.

Chapter 7

A research agenda on oral health care as a boundary-object that unites the perspectives of patients and practitioners

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Health Expectations 2021;24:1701–1712

ABSTRACT

Context: A research agenda for oral health care was established in the Netherlands using the Dialogue Model. This project served as a case study in which we applied boundary-work theory as a framework to understand boundaries (i.e. demarcations) between and within groups, and how these boundaries can be overcome.

Objective: To gain insights into the boundaries encountered when setting a research agenda, we analysed how this agenda served as a boundary-object (i.e. circumstances, situations or material that connect actor groups and allow boundary crossing) that facilitated crossing boundaries and uniting the perspectives of patients and practitioners.

Methods: We used a thematic approach to analyse researchers' observations, meeting materials, emails, interviews with patients (n = 11) and a survey among patients and practitioners (n = 18).

Results: Setting the research agenda helped to cross boundaries in oral health care, which demonstrates its role as a boundary-object. First, this made it possible to integrate research topics representing the perspectives and priorities of all patients, and also to unite those perspectives. It was essential to involve practitioners at an early stage of the project so that they could better accept the patients' perspectives. This resulted in support for an integrated research agenda, which facilitated the crossing of boundaries.

Conclusions: The research agenda-setting project was found to serve as a boundary-object in uniting the perspectives and priorities of patients and practitioners.

Patient contribution: Patient involvement in this case study was structured in the process of research agenda-setting using the Dialogue Model.

INTRODUCTION

A research agenda – a list of prioritized research topics – is an essential tool for providing directions for future research. At the same time, it also supports funding agencies and research institutes in their programming and implementation of health care research.[137] Traditionally, agenda-setting for health care research has been driven mainly by those involved in conducting research, notably researchers and funding agencies. Patients are rarely involved in initiating health care research [138,139] and as such agenda-setting in health care can be viewed as an approach that is driven by interest and supply. From 2000 onwards, patient involvement in medical research has gradually increased.[139,140]

Involving patients in research agenda-setting allows them to represent their preferences and experiences as the end-users of health care, and taps into their views, needs and perspectives in daily life and health care practice. As such it is assumed that patient involvement will result in research that caters more specifically to their needs because they provide unique insights as experts in their own right. [119,135,141–144] Moreover, it has been argued that it is a patient's right to be involved in issues that affect them personally.[145]
The involvement of patients in research agenda-setting has shown to enhance their empowerment [146] and may facilitate acceptance of a research agenda. [118,147] Patient involvement also adds to the legitimacy of research policies and decision-making processes [115,119,148] by stimulating research topics that patients consider important.
Involving patients is, however, not self-evident and presents various challenges. Elberse and colleagues [135] identified ways in which patients were excluded from setting research agendas. Exclusion can occur when patients' input is dismissed or regarded as irrelevant or when researchers and practitioners use too much jargon. Apart from their exclusion, involving patients in health care research involves addressing other challenges: (1) policies on involving patients as co-creators of research can be ambiguous; (2) identifying the target group of patients and how they should be approached is not straightforward; and (3) researchers and other stakeholders do not value patient involvement.[149]

While patient involvement is becoming common in research on health care issues, this often lags behind in domains in which a patient group is not easily defined, such as oral health care.[135,150,151] To address this, a research agenda for oral health care was established in the Netherlands. The two most important stakeholder groups for this research agenda, patients and OHPs, were consulted. The OHPs included general dentists, specialized dentists, oral and maxillofacial surgeons, orthodontists, dental hygienists and (prosthetic) dental technicians. The patients consulted were high-risk groups in relation to oral health care issues (patients with diabetes, lung problems, cardiovascular diseases, depression or rheumatism).

In this study we explored boundaries in relation to the involvement of and interaction between patients and practitioners in the process of research agenda-setting using boundary-work theory as a theoretical framework.

Boundary-work theory

Boundary-work theory [152,153] was used to guide this study. Boundary-work theory originates from sociology and was used to explain boundary-work in the domain of science by examining social boundaries that scientists set to distinguish science and its products from non-scientific activities.[152] Other social domains, such as educational sciences [154] and health care practice,[151,155,156] later adopted the concept of boundaries.

Boundaries can be viewed as dissimilarities between objects, individuals, ideas or actions that create distinctive categories among these.[148,157,158] They are demarcations of professions, and within that, demarcations of disciplines, specialties, theoretical orientations or interests within a profession may emerge.[152] Such demarcations manifest as socially constructed boundaries of a social or symbolic nature.[157] They often contribute to the autonomy and authority of professions and disciplines [159] and play a role in inter-professional interactions. In this way, a boundary is often perceived as an obstacle that persons or groups experience that hinders or precludes their communication or collaboration or both. Such boundary separates them, but can be crossed when they are brought together to engage in resolving this hindrance. For example, an obstacle that could occur between patients and practitioners could be a lack of understanding for each other's perspective. This lack of understanding enhances the difference between the distinctive categories of patients and practitioners and in this way acts as a boundary. Individuals or groups are continually able to define, sharpen or soften these boundaries in an attempt to maintain or strengthen their autonomy, authority and interests. Such action is referred to as boundary-work.[152,153]

Three types of boundary-work can be distinguished: (1) *protection*, (2) *expulsion*, and (3) *expansion.*[153] Protection is directed at maintaining the existing boundaries. Expulsion sharpens boundaries through the monopolization of professional authority, resources and results by the rejection of other individuals, while expansion implies crossing or entering different categories and creating a new, broader perspective. The Dialogue Model is based on this latter principle of boundary-work.[151]

In relation to expansion boundary-work, *boundary crossing* is especially relevant. Boundary crossing was established by Suchman [160] (p.25), who defined it as "to enter onto territory in which we are unfamiliar". Engeström et al [161] (p. 319) defined boundary crossing as "negotiating and combining ingredients from different contexts to achieve hybrid situations". Crossing boundaries therefore describes the process of entering different categories by negotiation and interaction, which leads to the transformation of categories and the creation of a new, broader perspective. In relation to oral health care,

one could think about practitioners going beyond their focus on technical procedural aspects of oral health care. By crossing the boundary to reach patients and using insights from patients' perspective, a more complete picture about oral health care arises.

To facilitate boundary crossing, the identification or development and use of boundary-objects is an essential process. Boundary-objects were defined by Star & Griesemer [162] (p 393) as "…objects which both inhabit several intersecting social worlds and satisfy the (informational) requirement of each of them." In this way, boundary-objects fulfil a symbolic role as a bridge because they connect actor groups and allow them to cross a boundary.[162] Boundary-objects should allow the involved actor groups, on the one hand, to adapt to the conditions and needs of all, and, on the other hand, to establish a common identity.[162] A boundary can thus be crossed when persons or groups engage to jointly remove boundaries or when a boundary object initiates communication or collaboration. For example, the research agenda might act as a boundary object between patients and OHPs, because setting the research agenda helps to understand each other's perspective better. In this way, the possible boundary of lack of understanding is crossed. In addition, the research agenda can thus be seen as a communication tool which allows people from different groups to talk to each other.

METHODS

To gain insight into boundaries encountered when setting a research agenda and how the research agenda might function as a boundary-work object, we evaluate the process of developing a research agenda in the area of oral health care as a case study and reflect on how each method used in this process helped to move toward the development of the research agenda.

Case description

In the Netherlands, a research agenda for oral health care was constructed with input from oral health care patients and OHPs using the Dialogue Model.[115] To accomplish this, a staged approach was used. First, a research topic list of OHPs was created in 2016 and 2017. Next, a patients' research topic list was constructed in 2018. Finally, in 2019, the perspectives of patients and OHPs were combined in a consensus session to establish a shared research agenda. Box 7.1 describes the stages of the Dialogue Model and corresponding research activities, while Box 7.2 presents the shared research agenda. The construction of the research agenda is discussed in detail elsewhere.[120]

BOX 7.1 – Phases of the Dialogue Model and corresponding research activities

The Dialogue Model, consisting of six phases, was developed and validated to structure the process of patient involvement in research agenda setting in the Netherlands.[115] Central to the Dialogue Model is the recognition of stakeholders' different perspectives, which stimulates direct interaction and the co-production of knowledge.[123] The Dialogue Model is a multi-phased participatory approach that is used for setting a research agenda with multiple stakeholders including patients. It is based on six underlying key principles specifying how the process needs to be conducted: (1) active involvement of patients; (2) conductive social conditions; (3) respect for patients' experiential knowledge; (4) ongoing dialogue, paying particular attention to reflexive learning processes; (5) emergent and flexible design; and (6) impartial process facilitation. The Dialogue Model operationalizes *consultation* and *collaboration* among multiple stakeholders and emphasizes learning processes by stimulating dialogue between stakeholders.[115] The model has been applied in many agenda-setting processes.[135] The model has an emergent design in which activities are structured in six phases: exploration, consultation, prioritization, integration, programming and implementation. Programming (phase 5) and implementation (phase 6) were beyond the scope of this research. In this project we focused on the first four phases:

1. ***Exploration:*** In this phase, the first insights into the problem are gained and stakeholders' various needs and wishes in relation to the required process are identified (*identification of conductive social conditions*). During the exploration phase, a professionals' stakeholder meeting was organized to gain support for the project. Participants (n=25) included a broad variety of opinion leaders in the oral health care field (n=15), researchers (n= 5), research policy makers (n=3), a representative from the dental industry and an expert in patient involvement. In addition, five patients' organizations were approached to explore the feasibility of the project and to collaborate in recruiting patients.
2. ***Consultation:*** During this phase, the goal is to identify separate research topics for each stakeholder group to ensure enclave deliberation. OHPs were asked via a questionnaire (n = 210) to name subjects for future research. These were grouped into themes and translated into research topics. A different approach was used for patients. The problems that patients experience in their daily lives regarding oral health care were mapped during focus groups. A total of four focus groups took place with high-risk groups (patients with diabetes [n = 7], lung problems [n = 6], cardiovascular diseases [n = 6], or rheumatism [n = 8). One focus group was arranged for each high-risk group. It was difficult to recruit patients with depression to participate in a broad discussion, so to take account of their perspective on barriers, it was therefore decided to conduct interviews (n = 3) separately with this particular patient group. Subsequently, the problems were grouped into themes and translated into research topics by the researchers.
3. ***Prioritization:*** In this phase, the goal is to prioritize research topics for each group separately. In a second survey, OHPs (n = 235) prioritized the research topics extracted from the first survey, which resulted in a top-10 list for future research. Regarding patients, the research topics extracted from the focus groups and interviews were checked for endorsement and prioritized in a survey study among a larger sample of patients (n = 1495) to establish their top-10 topics for future research.
4. ***Integration:*** During this phase, the goal is to integrate the list of research topics of OHPs with the research topic list of patients via dialogue. To create a fruitful consensus meeting, values like respect, tolerance, willingness to listen, openness and inclusion are vital to both stakeholder groups and researchers.[135] Integration was accomplished via a consensus session in which the perspective of OHPs (n = 10) and the perspective of patients (n = 11) were combined to establish a shared research agenda. OHPs included general dentists, specialized dentists, dental hygienists and a dental technician. We approached patients who had indicated they wanted to participate in the consensus meeting in the prioritization survey. We invited patients with a diverse background in terms of diseases, whose three priority topics were included in the top-10. The top-10 topics of patients and OHPs were used as a starting point for discussion. At the end of this meeting a final voting took place in which three topics were selected per participant. The shared research agenda consisted of 8 topics.

BOX 7.2 – Research agenda

A shared agenda with eight priority topics for future oral health care research was established, containing eight topics prioritised by patients and OHPs. The shared research agenda consists of five topics originating from the patients' topic list (#3, #4, #5, #6 and #8), two topics originating from the OHPs' topic list (#1, #7) and one topic that was found on both lists (#2).
Topics on the shared research agenda:

1. How can we change behaviour to improve oral health care?
2. What is the relation between oral health care and (medical and psychological) conditions?
3. How can we increase the involvement of OHPs with other health care practitioners?
4. Research on how oral health care can be adapted for patients with chronic diseases
5. Research on how insurance for oral health care can be added to basic health insurance
6. Research on how the knowledge of OHPs can be increased beyond their expertise
7. Oral health care for elderly people: what are the consequences of treatment and treatment planning?
8. How can shared decision making in oral health care be implemented?

Data collection and participants

The activities that were carried out to establish the research agenda are presented in Box 7.1. In addition to these activities, we also took steps to evaluate the process and to identify boundaries encountered, how they were crossed and to what extent the research agenda functioned as a boundary-object. These evaluation actions served as our central data gathering methods and comprised the following data sources:

- *Researchers' observations during each phase of the Dialogue Model:* Observations were made during all the activities that were undertaken to create the research agenda (Box 7.1). During these activities, the researchers observed the participants' behaviours, their input into the research agenda and their behaviour towards each other. In addition, possible boundaries of setting the research agenda and how they were addressed were observed.
- *Documents related to stakeholder meetings:* During the project, three stakeholder meetings took place (see Table 7.1). These meetings were attended by approximately 30 participants, of which half were OHPs. Other stakeholders were patient representatives, researchers, medical practitioners, policymakers, representatives from the dental industry and research funders. Documents related to stakeholder meetings, such as reports, e-mails and notes from group discussions, were collected and studied.
- *Emails received from patient organizations (n= 5):* Responses from patients' organisations were filed and studied to map the boundaries encountered.
- *Interviews with patients:* After the four focus groups that were conducted in the consultation phase (see Box 7.1), we interviewed several patients who participated in them. During these semi-structured face-to-face interviews (n = 11), the emphasis

was on the experience of meaningful involvement and not on the outcomes of the focus groups.

- *Questionnaire after consensus session:* After the consensus session (Box 7.1), participants (n = 21) received a short questionnaire (see Appendix A) on how they had experienced this session and were asked how they thought the session could be improved. The questionnaire was filled out by 18 participants.

Table 7.1: Number of participants and main results of the stakeholder meetings

	Meeting 1: 2015	Meeting 2: 2017	Meeting 3: 2018
Total number of participants (oral health care practitioners / other stakeholders)	25 (15/10)	31 (16/15)	32 (14/18)
Main goals of the meeting	• Introduce project • Consultation on method of topic collection among OHPs • Support and commitment for the project	• Discuss results of topic collection • Consultation on method of prioritization among OHPs • Introduction of patient engagement during project • Support and commitment for the project	• Discuss results of prioritization and reach consensus on top 10 • Further consideration of patient engagement in project • Support and commitment for the project
Main results	• Consensus about the target group was reached: the full range of OHPs should be included (e.g. dental specialists, dental hygienists) • Recommendation: development of an online survey to identify and collect topics	• The final research agenda will have to include an equal contribution from patients and OHPs • Consensus on the suggested method for prioritization was reached	• Agreement on the top-10 research topics was reached among OHPs

Data analysis

All interviews were audio-taped and transcribed verbatim in Dutch. Observations, document analysis and conversations within the project team and with others (in person or via email) were noted in detail in the researchers' logbook.

The interview-transcripts and logbook (including observational data) and questionnaire on points for improvements after the consensus meeting were analysed using thematic content analysis.[163] Thematic analysis is a method to identify, analyse and report under-

lying patterns and themes. The data were analysed by applying the theory of boundary-work; anticipated and encountered boundaries formed the basis of the coding. In this process, information from the transcripts and logbook was complemented with improvements points gathered in the questionnaire to extract information on boundaries encountered in the process of establishing a research agenda. General boundaries were defined, as well as boundaries within stakeholder groups and between stakeholders. For example, we had expected to find a boundary between patients and practitioners, but analysis of the data also revealed a boundary among groups of patients, arising from the diversity of oral health care patients. The strategies that were used to cross boundaries were examined and the role of the research agenda as a boundary-object was also investigated. The coding process was performed in an iterative manner by authors FH and PvdW with assistance from CP. Coders checked each other's coding and discussed differences until consensus was reached. In addition, coding was discussed within the research team, regularly.

Ethical consideration

All participants who took part in activities related to setting the research agenda as well as activities that were carried out to evaluate the process received written and verbal information beforehand about the goal of this research project. It was explained to them that participation was voluntary and that they were able to withdraw at any time without any consequences.

Approval of Ethics Committee of Academic Centre for Dentistry Amsterdam was provided on 15 February 2018, with the document number: 2018009. During the collection and handling of data, the applicable privacy and data protection regulations were followed so that data could not be traced back to individuals.

RESULTS

Several boundaries were encountered during the research agenda-setting process. We differentiated between general boundaries, such as possible lack of support, and boundaries related to specific stakeholders, such as the difficulty in reaching oral health care patients. In addition, boundaries between and within groups of patients and OHPs were distinguished. For each boundary, we describe which strategies were used to overcome them and the role of the research agenda in this process. An overview of the results is presented in Table 7.2.

Table 7.2: Boundaries, strategies and the role of the research agenda

Stakeholders	Boundary	Strategy/reaction	Role of research agenda
General	Possible lack of support for the research agenda	Engagement of stakeholders from the start of the project and during the entire process (e.g. via structural stakeholder meetings during project)	Setting the research agenda created the involvement of different stakeholders in the agenda-setting process
	Reach representative group of patients and OHPs	Inclusion and transparency; Dialogue Method	Creating a research agenda via the Dialogue Method ensured representation of patients and OHPs
Patients	Difficulty in reaching oral health care patients because they are not a well-organized patient group	Focus groups with patients with chronic diseases (for which a patient organization or patient platform exists)	Research agenda-setting created awareness of oral health care issues among patients (with and without chronic diseases)
	The perception of patient organizations that oral health was not a topic of interest for their patients	Bottom-up recruitment strategies: approaching individuals (via social media or patient meetings) with specific interest in the topic	Awareness is created among patient organizations that oral health care problems are important to patients because they influence wellbeing/ quality of life
	Diversity of oral health care patients	Initial consultation of patients per chronic disease group, where after a survey among broader group of patients was conducted	Research agenda-setting stimulated patients to think about a variety of issues related to oral health care. Discussing and recognizing oral health care problems made it possible for them to learn from each other
Patients and OHPs	The difference in perspectives and interests of patients and OHPs	Consult each actor group separately, then have a consensus meeting	Creating a research agenda via dialogue ensured that shared topics were prioritized
	Uncertainty about the value of patient involvement	Gradually increase the role of patients in the project: step-by-step introduction. Meetings were moderated in a way that meant patient input was secured and valued	Research agenda-setting made the patients and OHPs involved realize that patients can supply valuable information from their experiences
OHPs	Unfamiliarity of OHPs with research agenda-setting	Consult patients and OHPs separately and sequentially	Setting the research agenda resulted in the involvement of OHPs in the agenda-setting process

Table 7.2: Boundaries, strategies and the role of the research agenda (*continued*)

Stakeholders	Boundary	Strategy/reaction	Role of research agenda
	Lack of urgency for a research agenda	Emphasis on communication about the project and long-term benefits for the individual professional as well as the profession	The research agenda created awareness that increased evidence was needed for oral health care
	OHPs prefer topics that fit their own specialty	Design of the survey: maximum of 2 topics per domain in the top 10	Research agenda-setting stimulated OHPs to broaden their focus and to reflect on uncertainties in daily practice

General boundaries

Two general boundaries were encountered. These boundaries were present for patients as well as OHPs. Firstly, in the exploration phase we discovered *a possible lack of support for the research agenda* to be a general boundary. This boundary occurred on the institutional level, meaning that lack of support was expected or found on an organisational policy level rather than individual patients or OHPs expressing lack of support. During the first stakeholder meeting participants mentioned that the profession of oral health care does not value patient input to the same extent as input from OHPs, and thus little interest in creating a shared agenda was expected. In addition, it became apparent during this phase that patients' organizations did not perceive oral health care to be an important topic for their members. To overcome this experienced lack of support, or even resistance, we stimulated engagement of stakeholders from the start of the process via structural stakeholder meetings during the project. During these meetings, the involvement of different stakeholders in the agenda-setting process was assured by involving them closely in the research process and hearing their perspective. At the first meeting, stakeholders signed a commitment form, making their commitment to the research agenda-setting process explicit.

Secondly, we anticipated that it would be challenging to *reach a representative group of patients and OHPs*. Using the Dialogue Method in setting the research agenda allowed for co-creation and inclusion during the research agenda-setting process. Creating a research agenda via the Dialogue Method stimulated engagement of patients and OHPs and structured the dialogue about perspectives and priorities among and between them. However, to be able to reach patients and OHPs multiple recruitment strategies might be needed. To ensure representation of both patients and OHPs, continuous active recruitment and involvement was required.

Boundaries in relation to patients

Three boundaries were experienced in relation to patients: (1) the difficulty in reaching oral health care patients because they are not a well-organized patient group, (2) the

perception of patient organizations that oral health care was not a topic of interest for their patients, and (3) the diversity of oral health care patients that we encountered.
The first boundary encountered in relation to patients included *the difficulty in reaching oral health care patients because they are not a well-organized patient group*. Generally, oral health care patients are not recognized as patients and do not recognize themselves as patients. As a consequence, there is no patient organization that represents oral health care patients. This complicated the recruitment of oral health care patients. During the second stakeholder meeting, participants were consulted about how to establish patient involvement for the research agenda to bypass the lack of organization of patients. During this meeting, the suggestion to focus firstly on patients with chronic diseases was widely supported. There are organizations that represent these patients, such as individuals who suffer from diabetes, and thus are easier to reach. We focused on patients with chronic diseases who have an increased risk of oral health (care) problems because they had diabetes, cardiovascular diseases, depression, rheumatic disorders or a lung disease. This resulted in deciding to organize focus groups for individuals with chronic diseases first. The results from these focus groups were used to design a survey study that was conducted among a broader group of patients. Using this approach, with an enormous response rate, research agenda-setting created awareness of oral health care issues among a wide range of patients, with and without chronic diseases.
Secondly, during the exploration phase, it became clear that most *patient organizations perceived oral health care not as a topic of interest for their patients*. While the Netherlands Patient Federation, a large Dutch patient organisation for patients with a variety of diseases, perceives oral health care as an important topic, most patient organizations did not perceive oral health care to be a problem for their patients, whereas they were familiar with the increased risk and prevalence of oral health care issues that concerned their patients. They were unwilling to assist with recruitment. When we contacted these organizations (by email or phone), they explicitly dismissed oral health care as a priority topic for their patients and protected their boundaries by refusing to help. One of the organizations' contact persons replied: *"After internal discussion, I confirm that this topic has no priority for us and that there are other projects that are closer to us..."*. This feeling must have been shared by the other organizations, because similar responses were obtained. We responded to this boundary by using different recruitment strategies. We first of all used a bottom-up strategy to overcome this boundary, and we approached individual patients with a specific interest in the topic via social media or (informal) patient meetings. We asked moderators of targeted Facebook groups (for lung disease and depression) if we could use their platform, and liaised with medical specialists to announce our research project and provide our contact information for those interested in receiving further information. In addition, events announced on websites of patient organizations were attended by research team members. After gaining the explicit per-

mission of the organizers of such events, we distributed flyers or approached patients (for cardiovascular diseases and diabetes). Only patients with rheumatic disorders were recruited directly via the patient organization, since this patient organization has a very committed body of patients and the organization did acknowledge the importance of oral health (care) problems for its members.
Later on, in the consultation phase, it was found that patients were more than willing to help and they indicated that oral health (care) is an important topic. This was shown by the participants in the focus groups, who listed 'contribute to research' as the main reason to participate, in addition to gaining knowledge. One participant explained: *"My motivation was to make a positive contribution to science and you always learn something from exchanging experiences" (focus group, patient 11)*. In addition, it was shown by the enormous response of 1,495 participants to the survey distributed among patients that oral health care is indeed a topic that concerns patients, even though patient organizations are not aware of their patients' interest in this topic. Establishing a shared research agenda helped to generally expose the patients' interest in oral health care, but more specifically it helped to alert practitioners and the patient organizations to this interest.

A third boundary was related to the *diversity of oral health care patients*. Although everyone qualifies as an oral health care patient, experiences might diverge significantly across the high-risk patients' groups on which our study focused. We expected that patients with different types of chronic diseases would ensure that their perspective was heard during the focus groups and thus protect their boundaries, making boundary crossing difficult or even impossible. Therefore, we consulted patients within each chronic disease group separately. We anticipated that recognition of daily problems related to oral health care among patients with a similar medical background would stimulate discussions and avoid conflicts during the focus groups. Although there were no conflicts, it became clear that patients with the same disease encounter a range of problems in their daily life related to oral health care. Therefore, many topics discussed during the focus groups were largely related to problems concerning patients' individual situation. As a participant from one of the focus groups explained: *"There are so many types of rheumatism, and you can never actually say something that applies to everyone... So, that's why I say you won't find consensus among all patients with rheumatic diseases" (focus group, patient 2)*. Although patients faced a variety of problems in their daily life, our approach stimulated them to consider each other's perspective and find common denominators, i.e. boundary crossing was facilitated by the research-agenda setting process. The interviews after the focus groups revealed that a moderated discussion of the various individual (oral) health care problems fostered learning from each other. One participant explained how he had learned about sleep apnoea: *"Especially about sleep apnoea (I learned from other participants about), a topic I also came into contact*

with when among heart patients, but I was surprised how often this occurs... I found that informative, that it is actually so often present" (focus group, patient 10).

Boundaries between patients and OHPs

Two main boundaries between patients and OHPs were identified and can be described as follows: (1) the differences in perspectives and interests of patients and OHPs, and (2) the uncertainty about the value of patient involvement.

In line with the Dialogue Model[115] and based on the expected heterogeneity between stakeholders[116] we first consulted each actor group separately to address *the differences in perspectives and interests of patients and OHPs*. These differences were reflected in the data collected during the exploration and consultation phase. The topics supplied by OHPs mainly focused on treatment decisions, while the impact of oral health (care) on patients' daily life was rarely considered. Patients expressed different ideas and needs about oral health (care), specifically concerning their experiences in daily life. Patients often doubted whether the decisions OHPs made were in their best interests. One patient explained: *"I am very positive [about patient involvement]; [it is] useful that practitioners are confronted with the needs of the patients – they don't take that sufficiently into account" (focus group, patient 8)*. After the consultation and the prioritization of topics, a consensus meeting was organized to create the shared research agenda. Following this two-step procedure ensured that the topics on the final research agenda were of interest to both patients and OHPs. This procedure was needed to create mutual appreciation and establish an equitable discussion.

Moreover, both patients and OHPs expressed *uncertainty about the value of patient involvement*. During the first stakeholder meeting in the exploration phase, an OHP noted*: "If the priorities of patients and practitioners do not match, the professional should have the final say"* One patient also expressed uncertainty about what to expect of the focus group: *"My goal was to contribute of course, and I didn't know what else to expect. At first, I thought the researchers and discussion moderator would take the initiative, but we [the patients] were in the lead and it was all about us" (focus group, participant 9)*. Because the value of patient involvement was unclear to both OHPs as well as patients, it was decided to gradually increase the role of patients in the project.

During each stakeholder meeting, the focus on patient involvement was gradually emphasized. This was reflected by the number of patient representatives attending the stakeholder meetings, which increased from one during the first meeting to four during the third meeting. Accordingly, the number of topics concerning patient involvement that were discussed during the stakeholder meetings increased too. In addition, all meetings were moderated so that patient input was secured and valued.

At the end of the project, topics identified by patients and by OHPs separately were discussed among groups during the consensus meeting. The design of the consensus meeting ensured that patients and OHPs were equally represented and given sufficient room to present their respective perspective in a safe environment and an open atmosphere. The discussions during this meeting were facilitated carefully. The research agenda-setting process made patients and OHPs realize that experiential knowledge from patients is a valuable source of information in research agenda-setting.

Boundaries in relation to OHPs

Three boundaries for OHPs were identified: (1) the lack of familiarity of OHPs with research agenda-setting, (2) the existence of a lack of urgency for a research agenda, and (3) OHPs prefer topics that fit their own specialty.

Firstly, we expected a boundary that was created by the *lack of familiarity of OHPs with research agenda-setting*. During all stakeholder meetings, this was brought to our attention by the participants. It was not only the lack of familiarity of individual OHPs that shaped this boundary but also the lack of interest of professional oral health care organizations. The response rate of OHPs to the first survey was initially low; it took nearly eight months to attract a substantial number of respondents and collecting topic suggestions was therefore more time-consuming than anticipated. A similar response rate to the second survey was reached in less time (three months). Since the same outreach strategies were used to reach OHPs who wanted to participate, we interpreted this difference as being the result of fostering the involvement of OHPs in the agenda-setting process.

Secondly, related to the first OHPs' boundary, there was a *lack of urgency for a research agenda* among OHPs. They felt that there was no need for change and were satisfied with their current way of working. During the first stakeholder meeting, this was brought to attention of the researchers: *"One of the hurdles will be the lack of urgency for a research agenda. The feeling exists that things are fine the way they currently are."* Therefore, the emphasis in communication about the project (in professional media) was placed on the profits for both the individual OHP and the profession. Setting the research agenda created an awareness that increased evidence was needed to improve the quality of oral health care.

A final boundary involved the expectation that *OHPs prefer topics that fit their own specialty.* For example, we expected OHPs with specific interest in endodontics to prioritize topics in this research area. However, to develop a broad research agenda we challenged OHPs to also consider topics beyond their expertise. We implemented this in the design of the second survey that was distributed among OHPs in the following way: after the collection of suggestions of topics for future oral health research via a first survey, a second survey study was conducted in which OHPs prioritized research topics based on

the collected subjects. The research topics were categorized into ten research themes. OHPs could only select a maximum of two topics within a research theme. In this way, a constraint was placed and OHPs had to prioritize topics covering all domains of oral health care. This stimulated them to broaden their focus and to reflect on uncertainties in daily practice that might be relevant to a larger and more diverse group of OHPs.

DISCUSSION

In the last decade involving patients in research agenda-setting is gradually becoming more common. However, health care domains with a wide range of diverse patients who are poorly organised, such as oral health care, may lag behind.[135,151] In the Netherlands, a research agenda for oral health care was established with input from oral health care patients and OHPs. This project applied the boundary-work theory[152,153]. In order to gain an understanding of the boundaries that were encountered and crossed in the process of setting a research agenda this case study was successfully used as a boundary-object. This study showed that the research agenda itself might function as a boundary-object to cross boundaries between patient groups, and between patients and OHPs. Using the Dialogue Model in setting the research agenda helped to overcome and transform expulsion and protection boundaries into mutual appreciation, via expansion boundary work. The concept of boundary-object was useful with respect to this. In the process of setting the research agenda, expansion boundary work was established by carefully crossing boundaries between patient groups, and between patients and OHPs. Reflexive learning made a significant contribution to this boundary crossing by enabling groups to gain insight into each other's underlying perspectives. In this way, boundaries which seemed problematic initially, were translated into productive processes and outcomes via the use of a boundary-object.

It should be recognised that most topics of the shared research agenda are related to preventative care and the healthcare system rather than curative care and treatments, which is in line with the contemporary shift in focus in oral health care.[164] This indicates a broader view of oral health care and oral health, and reflects the interests of both patients and OHPs.

Regarding general boundaries, boundaries that were found for patients as well as OHPs, we have encountered the difficulty of obtaining the support of a diverse group of stakeholders. Lack of support on institutional level (i.e. the urgency of oral health as an important research topic is not supported on an organisational policy level) was specified by patients' boundaries (lack of interest in the topic by patient organizations despite worldwide ranking in burden of diseases) and boundaries of practitioners (lack

of urgency for research agenda). To deal with these boundaries multiple boundary crossing strategies were needed, such as scheduling regular stakeholder meetings, promoting the project and using many recruitment strategies to include a wide range of oral health care patients and OHPs. However, we did not bring together officials of patient organisation and professional organisation to engage in boundary crossing. Therefore, the boundary may still exist at the institutional or organisational policy level. We considered the equal representation and support of patients and OHPs to be essential to establish a shared research agenda representing topics that are important to both patients and OHPs.

In relation to patient boundaries, setting the research agenda helped to cross multiple boundaries. One of the major boundaries for patient involvement is not knowing who the target group is and how they should be approached.[149] We dealt with this boundary first by focusing on patients with diseases that carry a high-risk for poor oral health and second by considering a variety of recruitment strategies. During the focus groups, it was shown that within specific patient groups that included people who were suffering from the same disease, a wide variety of oral health (care) problems were encountered. However, proposing these topics to a wider range of individuals in the survey study showed that these topics did not only apply to the consulted patient groups. Consulting patients via this survey confirmed the diversity of oral health care patients and the needs of different types of patients.[116,119] Our approach ensured that the individual voice of high-risk patients was transformed into a voice representing a larger patient group.[123] In line with previous studies,[146] we found that patients felt empowered by participation.[165]

Ultimately, the approach to setting the research agenda helped to overcome existing boundaries among OHPs. It encouraged a broad range of OHPs to reflect on uncertainties in daily practice which broadened their focus and shaped their awareness of the greater need for evidence in oral health care. As a result, this research agenda reflects the interests both of OHPs and of patients.

We acknowledged that dynamics between insider-outsider groups (patients versus OHPs) are shaped by multiple boundaries rather than by one single boundary,[166,167] and we therefore decided not to address single boundaries in isolation from each other. To illustrate this point, the research agenda setting served as a boundary-object that unites the perspectives of patients and OHPs. To achieve this, it was essential to involve the OHPs at an early stage and to gradually increase the patients' role. At the start, it was unclear how to value patient involvement. Previous research[149] has shown the existence of boundaries regarding patients' involvement in policy and in the relevant guidelines for its implementation. It is therefore important to emphasize the role of the patients from the start and to increase their role gradually. The patients and OHPs realised and acknowledged the value of experiential knowledge of patients. This is essential for the

success of the research agenda, as dismissing the input of patients will lead to the exclusion of patients.[135]

Hence, our study showed that to unite perspectives of patients and OHPs it is essential to be aware of possible boundaries that might be encountered to respond adequately. Based on our study, we acknowledge that boundary work is a process, dispersed and also political.[166] Identifying and addressing boundaries is a time-consuming process: it is necessary to give stakeholders enough time to become familiar with research agenda-setting and each other's perspectives. To accomplish this, the underlying principles of the Dialogue Model – such as enclave deliberation, reflexive learning and an emergent design - seemed particularly appropriate. Boundaries in our study mostly occurred because patients as well as OHPs were unfamiliar with setting a research agenda and lacked knowledge about the process and each other's viewpoints. Structuring patient involvement according to the Dialogue Model – and acknowledging and acting on the different perspectives of the involved stakeholders - helped to overcome these boundaries, as the strategies in this model are on a rational level. In contrast, when boundaries are grounded in emotions rather than lack of knowledge or familiarity, the Dialogue Model might not be able to solve these boundaries.[151] This is in line with ideas put forward by Star & Griesemer[162] about boundary-objects. Although the concept of boundary-objects can be useful to cross boundaries and create a shared reality, these boundary-objects are always context dependent. Boundary-objects are one way to deal with conflicting perspectives. In other situations, other approaches, such as fragmentation (i.e. breaking into smaller groups rather than uniting groups[168]), might be more suitable. It is, therefore, essential to be reflective and anticipate the type of boundaries that might occur and why before deciding upon a particular strategy. Boundary-objects are not a guaranteed solution for overcoming boundaries.

Strengths, limitations and future research

In this study we chose a qualitative process evaluation approach based on a multi-stakeholder perspective. While this approach might have limited the transferability of our results, our study provided unique and diverse insights into the boundaries encountered during the process of research agenda-setting in relation to oral health care, using boundary-work theory. This way, the chosen evaluation approach helped us to deepen our understanding of how the Dialogue Model served to expand and cross boundaries. We have included a variety of oral health care patients and OHPs. The use of the structure of the Dialogue Model helped to gain support from the OHPs and the patients during all phases of the agenda-setting process. Setting the research agenda helped to enhance the value of patient involvement and created patient empowerment and shared ownership of the research agenda.

This study only reports on the boundaries of two relevant stakeholder groups, patients and OHPs, that are often ignored in setting a research agenda. Still, other stakeholders, such as policymakers, insurance companies and researchers, might have introduced additional boundaries. Moreover, this study only reports on boundaries for the research agenda-setting. Therefore, the boundaries which might arise during programming and implementation of this research agenda remain unknown.
Previous research[137] has shown that patient involvement is often not continued in these subsequent phases. When this research agenda is taken further into programming and implementation, the boundary-work theory and Dialogue Model may also serve to maintain the involvement of a diverse group of patients and OHPs and unite their perspectives and priorities with those of other relevant stakeholders.

CONCLUSION

The established research agenda for oral health care was endorsed by both patients and OHPs. This case study showed that setting the research agenda using (the principles of) the Dialogue Model contributed to elucidating boundaries within and between groups of patients and OHPs in the field of oral health care. Structuring patient involvement according to the Dialogue Model enabled patients and OHPs to safely cross boundaries that emerged during different phases of patient involvement in this case study. The principles of reflexive learning, neutral process facilitation and using an emergent design seemed to be particularly valuable.

APPENDIX A

Questionnaire items

1. The number of OHPs and patient (representatives) was well balanced.
2. In my experience I adequately represented my stakeholder group.
3. The goal of the consensus meeting was clear to me.
4. I knew what was expected of me during the meeting.
5. There was sufficient time to share my ideas during the meeting.
6. The supplied information and presentations were easy to follow and understand.
7. I felt taken seriously by other participants.
8. I felt involved in the discussions during the meeting.
9. The atmosphere at the meeting was pleasant.
10. I felt free to give input during the meeting.
11. I felt like everyone was given equal opportunity to give input.
12. I was actively asked for my opinion/vision.
13. I could give a valuable contribution.
14. I found the contribution of others valuable.
15. A dialogue between patients and OHPs is a useful method to establish a shared research agenda.
16. I was satisfied with the procedure of the meeting.
17. As a participant of this meeting I gained insight into the perspectives of other participants.

Chapter 8

General Discussion – Connecting perspectives

GENERAL DISCUSSION

In setting a research agenda for oral health care we have connected several perspectives. Through this approach we aim to contribute to the reduction of research waste which can be attributed to the irrelevance of research to clinicians and patients, as displayed in figure 1 in the introduction of this thesis. We thereby contribute to overcome the mismatch between the priorities of researchers, patients and OHPs.
This thesis consists of two parts. In part one (chapter 2, 3 and 4) we report on our analysis of the oral health research field to provide context for research programming. Expenditures in oral health care were analyzed to determine if high expenditures in oral health care match high numbers of publications in oral health research. In part two of this thesis (chapter 5, 6 and 7) we have established a research agenda to provide directions for future research. In this, we have succeeded in connecting the perspectives and priorities of patients and OHPs.
Based on the studies presented in this thesis, we conclude that currently, in research programming in oral health research the interests of patients and OHPs are insufficiently considered. This is mainly reflected by the finding that the topics prioritized by both patients and OHPs are not represented in the oral health research portfolio.
In this *General Discussion* we provide an overview of our approach, reflect on the meaning of our findings, and make recommendations for future programming of oral health research. These recommendations provide directions for bridging the gap between research and practice by meeting the information needs of OHPS and patients, and thereby reduce the research waste.

PART ONE

Context for research programming

In part one of this thesis we have analyzed the current oral health research portfolio. Insight into the activities in a research field provides important context for the programming of research. It enables us to identify which topics are highly represented, and which topics are not. This way, differences between current and new identified research directions become visible and more explicit. In chapter 2 we analyzed if and how academic drift influences the oral health research activities. We found that due to academic drift related to the academic reputation and reward system, dental research institutes increasingly focus on basic science. This basic science, however, seems often not related to what is generally conceived as oral health research. As a result, research activity of dental research institutes moves away from oral health research, thereby failing to address the core of oral health care practice.

Next, we analyzed the volumes of and expenditures in oral health care (chapter 3). The results of this study were used in chapter 4. In chapter 4 we studied the content of a Dutch dental journal (NTvT) as this gives insight in what scientific knowledge Dutch OHPs are provided with and how this content correlates to international oral health research. Strikingly, the content of publications in NTvT was found to represent the research activities of the Dutch dental research institutes only to a limited extent. Especially for the dental subfields that account for a large share of international publications (*periodontology, implantology* and *dental materials*), the share of publications in NTvT was limited.

Context for programming oral health research

From our analysis of the oral health research field we can draw some conclusions relevant for future research programming of oral health research.

When we analyzed the focus of publications, differences were found between dental subfields in terms of their (inter)national orientation. For most dental subfields, the share of publications in international journals is larger than the share in NTvT. Only the dental subfields *special needs dentistry, prosthetic dentistry* and *preventive dentistry* have a relatively large share of publications in NTvT. The accessibility of publications in NTvT, in contrast to international publications, is easier for Dutch OHPs. Therefore, we conclude that the main users of oral health research are informed only about a small part of the findings from (Dutch) oral health research.

With regards to research intensity, differences between dental subfields exist. We found that the subfield *OMFS* is a clear outlier. This subfield has the highest research intensity of all dental subfields, which can be concluded from the large numbers of publications from this subfield (chapter 4). Also, in our study in chapter 2 we found the subfield *OMFS* as well as the subfield *dental materials* are the only two dental subfields that substantially use knowledge from non-dental research fields, as shown by citation relations. Probably, these subfields are the most interdisciplinary dental subfields, as research from these subfields transcends the dental research field. Interdisciplinary research is often recognized as research that brings forth more scientific breakthroughs and fosters innovation.[169]

For the oral health research field at large, we found that academic drift has strongly influenced the research activities. As a result, the dental research institutes increasingly focus on basic science, at the expense of applied oral health research. This was found for both the entire oral health research field as well as for Dutch oral health research. The sparse and thin citation relations we found between (applied) oral health research and basic science suggest a divergent focus within dental research institutes.

We also used the perspective of expenditures in patient care to signify research activities. Publications from the dental subfields that account for the largest share of expendi-

tures in patient care (*caries* and *preventive dentistry)* are underrepresented in the Dutch research portfolio. This accounts for both publications in NTvT as well as in international publications. From the perspective of research waste this is important, as the impact from research that improves oral health outcomes in these subfields will likely be large and can be of great benefit to both OHPs and patients.
From the findings in the studies described in the first part of this thesis we conclude that currently, oral health research does not serve the interests of OHPs and patients. As a consequence, the aim of research to bring progress and benefit to society is neglected. This is especially relevant for oral health care subfields in which the expenditures and volumes of health care are high.

The reputation system

From our study in chapter 2 we have concluded that academic drift influences the oral health research portfolio. The influence of academic drift in the field of oral health is not unique.[43] The current health research system is often being criticized as it mainly functions as an academic reputation system. As a result, selection of research lines and publication strategies are based on self-governing incentives, while this impedes systemic innovation.[16,17] High impact research in this system is rewarded, while research that is cited (valued) less is implicitly discouraged. This reputation system is also reflected in the report of the Dutch Research Council (NWO) "Wetenschapsvisie 2025. Keuzes voor de toekomst" [56], in which three ambitions are prioritized: The Dutch science 1) belongs to the global top 2) is increasingly connected to society and industry, and 3) breeding ground for scientific talents. The first ambition, to belong to the global top, is not only an ambition that is associated with higher status. In the current research system, this ambition is much more rewarded, for example though funding allocation, than the second and third ambition described in the report of NWO.[7,56] Many policy reports reinforce the focus on excellence in the Dutch research system, which results in a tendency to (try to) publish in high impact international basic research journals. The rewarding system impedes the implementation of other criteria to value research like valorization and societal impact. Although we are aware a transition towards a different system to value research has been initiated, it remains to be seen if this induces structural change towards addressing societal needs.
Criticism on the current research system has increased over the last decade(s).[15,40] Calls for new and different methods to measure research quality and research impact have been made. This mainly touches on the publication of research findings which is the final stage of the research process as seen in figure 1 in the introduction. However, from the perspective of research waste, the research system sustains waste not only in the publication stage, but in other stages of the research process as well. Therefore, changes are needed in the other stages of the research system. Other principles and incentives

that stimulate researchers, research policy makers and funders to target new research directions are essential to establish a sustainable change in the research system.
Above we have explained how the current oral health research system is influenced by academic drift. Research activities in the oral health research field suggest that researchers are mainly driven by incentives that benefit the researchers' career. The research needs of the potential users of research results are hardly considered. The research system thereby disregards questions relevant to the society, oral health care patients and OHPs. Therefore, the current oral health research system enhances research waste.[6,28]
In part one of this thesis (chapters 2 to 4) we have used observational studies to determine how the current oral health research field is composed. This provided insight in important mismatches between oral health expenditures and research activities. Next, we will describe the studies of part two of this thesis (chapters 5 to 7) in which we have studied the research needs of patients and OHPs. To conclude this *General Discussion*, we will connect the findings of part one and two of this thesis and provide some recommendations for future research policy in oral health care.

PART TWO

Setting the research agenda

A research agenda is an instrument that can provide valuable information in research programming, and is regarded indispensable in the reduction of research waste.[6] Traditionally, research programming in health research has been the domain of researchers, research policy makers and funders. In recent years, the focus has shifted to more inclusive methods of research programming that provide a role for both health care professionals and patients. In oral health research however, the setting of a research agenda that includes the perspective of clinicians and patients is rare.[112,136] The research agenda setting for oral health is described in part two of this thesis: In chapter 5 the process of setting the research priorities of OHPs is described. We found that although OHPs mainly suggested rather specialized and technical topics, they prioritized preventative and interdisciplinary oriented topics. In chapter 6, the process of setting the research priorities of patients and the integration of these with those of OHPs into joint priorities is described. The resulting joint research agenda includes several relevant areas for future research. While the top-8 topics of the joint research agenda were agreed upon by both patients and OHPs, a majority of these originated from the research priorities of patients. The topic *behavior change to improve oral health* was considered most important, while other topics address the oral healthcare system design or concerned the need for a more personalized and more integrated approach in oral health care.

Chapter 7 describes the research agenda setting project as a boundary object, and elaborates it as a metaphor of a bridge that allowed clinicians and patients crossing the boundaries between them. In the process of research agenda setting, this approach helped them to deliberate and appreciate each other's perspective, and proved essential to overcome their initial boundaries.

Reflecting on the research agenda topics

Some recurrent themes can be distilled from the topics on the research agenda for oral health. Research on how oral health care can implement a more holistic and patient-centered or even a person-centered was prioritized highly. Some of the prioritized topics reflect the need of a more coherent health care approach. With regards to the healthcare system, oral health care is not integrated with other domains of health care.[170,171] This can explain the strong need for more connection, expressed in our studies. The aforementioned topics obviously reflect the perspective of patients, however through our agenda setting method, the list of topics is based on the integration of both perspectives.[115]
The perceived need of patients for connection to other health care fields is especially applicable for the patient groups that we have consulted, namely patients with chronic diseases. Multi morbidity is associated with a poorer experience of care [172] while it has been acknowledged that patients suffering from multi morbidity would benefit most from more integrated care models [173]. Strikingly, oral health care is not being considered in these integrated care models at all. The research agenda indicates, however, that the integration and connection of oral health care with other fields of health care should be a priority in research, according to both patients as well as OHPs.

Reflecting on the research agenda setting process

The Dialogue method we used in research agenda setting facilitates a learning process that aims at uniting and integrating the perspectives of both OHPs and patients about priorities on oral health research. It is based on the premise that after knowledge articulation, notably expressing what is known and what is unknown, integration of articulated knowledge can take place, incorporating different perspectives of actors. Hereafter we will reflect on the process and facilitation of the articulation and integration of knowledge for both OHPs and patients in the context of the research agenda setting project.

Knowledge articulation

For the research agenda on oral health we aimed to collect topics that reflect uncertainties or problems from everyday practice or life, from the perspective of health and wellbeing. Such situations, however, are often implicitly encountered. With regard to the research agenda, it was important that both OHPs and patients made this tacit knowledge explicit.

The experiential knowledge of OHPs is constructed by their educational and scientific background, and their patient care proficiency. The patient care proficiency is, to a large extent, rather implicit and unconscious. Therefore, questions used in the survey of the consultation phase targeted treatment uncertainties and knowledge gaps.[174,175] This challenged OHPs to reflect on their tacit knowledge, which required them to reveal their uncertainties and show their vulnerabilities. Nonetheless, most topics in the first survey were rather specialized and technical and mainly cure-driven. Moreover, only a small number of topics concerned the perspective of health and wellbeing. The highest prioritized topics in the second survey however, were rather care oriented. From this perspective, the second survey served as an instrument to create awareness of the tacit knowledge among OHPs and to explicitly articulate their knowledge gaps. We considered these knowledge gaps expressed by OHPs essential for establishing a research agenda.
The value and importance of experiential knowledge of patients concerning their oral health is underestimated, by both researchers and health care professionals.[116] In the scientific literature, the perspective of patients regarding oral health is rarely considered. We considered the experiential tacit knowledge expressed by patients essential for establishing a research agenda. We facilitated patients in their knowledge articulation through focus group discussions and interviews. In these, we used the encountered problems in daily life regarding oral health (care) as a starting point. In the focus group discussions, many individual problems of participants were shared, recognized, and agreed upon by other participants. This approach of knowledge articulation, by means of exchanging experiences, contributed to the empowerment of patients, and is regarded an essential prerequisite for the knowledge integration in the research agenda setting process.[123,165]

Knowledge integration

The Dialogue meeting was used to establish knowledge integration among and between groups of OHPs and patients. Knowledge integration has been successfully achieved in this project, which can be attributed to a number of factors. First of all, in the design of the Dialogue meeting we deliberately aimed to include an equal representation of both OHPs and patients. In addition, we allowed room for individual consideration and choice while mutual appreciation and understanding for other opinions or perspectives was facilitated and encouraged. The independent facilitator especially focused on the creation of an open and safe climate, and stimulated an atmosphere of respect and interaction.[131] During the Dialog meeting, the experiential knowledge of patients was acknowledged as important and essential by both patients and OHPs.
During the dialogue meeting, it was observed that patients and OHPs considered the knowledge of both groups complementary. This was reflected in the final list of topics,

which consists of topics on patient-centered oral health care and the healthcare system articulated by patients, and preventative topics that were articulated by OHPs.

Learning process

An important benefit in the research agenda setting was the learning process amongst participants. This was especially evident with OHPs. The most prominent learning effect for OHPs was observed with regards to their initial resistance towards patient involvement in research agenda setting, which after the early project stage diminished, and apparently has been resolved through the Dialog meeting (chapter 7). In addition, with regards to knowledge articulation, the topics OHPS identified (survey 1, consultation phase) and selected (survey 2, prioritization phase) were of different nature: the former rather specialized and technical oriented, the latter rather interdisciplinary and prevention oriented.

The Dialog meeting challenged participants to reflect on their own perspectives. It clearly accelerated reflection on perspectives and promoted interaction among OHPs. Moreover, it stimulated the integration of perspectives of OHPs and patients. This resulted in a process of knowledge co-production, in which eventually the prioritized topics were rather patient-centered and healthcare system oriented.

ADDITIONAL CONSIDERATIONS ON THE MAIN FINDINGS

In our study, choices had to be made as time and resources were limited. Two important methodological choices are discussed here, as they relate to the legitimacy of the results. First, we explain why we chose to not perform a literature study to distinguish between knowledge and research gaps. Next, the representation of OHPs and patients is considered.

Knowledge gap versus research gap

For the research agenda, we identified experienced knowledge gaps of both OHPs and patients. We deliberately chose to not further investigate the nature of these knowledge gaps. Therefore, we did not differentiate between a knowledge gap and a research gap by means of a literature study before the prioritization phase, as both were regarded as relevant and highly informative. In this project, knowledge gaps are defined as the topics for which sufficient high-quality evidence is available but has not reached its end-users yet. Research gaps, on the other hand, are the topics that cannot be answered by current scientific literature. As research gaps provide basis for new research directions, knowledge gaps provide basis for dissemination of available knowledge, both to OHPs and patients.

To perform a systematic literature review on the broader research topics that were extracted from the consultation phase in our study would require specification to define a research question. This could have been used to inform the dialog meeting. Such systematic literature review inevitably will require interpretation of what has been researched. This then, would easily override the input of the stakeholders, and distract from their reflection on their tacit and experiential knowledge. Moreover, it would have provided guidance in a direction that would result from previous literature that has been shown to be subject to academic drift and merely address the priorities of researchers instead of patients and OHPs.

The aim of the research agenda was to provide directions for future research that connects the knowledge gaps and information needs as expressed by patients and OHPs. To fully implement stakeholder involvement in the subsequent phase of programming oral health research, defining a research question should be done in conjunction with both OHPs and patients and through deliberate facilitation of co-creation. Before initiation new research, there are a few important aspects that will need to be considered [6]: Define a focused three-part research question together with patients and OHPs; followed by a systematic research of literature to provide insight in the nature and breath of the knowledge gap and learn from methodological flaws in prior studies.

Representativeness and Representation

So far, researchers and policy makers have been the traditional stakeholders defining the research agenda. Little discussion about the representativeness of groups of researchers and policy makers that have established science-driven research agendas has arisen.

Since the last decade the importance of empowering and involving patients and health care professionals in research agenda setting has been acknowledged. While OHPs and patients are important stakeholders in oral health care, they have rarely been included in the programming of oral health research. The issue of representativeness is sometimes used as an argument to refrain from including their perspective in research programming.[176]

The oral health care work field includes a wide variety of OHPs and the variety amongst oral health care patients is even greater. In our project, the Dialogue meeting was used to integrate the perspectives of OHPs and patients and establish a joint research agenda. Prior to this meeting we used the prioritization survey to formulate a we-voice for each group.[123] A we-voice can be regarded as an instrument that represents the perspective of an entire group of stakeholders. One can argue a we-voice can only be identified as such as everyone has contributed to this we-voice, as it implicitly reflects representativeness.

However, an important distinction can be made between representativeness of groups (e.g. OHPs and patients), and representation of groups. The former is a notion from quantitative social sciences, the latter from qualitative health care research.
Due to time constraints in this project, it was unrealistic to acquire full representativeness. However, attempts were made to maximize representation by including as many different perspectives as possible. In the research agenda setting for OHPs, targeted actions were undertaken when a specific OHP group (e.g. dental hygienists) was underrepresented. As a result, we did accomplish to include a broad variety of OHPs. As for patients, this was more complex.
The oral health care patient is not identified as such. To facilitate targeting of organized patient groups, we included patients with chronic diseases in the consultation phase. To establish the we-voice for this stakeholder group, there were no restrictions on participation in the prioritization survey. A substantial number of patients without chronic disease participated in this survey. We strengthened the value of their input by adding their prioritized topics additionally to the topics used in the Dialogue meeting in the integration phase. Hereby we enhanced the legitimacy of the articulated knowledge by patients without chronic diseases and strengthened the we-voice of all patients, not only those with chronic diseases. This is reflected in the joint top-8 of research topics, of which 5 topics originate from the prioritized research topics of patients.
Through our approach, we succeeded to develop a we-voice for a wide diversity of patients and establish a joint research agenda in a field of health care that lacks a strongly defined patient group. In this research agenda setting project, the we-voice of the two stakeholder groups that have often been overlooked in research programming were deliberately included in this knowledge co-creation process.

CONNECTING THE MAIN FINDINGS FROM PART ONE AND TWO

In this thesis we have demonstrated the current gap that exists between research and practice in the field of oral health care. We have explained how a research agenda can help reduce research waste and reduce the gap between research and practice. We end this chapter with a few concluding remarks and provide some recommendations for future programming of oral health research in light of the main finding of this thesis: the current oral health research portfolio does not address the interests of both OHPs and patients. These recommendations are aimed to contribute to bridging the gap between research and practice in oral health care.

In part one we have seen that the current oral health research field shows an increased focus in basic sciences. This academic drift is an autonomous science-driven process,

which is different from what happens in outside world (e.g. oral health care practice). Therefore, oral health research is increasingly disconnected from daily oral health care practice. This is reflected in the discrepancy between expenditures and publications in some oral health care subfields. Also, knowledge gaps in patient care and the interests of OHPs and patients are overlooked in the current system. As a result, research addressing societal challenges and information needs in oral health care practice are increasingly underrepresented.

In part two we have used a method of research agenda setting to provide guidance for researchers towards new directions relevant for OHPs and patients. Their joint priorities, established through knowledge co-creation, concern mainly preventative, patient-centered and health system topics. These topics are currently overlooked in the oral health research portfolio. This corroborates the findings from our two bibliometric studies.

Recommendations for programming future oral health research

Most Dutch dental research institutes resemble a structure as the Dutch university medical centers.[7] It consists of departments that are all highly specialized in a subfield of oral health care. While there is no clear research policy in place among the dental research institutes, they determine the activities and output for the dental research field. Still, in terms of bibliometric indicators these rather specialized departments are regarded as excellent in their field.[67,177] As a result, oral health research affiliated to the Netherlands ranks high.

But the specialized departments have too little interest in general patient care, as can be concluded from the current activities of dental research institutes. Moreover, none of the Dutch dental research institutes explicitly focuses on general oral health care. Therefore, dental research institutes appear to be disconnected to a large extent from the daily practice of oral health care. To facilitate a change of focus in oral health research towards more patient-centered, general oral health care topics, the focus of the dental research institutes requires a change.

It is recommended to establish a strong connection between research and daily patient care through prioritizing research on information needs and knowledge gaps in general oral health care. In addition, such research programming should aim to overcome the observed mismatches between oral health expenditures and research activities. At the same time, strengthening of the research network, capacity and infrastructure for conducting such research needs urgent attention.

With their joint research agenda, OHPs and patients have provided clear topics and directions for future programming research topics. The added value of the perspective of these users of research has proven to add to the legitimacy and value of research.[6,178] Given the clarity of the topics prioritized by OHPs and patients for future oral health research, the different actors, notably the dental research institutes, the organizations of patients, the organizations of OHPs and policymakers, should take their role in future research programming.

The dental research institutes, as the main performers of research, should take their responsibility and lead the field towards oral health research that includes the perspectives of both OHPs and patients. In this, patient-centeredness in oral health care, as well as in oral health research should become their priority.
Patient organizations can further patient-empowerment and facilitate patient involvement in research programming, as well as disseminate results of successful patient involvement. Their explicit and intensive efforts are needed to secure the embedding of the perspective of patients in research programming and to foster a continued connection of stakeholder perspectives.
To sustainably embed the inclusion of the different perspectives, reciprocity is required. Hence, a more active role of OHPs and their professional organizations is required in order to reduce the gap between research and practice and to foster a continued connection of stakeholder perspectives. A dental practices network is a tool that can contribute to achieve this more active role of OHPs. Participation and collaboration of OHPs in dental practices research network can help to increase the feeling of responsibility and ownership of research. This has shown to facilitate the implementation of findings from pertinent research. A network of dental practices provides a continuous living lab with daily patient care in high volumes.
As shown in part two of this thesis, most topics of the research agenda concern issues that touch on daily patient care. Therefore, advantages of such a network apply to multiple facets of the reduction of the gap between research and practice.

Based on the results of the research agenda setting, a broader approach in oral health care is needed. We argue that policymakers should address improving integration of research and care in oral health care with research and care in other health care fields. Such integration is expected to strengthen the patient-centeredness on the level of health care delivery. From this viewpoint, oral health research can be regarded as a boundary object, that can bridge the gap between the rather isolated care delivery in oral health care and care delivered in other fields of health care.
Oral health researchers should actively endeavor to collaborate with primary health care (research) institutes as this can help reduce the gap. Examples of such institutes

are Amsterdam Public Health Institute (APH), the general medical practice networks (netwerken huisartsengeneeskunde), the Netherlands Institute for Health Services Research (NIVEL), the Netherlands Organization for Applied Scientific Research (TNO) and the National Institute for Public Health and the Environment (RIVM), and the local and regional public health authorities (GGD).

CONCLUDING REMARKS

As the reduction of research waste is a priority in health care research in general, it should be a priority for all actors in the oral health research field. The waste of resources in research has far reaching consequences. Not only are valuable resources wasted, because the research does not meet the needs of the users. The current distribution of resources impedes new research directions that do connect to the needs of the users.
Our above recommendations are expected to contribute to the reduction of impact of the current scientific reputation in terms of bibliometric acknowledgements and the related reward system in terms of research funding that is considered the main driver of the observed scientific drift in oral health research. Therefore, all Dutch dental research institutes are recommended to contribute to the collaboration aimed towards reshaping the current oral health research field. They should join forces in convincing funders and research policymakers on the importance of our recommendations guiding towards new directions for oral health research, and encourage them to support the implementation thereof. These new directions will serve to address knowledge gaps and information needs of OHPs and patients, and therefore reduce the gap between research and oral health care practice. Thereby, the future programming of oral health research will contribute to the current societal challenges on a sustainable healthcare system.[179]

Summary

SUMMARY

Research waste is defined as research outcomes with little or no societal benefits. As a result, valuable resources, time, and efforts, required for scientific studies are wasted. Causes for this waste can be identified in various stages of the research process: First, in the stage of defining a research question, second, in the design of a study, and finally, in the stage of reporting and publishing on the study and its results.
Defining a research question which does not address a societal need is a hallmark of research waste, and contributes to the gap between research and practice.

In the field of oral health care, an important reason for the lack of implementation of research findings into patient care is the gap between oral health research and daily practice. This raises the question on the societal benefits of the current oral health research and whether this research meets societal needs and the needs of end-users of oral health research, notably oral health care professionals (OHPs) and patients. If it does not, the oral health research portfolio needs to be redefined, so that the gap between research and practice is reduced.

As to date, the biomedical research portfolio is predominantly determined by researchers, funders, and research policymakers with a background in the basic sciences. Consequently, the research activities predominantly focus on basic and translational science, and address disease curation. The interests of researchers, funders, and research policymakers rarely align with the interests of health care professionals and patients. As a result, fewer research activities in medicine and health care concerns research on disease prevention and quality and outcomes of health care. Not surprisingly, this misalignment was reported for oral health research as well, in a 2012 report of the Health Council of the Netherlands.

In this thesis, we aim to provide insight into how the oral health research field is currently composed and what the research priorities of OHPs and patients are. We then attempt to connect these perspectives.
In **part one** of this thesis, we assess the composition of the oral health research field and gain insight into the research topics that are addressed in the current research portfolio. By this, we provide context for part two of this thesis, in which a research agenda for oral health care is developed.

In **chapter 2**, we have examined if and how academic drift has changed the dental research field. This academic drift can result in a research portfolio that moves away from research that serves oral health care. We developed a network map for dental research

containing journal clusters that show similar citation behavior. From the years 2000 up to 2015, we explored the intensity of knowledge exchange between the different journal clusters through citation relations. We found that dental journals mainly cite publications in other dental journals. In addition, dental publications hardly cite publications from non-dental journals.
Next, we analyzed changes in research focus of dental research institutes in seven countries, in the categories *dental research*, *clinical medicine research*, *basic science*, *public health research*, and *other fields*. We found that, relatively, the output of dental research institutes in dental research has declined. This is accompanied by a relative increase in non-dental research, mainly found in the category *basic science*.
Our findings suggest that the dental research portfolio is influenced by academic drift, as the focus on basic science has increased at the expense of research that serves oral health care.

In **chapter 3**, we have explored the expenditures of oral health care in the Netherlands for the years 2011, 2013, and 2014. In the current oral health system in the Netherlands, oral health care coverage by basic health care insurance for adults is limited. Therefore, much of the oral health care for people of 18 years and over, is self-paid. Currently, there is limited insight into these self-paid oral health care expenditures.
In this study, we used claims data and data from a large invoicing company to estimate oral health care expenditures that are self-paid. For this, we used the ratio between claims data from insurances and data from a large invoicing company. Based on this estimation we concluded that between 21% and 32% of all oral health care expenditures concern self-paid expenditures in oral health care.

In **chapter 4**, the content of the Dutch Dental Journal (Nederland Tijdschrift voor Tandheelkunde – NTvT) over an 18-year period was analyzed. The Dutch Dental Journal is the largest scientific journal for OHPs in the Netherlands and Belgium.
Publications in NTvT from 2000 onwards, were systematically mapped, based on a co-word analysis, to determine which research fields were addressed. This was compared to dental publications written by authors with a Dutch affiliation in the international literature. This analysis showed that the number of publications covering topics such as social dentistry has increased, while other topics (e.g. basic science topics) received less attention. For some research fields, a large share of publications was published in international journals, compared to the share of publications in NTvT.
In addition, we analyzed how the research output in different dental research fields correlated to the oral health care expenditures from these fields, as found in chapter 3.

We concluded that there is a limited correlation between fields with the highest share of oral health care expenditures (e.g. cariology and prevention) and the share of publications in these fields.

Based on the results from chapter 2, 3, and 4 we conclude that:

- The research portfolio of dental research institutes increasingly focuses on basic science, while the focus on dental research declines.
- The knowledge that is produced by dental research institutes in the field of basic science is used only to a limited extent in dental publications. Moreover, basic science is rarely covered by the Dutch Dental Journal.
- In the Netherlands, there is a discrepancy between the expenditures in oral health care and oral health research by authors with a Dutch affiliation.

In **part two** of this thesis, we provided recommendations for new research directions for (Dutch) oral health research based on the joint priorities of OHPs and patients. For this, we have developed a research agenda for oral health care in the Netherlands. The Dialogue method was used to develop a research agenda, for which the most important knowledge gaps of both OHPs and patients were identified.

In **chapter 5**, we used a two-stage survey method to develop a research agenda from the perspective of OHPs. In the first survey, OHPs were asked to suggest topics for future research based on their treatment uncertainties and knowledge gaps. In the second survey, the research topics derived from the first survey were prioritized. Based on these results, the topics '*Behavior change for oral health*' and '*Oral health care for geriatric patients'* were ranked as most important. Furthermore, findings showed that although OHPs mainly suggested very technical topics initially, the second survey resulted in the prioritization of preventative and interdisciplinary topics.

In the final stage of the project, described in **chapter 6**, the research priorities of OHPs were integrated with the research priorities of patients. We identified the challenges and needs in oral health(care) of patients with chronic diseases (e.g. lung diseases, rheumatic disorders) in focus group discussions and interviews. Based on this consultation, we defined research topics. These research topics were then prioritized in a larger group of patients via an online survey.
Finally, in a Dialogue meeting, the research priorities of both patients and OHPs were used to develop the research agenda. The participants of this meeting - OHPs and patients - agreed upon a joint research agenda of 8 research topics. Many of the topics were suggested by patients but were prioritized by both groups. The most important topics concerned '*Behavior change for oral health*' and '*The relation between general and*

oral health'. Other topics that were prioritized covered affordability and accessibility as well as health system research and organizational issues.

During the process of setting the research agenda, some boundaries were encountered. To gain a deeper understanding of these boundaries we applied the boundary-work theory as a framework. This study is described in **chapter 7**. Here, we analyzed how the research agenda served as a boundary object (i.e. circumstances, situations, or material that connect different groups) that facilitated crossing boundaries and uniting the perspectives of patients and OHPs.
We facilitated the crossing of boundaries between different patient groups by consulting each patient group in a separate focus group, where after a survey among a larger group of patients was conducted. This allowed us to integrate research topics representing the perspectives and priorities of different patient groups.
The crossing of boundaries between OHPs and patients was facilitated by involving OHPs at an early stage of the project and gradually introducing the role of patients. This resulted in the acceptance and acknowledgment of the importance of the patients' perspective. As a result, support for an integrated research agenda was obtained.
Based on our findings, we concluded that the research agenda helped to cross boundaries in oral health care, which demonstrates its role as a boundary object.

In the process of setting the research agenda, as described in part two of this thesis, different perspectives were considered. The research agenda has uncovered directions for future research that go beyond evident research topics: most of the prioritized topics are currently underrepresented in oral health care research. To expose these preventative, patient-centered, and health system topics, it was essential to consult OHPs as well as patients. Their joint priorities, established through knowledge co-creation, are often overlooked in the oral health research portfolio.

Based upon the studies reported in this thesis we draw the following conclusions:
In part one of this thesis, we have demonstrated the current gap that exists between research and practice in the field of oral health care. Therefore, the societal benefits of the current research portfolio can be questioned.
In part two, we have developed a research agenda to provide guidance for researchers towards directions for future oral health research which is relevant for end-users, and as such meets the needs of OHPs and patients and produce societal benefits.
In the introductions of this thesis, we have explained how the identification of relevant research questions can help reduce research waste as well as reduce the gap between research and practice. Engagement of both OHPs and patients in the composition of

a research agenda is essential to reduce the gap between research and practice and thereby generate more impact.

To reduce the gap between research and practice, changes in the current oral health research system are required. This is the responsibility of all actors in the research system.

For OHPs, a more active role is required to foster a continued connection of stakeholder perspectives. A dental practices network is a tool that can contribute to achieve an active role of OHPs. Participation and collaboration of OHPs in a dental practices research network can help to increase the feeling of responsibility and ownership of research.

Patient organizations can further patient empowerment and facilitate patient involvement in research programming, as well as disseminate results of successful patient involvement. Their efforts are needed to secure the embedding of the perspective of patients in oral health research programming.

Policymakers should address improving the integration of research and care in oral health care with research and care in other health care fields. Such integration is expected to strengthen the patient-centeredness on the level of health care delivery. From this viewpoint, oral health research can be regarded as a boundary object, that can bridge the gap between the rather isolated care delivery in oral health care and in other fields of health care.

We believe that reshaping the current oral health research field must be initiated by the Dutch dental research institutes. They have the resources and the access to knowledge to initiate a collaboration between researchers, OHPs and patients. Patient-centeredness in oral health care, as well as in oral health research should become their priority. They should join forces in convincing funders and research policymakers on the importance of our recommendations guiding towards new directions for oral health research, and encourage them to support the implementation thereof.

Appendices

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Agendering van onderzoek in de mondzorg – Perspectieven verbonden

SAMENVATTING

Onder *research waste*, oftewel onderzoeksverspilling, wordt onderzoek verstaan waarvan de uitkomsten niet of nauwelijks van toegevoegde waarde zijn voor de maatschappij. Hierdoor worden – kostbare - middelen, tijd en moeite, die nodig zijn voor wetenschappelijk onderzoek, verspild.
De oorzaken voor deze verspilling zijn in eerdere studies geïdentificeerd in verschillende stadia van het onderzoeksproces: In het stadium van het bepalen van de onderzoeksvraag, het ontwerp van de studie, de rapportage over de studie, en tenslotte in het stadium van publicatie over de studie en de onderzoeksresultaten.
Een belangrijke oorzaak van onderzoeksverspilling is dat een onderzoeksvraag niet aansluit bij de behoeftes die leven in de maatschappij. Dergelijke onderzoeken dragen zodoende bij aan de kloof tussen onderzoek en praktijk.

De kloof tussen het onderzoek en de dagelijkse mondzorg praktijk is een belangrijke oorzaak voor het gebrek aan gebruik van bevindingen uit wetenschappelijk onderzoek in de patiëntenzorg. De vraag die hieruit volgt is of het huidige onderzoek eigenlijk wel van toegevoegde maatschappelijke waarde is. Bovendien is het de vraag of het onderzoek wel aansluit op de behoefte vanuit de maatschappij en de behoefte van de eindgebruikers van mondzorg onderzoek, mondzorgverleners en patiënten. Als dit namelijk niet het geval is, is het belangrijk dat de huidige onderzoeksportefeuille wordt aangepast, om zo de kloof tussen onderzoek en praktijk te verkleinen.

Onderzoekers, subsidieverstrekkers en onderzoeksbeleidsmakers bepalen voor een belangrijk deel de huidige biomedische onderzoeksportefeuille. Hun onderzoek is vaak gericht op fundamentele of translationele wetenschap en heeft een sterke focus op behandeling van ziekte. Hun belangen zijn echter wezenlijk anders dan de belangen van patiënten en zorgverleners. Voor patiënten en zorgverleners zijn vaak onderwerpen als de preventie van ziekte, de kwaliteit van zorg en gezondheidsuitkomsten van belang. Ook in de mondzorg werden deze uiteenlopende belangen gerapporteerd in het Gezondheidsraad rapport “De mondzorg van morgen” uit 2012. Het signaal van deze uiteenlopende belangen en de kloof tussen onderzoek en de mondzorgpraktijk zijn de aanleiding geweest voor dit proefschrift.

Het doel van dit proefschrift is, ten eerste om inzicht te krijgen in het huidige mondzorg onderzoeksveld en, ten tweede om te bepalen wat de onderzoeksprioriteiten van mondzorgverleners en patiënten zijn. Vervolgens worden deze perspectieven met elkaar verbonden.

In het **eerste deel** van dit proefschrift hebben we het huidige mondzorg onderzoeksveld geanalyseerd en in kaart gebracht welke onderwerpen in de huidige onderzoeksportefeuille worden onderzocht. De uitkomsten van deze analyses geven de context voor het tweede deel van het proefschrift, waarin we een onderzoeksagenda voor de mondzorg hebben ontwikkeld.

Allereerst hebben we in **hoofdstuk 2** onderzocht of en hoe *academic drift* het onderzoeksveld in de mondzorg heeft veranderd. Deze *academic drift,* als gevolg van het reputatie gedreven onderzoeksveld, kan er namelijk toe leiden dat het aandeel van onderzoek dat aansluit bij de mondzorg in de onderzoeksportefeuille steeds kleiner wordt. Voor deze studie ontwikkelden we een netwerk kaart voor mondzorg onderzoek. Dit netwerk bestaat uit clusters van tijdschriften met vergelijkbare citatiepatronen. We hebben vervolgens de intensiteit van kennisuitwisseling, door middel van citaties, tussen de clusters van tijdschriften bekeken gedurende de periode 2000 tot 2015. Uit deze analyse blijkt dat tandheelkundige tijdschriften met name publicaties uit andere tandheelkundige tijdschriften citeren, terwijl publicaties uit niet-tandheelkundige tijdschriften nauwelijks geciteerd worden.
Ook hebben we geanalyseerd wat de focus van het onderzoek van tandheelkundige onderzoeksinstituten is. Hiervoor werd voor zeven landen de publicatie output van deze tandheelkundige onderzoeksinstituten gecategoriseerd in *tandheelkundig onderzoek*, *klinisch medisch onderzoek*, *fundamenteel onderzoek*, *volksgezondheidsonderzoek*, en *overig*. Hieruit bleek dat, relatief gezien, de output in het tandheelkundig onderzoek afneemt en dat de toename van output in de andere categorieën met name werd gevonden in de categorie *fundamenteel onderzoek*.
Deze bevindingen wijzen erop dat de onderzoeksportefeuille inderdaad wordt beïnvloed door *academic drift*. Hierdoor neemt de focus op fundamenteel onderzoek toe terwijl dit ten koste gaat van het onderzoek dat de mondzorg bedient.

In **hoofdstuk 3** hebben we de uitgaven in de mondzorg in Nederland in 2011, 2013 en 2014 bestudeerd. In het huidige zorgsysteem is de vergoeding vanuit de basis zorgverzekering voor mondzorg bij volwassenen beperkt. Veel van de mondzorg bij personen boven de 18 jaar wordt dus door patiënten zelf gefinancierd. Hierdoor is er weinig inzicht in deze door de patiënt betaalde mondzorguitgaven. Om hier meer inzicht in te krijgen hebben we op basis van declaratiedata bij verzekeringen en declaratiedata bij

een grote factoringmaatschappij een schatting gemaakt van deze uitgaven. Op basis van deze schatting concluderen we dat tussen de 21% en 32% van de mondzorg uitgaven door patiënten zelf gefinancierd worden.

In **hoofdstuk 4** beschrijven we de analyse van de inhoud van het Nederlands Tijdschrift voor Tandheelkunde (NTvT) gedurende de periode 2000 tot 2018. Het NTvT is het grootste wetenschappelijke tijdschrift gericht op mondzorgverleners in Nederland en België. Publicaties in het NTvT vanaf 2000 werden systematisch geanalyseerd op basis van een co-word analysis - de analyse van termen die in publicaties vaak samen gebruikt worden en dus over hetzelfde onderwerp gaan. Hiermee hebben we in kaart gebracht welke onderzoeksonderwerpen en -gebieden in de publicaties werden besproken. We zagen dat onderwerpen zoals sociale tandheelkunde toenamen, terwijl andere onderwerpen – bijvoorbeeld onderwerpen die fundamenteel onderzoek betroffen – nauwelijks werden besproken. Vervolgens hebben we dit vergeleken met de tandheelkundige publicaties met een Nederlandse affiliatie in de internationale tandheelkundige tijdschriften. Voor sommige deelgebieden van het mondzorgonderzoek geldt dat er vooral wordt gepubliceerd in de internationale tijdschriften. Met name voor mond-, kaak-, en aangezichtschirurgie, implantologie en parodontologie werd dit gevonden.
Daarnaast hebben we de aandelen van publicaties in het NTvT én in internationale tijdschriften voor verschillende deelgebieden van de mondzorg ook gerelateerd aan de uitgaven in die deelgebieden van de mondzorg (zoals beschreven in hoofdstuk 3). Hieruit bleek dat met name voor de deelgebieden waarin de zorguitgaven hoog zijn, namelijk cariologie en preventie, er relatief juist weinig publicaties uit deze deelgebieden zijn.

Op basis van de resultaten uit hoofdstuk 2, 3 en 4 trekken we de volgende conclusies:
- De onderzoeksportefeuille van tandheelkundige onderzoeksinstituten richt zich in toenemende mate op fundamenteel onderzoek, en juist steeds minder op tandheelkundig onderzoek.
- De kennis die door de tandheelkundige onderzoeksinstituten wordt gegenereerd in dit fundamenteel onderzoek wordt beperkt gebruikt in tandheelkundige publicaties. Bovendien worden publicaties over fundamenteel onderzoek nauwelijks besproken in het NTvT.
- Er bestaat een grote discrepantie tussen de uitgaven in belangrijke deelgebieden van de mondzorg en onderzoek in deze deelgebieden.

In het **tweede deel** van dit proefschrift worden een aantal aanbevelingen gedaan voor nieuwe onderzoeksrichtingen. We baseren deze aanbevelingen op de gezamenlijke prioriteiten van mondzorgverleners en patiënten. Hiervoor werd een onderzoeksagenda voor de mondzorg ontwikkeld door middel van de Dialoog methode. Door middel

van deze methode werden de belangrijkste kennishiaten van mondzorgverleners en patiënten in kaart gebracht.

In **hoofdstuk 5** beschrijven we de totstandkoming van de onderzoeksagenda vanuit het perspectief van de mondzorgverlener. Voor deze studie zijn twee enquêtes onder mondzorgverleners gehouden. In de eerste enquête vroegen we hen naar suggesties voor onderzoeksonderwerpen gebaseerd op hun kennishiaten of onzekerheden tijdens de patiëntbehandeling. In de tweede enquête werden de onderzoeksonderwerpen, die waren verzameld tijdens de eerste enquête, geprioriteerd. *Gedragsverandering ten behoeve van de mondgezondheid* en *Mondzorg voor de geriatrische patiënt* werden als belangrijkste onderwerpen gekozen. Wat in deze studie vooral opviel was dat mondzorgverleners in de eerste enquête vooral (materiaal-)technische onderwerpen noemden, terwijl in de tweede enquête met name onderwerpen over preventie en interdisciplinair samenwerken werden geprioriteerd.

De totstandkoming van de onderzoeksagenda van patiënten en de integratie van de beide onderzoeksagenda's tot een gezamenlijke agenda wordt beschreven in **hoofdstuk 6**. Hiervoor werden de knelpunten en behoefte van patiënten met chronische aandoeningen wat betreft hun mondgezondheid en mondzorg in kaart gebracht in groepsdiscussies en interviews. Hoewel de ervaren knelpunten in elke groepsdiscussie anders werden verwoord, bleken ze vaak over dezelfde onderwerpen te gaan. Deze onderwerpen werden vervolgens in een enquête door een grote groep patiënten geprioriteerd.
In de afsluitende Dialoog bijeenkomst werden de prioriteiten van mondzorgverleners en van patiënten gebruikt om de gezamenlijke onderzoeksagenda vast te stellen. De mondzorgverleners en patiënten die deelnamen aan de bijeenkomst bereikten overeenstemming over een gezamenlijke agenda van 8 van onderzoeksonderwerpen. Het merendeel van de onderwerpen op deze agenda waren afkomstig van de patiënten, maar werd door beide groepen geprioriteerd.
Gedragsverandering ten behoeve van de mondgezondheid en *De relatie tussen mondgezondheid en de algemene gezondheid* werden als belangrijkste onderwerpen gekozen. Andere onderwerpen gingen over toegankelijkheid en betaalbaarheid, maar ook over het zorgsysteem en de organisatie van de zorg.

Gedurende het proces van onderzoeksagendering kwamen we op meerdere momenten zogenoemde *boundaries* tegen. In deze context spreken we over boundaries als we de begrenzing tussen verschillende groepen die bij de totstandkoming van de onderzoeksagenda betrokken waren bedoelen. Om meer inzicht te krijgen in het hoe en waarom van deze *boundaries* hebben we het project vanuit de *boundary-work theory*

beschreven in een publicatie. In **hoofdstuk 7** is te lezen hoe de onderzoeksagenda, vanuit deze *boundary-work theory* heeft gewerkt als een object om verschillende groepen mensen en hun perspectieven met elkaar te verbinden. Zo hebben we er bewust voor gekozen om elke patiëntengroep apart te consulteren in een groepsdiscussie, maar de enquête om onderwerpen te prioriteren was voor alle patiënten (ongeacht het wel of niet hebben van een chronische aandoening) toegankelijk. Zo werden de perspectieven en prioriteiten van verschillende patiëntengroepen geïntegreerd.
Ook is er in het proces voor gekozen om de belangrijke rol van patiënten in het project stapsgewijs te introduceren bij de mondzorgverleners. Hierdoor werd het belang van het patiëntperspectief voor de onderzoeksagenda door alle deelnemers geaccepteerd en erkend. Dit heeft geresulteerd in brede steun voor een gezamenlijke onderzoeksagenda. In het licht van de *boundary-work theory* heeft de onderzoeksagenda eraan bijgedragen dat verschillende groepen in de mondzorg nader tot elkaar zijn gekomen, om zo een gezamenlijke agenda te kunnen formuleren.

In het proces van onderzoeksagendering, zoals beschreven in deel 2 van dit proefschrift, zijn verschillende perspectieven betrokken. Dit heeft geresulteerd in onderzoeksrichtingen voor toekomstig onderzoek die wellicht minder voor de hand liggen: veel van de geprioriteerde onderwerpen zijn immers onderbelicht in het huidige mondgezondheids- en mondzorgonderzoek. Door het betrekken van zowel mondzorgverleners als patiënten zijn de onderwerpen gericht op preventie, het zorgsysteem en het centraal zetten van de patiënt, als prioriteiten aan het licht gekomen. Hiervoor was de inbreng van beiden essentieel.

Op basis van de studies die in dit proefschrift worden beschreven kunnen we een aantal belangrijke conclusies trekken:
In deel één van het proefschrift hebben we aangetoond dat er binnen de mondzorg een kloof tussen het onderzoek en de dagelijkse mondzorgpraktijk bestaat. Doordat het onderzoek momenteel niet aansluit op de praktijk, is het onduidelijk wat de maatschappelijke waarde van het huidige onderzoek is.
In deel twee van het proefschrift hebben we een onderzoeksagenda ontwikkeld om nieuwe richtingen voor toekomstig onderzoek aan te reiken. Deze onderzoeksagenda bestaat expliciet uit onderwerpen die relevant zijn voor de eindgebruikers van het onderzoek, de mondzorgverleners en patiënten, waardoor de maatschappelijke waarde van dergelijk onderzoek groot kan zijn.

Het identificeren van relevante onderzoeksvragen kan bijdragen aan het verlagen van onderzoeksverspilling, en het adresseren van deze onderzoeksvragen kan de kloof tussen onderzoek en praktijk verkleinen. Het maken van een onderzoeksagenda, gebaseerd

op de kennisbehoeften van mondzorgverleners en patiënten, is essentieel om deze kloof te kunnen verkleinen en daarmee de impact van het onderzoek te vergroten.

Om de kloof tussen onderzoek en de mondzorgpraktijk te verkleinen is het daarnaast nodig dat het systeem van het huidige mondgezondheids- en mondzorgonderzoek verandert. Dit is de verantwoordelijkheid van alle partijen binnen het systeem.

Een actievere rol van mondzorgverleners is nodig om de verbinding tussen de verschillende perspectieven in stand te houden. Bijvoorbeeld via een onderzoeksnetwerk van mondzorgpraktijken. Een dergelijk netwerk van mondzorgpraktijken die actief betrokken zijn bij (praktijkgericht) onderzoek kan bijdragen aan een actieve rol van de mondzorgverleners. Betrokkenheid en samenwerking van mondzorgverleners binnen zo'n netwerk helpt om het verantwoordelijkheidsgevoel naar de maatschappij en eigenaarschap van zulk onderzoek te vergroten.

Ook patiëntenorganisaties kunnen bijdragen aan een verandering in het huidige onderzoekssysteem. Bijvoorbeeld door de rol van patiënten binnen het onderzoek te versterken en door structurele bijdrage en inzet van patiënten bij de programmering van mondzorgonderzoek faciliteren. Daarnaast kunnen zij hun leden informeren over projecten van succesvolle patiëntparticipatie en de resultaten hiervan. De inspanningen van patiëntenorganisaties zijn hard nodig om het patiëntperspectief in de programmering van mondgezondheids- en mondzorgonderzoek te verankeren.

Beleidsmakers zouden zich moeten richten op het verbeteren van de integratie tussen onderzoek en zorg in de mondzorg en onderzoek en zorg in andere deelgebieden van de zorg. Een verbeterde integratie van mondzorg met overige zorg kan leiden tot een meer centrale rol van de patiënt op het niveau van zorgverlening. Onderzoek dat zich richt op de relatie tussen mondgezondheid en de algemene gezondheid, maar ook mondzorgonderzoek gericht op verbeterde integratie met andere zorggebieden kan in deze worden beschouwd als een *boundary object*. Door zulke onderzoeken kan de kloof tussen het geïsoleerde mondzorgveld en andere zorggebieden worden verkleind.

Zo kunnen alle partijen binnen het mondzorgveld hun steentje aan een verandering bijdragen. We geloven echter dat het veranderen van het onderzoeksveld moet worden geïnitieerd door de tandheelkundige onderzoeksinstituten. Zij hebben de middelen, de toegang tot kennis en de connecties om samenwerkingen tussen onderzoekers, mondzorgverleners en patiënten te initiëren. Het centraal zetten van patiënten in de mondzorgverlening én in mondzorgonderzoek zou voor hen prioriteit moeten worden. Daarbij kunnen de tandheelkundige onderzoeksinstituten hun krachten bundelen

om subsidieverstrekkers en onderzoeksbeleidsmakers ervan te overtuigen de nieuwe onderzoeksrichtingen, zoals in dit proefschrift worden beschreven, daadwerkelijk te implementeren.

AUTHOR CONTRIBUTIONS AND ACKNOWLEDGEMENTS

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Peter A.A. van den Besselaar, PhD.
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Included chapters with author contribution

Chapter 2: Evidence and consequences of academic drift in the field of oral health research: A bibliometric analysis 2000-2015

Authors: Puck van der Wouden, Geert van der Heijden, Hagay Shemesh, Peter van den Besselaar

Contribution:

1. Idea & concept of study: Puck van der Wouden, Geert van der Heijden, Peter van den Besselaar
2. Design, methodology and protocol of study: Puck van der Wouden, Peter van den Besselaar
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Chapter 3: Financing and costs of oral health care

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8. Final approval for publication of manuscript: all authors
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Chapter 4: Publications in the Dutch Journal of Dentistry - an analysis for the period 2000 – 2018

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5. Analysis and interpretation of study data: Puck van der Wouden, Hagay Shemesh, Peter van den Besselaar
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7. Critical revision of manuscript draft: all authors
8. Final approval for publication of manuscript: all authors
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Chapter 5: Research priorities for Oral Health care - Agenda setting from the practitioners' perspective

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8. Final approval for publication of manuscript: all authors
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Chapter 6: Establishing the research agenda for oral health care using the Dialogue Model – patient involvement in a joint research agenda with practitioners

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4. Management and cleaning of study data: Puck van der Wouden, Femke Hilverda
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Chapter 7: A research agenda on oral health care as a boundary-object that unites the perspectives of patients and practitioners

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8. Final approval for publication of manuscript: all authors
9. Supervision of study conduct: Geert van der Heijden
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LIST OF PUBLICATIONS

Original scientific studies

- Wouden P van der, Heijden GJMG van der, Shemesh H, Besselaar PAA van den. Evidence and consequences of academic drift in the field of oral health care research: A bibliometric analysis 2000-2015. British Dental Journal Open (2022)8:3. *(Chapter 2 in this thesis)*
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DANKWOORD

Ruim 6,5 jaar na het starten van mijn promotietraject is het nu tijd voor de kers op de taart. Dit proefschrift is het resultaat van alle kennis die ik als promovendus heb opgedaan. Daar ben ik ontzettend trots op, maar ik realiseer me dat kennis niet het enige is dat ik tijdens mijn promotietraject heb opgedaan. De samenwerkingen en daaruit voortvloeiende vriendschappen zijn, wat mij betreft, onvoldoende vertegenwoordigd in het proefschrift tot dusver. Daarom wil ik op deze plek mijn dank uitspreken naar de mensen die ik gedurende dit traject ben tegengekomen. Een terugblik op de afgelopen periode doet me realiseren dat ik zowel in mijn professionele leven als daarbuiten een ontzettende geluksvogel ben met alle fijne mensen om mij heen. Een aantal daarvan wil ik in dit dankwoord benoemen.

Beste Geert,
In juni 2015 startte ik als jouw eerste ACTA-promovendus op het kennisagenda-project. De grote lijnen voor dit project lagen vast, maar mijn interesses gaven het een andere wending dan vooraf geschetst. Jij gaf me niet alleen die ruimte binnen het project maar je moedigde me aan om er mijn project van te maken. Ik ben je ontzettend dankbaar voor alle mogelijkheden die je me hebt geboden, inclusief het regelmatig volgen van mijn intuïtie. Onze reguliere overleggen en vele sparringsmomenten over een idee of bevlieging van één van ons waren ontzettend inspirerend. Dankjewel voor jouw begeleiding, onze fijne samenwerking en jouw steun op vele vlakken.

Beste Hagay,
In 2016 voegde jij je bij Geert in het promotieteam. Je hebt je, vanaf moment één dat je je bij ons voegde, ingezet om mee te denken en er een fijne samenwerking van te maken. Je was altijd razendsnel met het lezen van stukken en antwoorden van mails, waardoor het tempo er vaak goed in zat! Hoewel het project zelf wat verder af staat van jouw expertise gebied, kon en wilde je met jouw kennis van het werkveld en jouw netwerk altijd je steentje bijdragen. Dank voor jouw inzet, onze fijne samenwerking en jouw deur die altijd voor mij open stond.

Geachte leden van de promotiecommissie, prof. dr. J.E.W. Broerse, dr. K. Jerkovic-Cosic, prof. dr. A. de Jongh, prof. dr. E. Kalendarian-Groenewegen, prof. dr. K. Stronks, en prof. dr. C.M. Visscher, hartelijk dank voor het kritisch lezen van dit manuscript en het beoordelen van dit proefschrift.

Beste Peter,
Toen ik bij jou aanklopte voor hulp bij het opzetten van een bibliometrische studie was je meteen enthousiast. Zo enthousiast dat we, naast de internationale studie, ook nog een Nederlandse studie hebben uitgevoerd. Ik heb ontzettend veel geleerd van jouw kennis op het gebied van onderzoeksbeleid en genoten van onze samenwerking. Onze afspraken in Watergraafsmeer waren leerzaam en interessant, maar bovenal altijd gezellig. Ik ben ontzettend trots op het resultaat dat we met elkaar hebben neergezet!

Beste Carina en Femke,
Jullie kennis, ervaring en inzet was onmisbaar voor de Kennisagenda Mondgezondheid, want wat is een Kennisagenda Mondgezondheid zonder vertegenwoordiging van het patiëntenperspectief? Ons project ging niet altijd van een leien dakje – daar hebben we zelfs een artikel over geschreven - maar ik ben ontzettend blij en trots dat we met elkaar dit resultaat hebben bereikt. Carina, jouw kennis en ervaring wat betreft patiëntparticipatie waren voor mij een bron van inspiratie. Femke, zonder jou waren de focusgroepen, het analyseren van de data en het schrijven nooit zo succesvol (en gezellig!) geweest. Dank jullie wel voor de fijne samenwerking!

De Kennisagenda Mondgezondheid was een samenwerking met veel partijen. Dat maakte het project een uitdaging maar ook een inspirerende en leerzame ervaring. Het resultaat is tot stand gekomen door veel gedreven professionals: Daniëlle Boonzaaijer, Wolter Brands, Dyonne Broers, Monique Danser, Ad de Jongh, Jan de Lange, Joris Muris, Niek Opdam, Jacqueline van Rennes. De wetenschappelijke tandheelkundige verenigingen, de KNMT, NVM, ONT, Ivoren Kruis, het KIMO en Edwin Dekker van FME. En natuurlijk alle mondzorgverleners die hebben bijgedragen aan de Kennisagenda Mondgezondheid.
Daarnaast wil ik ook de betrokken ervaringsdeskundigen ontzettend bedanken voor hun inzet en het delen van hun ervaringen. De verhalen die jullie bereid waren met ons te delen waren voor mij de bevestiging dat het patiëntperspectief onmisbaar was voor de Kennisagenda Mondgezondheid.
Veel dank ook voor de patiëntenverenigingen die hebben geholpen de mondzorg en mondgezondheid te agenderen bij hun leden: Patricia Pennings (Reumazorg NL), Eglantine Barents en Hans de Rooij (Diabetes Vereniging Nederland), Harteraad en Jan Benedictus en Jan Willem Mulder van Patiëntenfederatie Nederland.

Zes jaar lang heb ik me ontzettend thuis gevoeld op de 5^{e} etage. Hoewel de afdeling geen sociale tandheelkunde meer heet, durf ik hier best te stellen dat het de sociaalste afdeling is die ACTA heeft. Lieve collega's Fatiha, Naichuan, Amy, Nelleke, Riët, Marieke, Joost, Michiel, Jan, Joseph, Hanny, Ilona en Arjen, dank jullie wel voor de onvergetelijke

tijd! Daarnaast wil ik ook de leukste buren van orale geneeskunde bedanken en dan met name mijn kantoortuingenoten Willem en Thijs.

Lieve Babette en Denise, dank voor al onze gezellige etentjes. Altijd fijn om met jullie onze levens als jonge onderzoekers te bespreken, en vooral veel te lachen!

Thijs de Jong, koffie?

Sinds juli 2021 ben ik weer terug op mijn oude nest op de 4e etage. Hoewel het er niet rustiger op is geworden, is het des te gezelliger. Ik wil mijn collega's bij integrale tandheelkunde, en dan met name Arjun, Marguérite, en Myrna bedanken.

Mijn paranimphen Irene en Jet.
Lieve Irene, dank voor alles wat je gedurende mijn tijd als promovendus voor mij hebt betekend. Jouw rol binnen de afdeling, jouw kennis en kunde, en vooral jouw luisterend oor, jouw steun en natuurlijk jouw gezelligheid. Voor mij is het meer dan duidelijk, je bent nooit te oud voor de rol als paranimph.
Lieve Jet, naast mijn jongste zusje en supertante van mijn kinderen, nu ook mijn paranimph. Deze rol past jou als geen ander. Dankjewel voor jouw hulp en steun bij dit laatste stuk van mijn promotietraject, en voor alles wat je voor mij en mijn gezin betekent.

Veel dank voor mijn twee zwagers wiens kennis en kunde ik voor mijn project heb mogen inzetten: Jort, dank voor jouw hulp en ondersteuning bij het optuigen van de website. En natuurlijk Dennis, dank voor jouw hulp bij alle grafische vormgeving van de Kennisagenda én dit proefschrift. Je weet er altijd weer iets fantastisch van te maken!

De afgelopen jaren was ik nogal drukbezet met mijn promotie en mijn gezin, maar gelukkig heb ik een groep vrienden waar ik altijd op kan terugvallen. Lieve Ghazal, Helen, Ilse, Margueritha, Purdey, Sioe Ien, Wibien, Emma Jane, Liesje, Marjolein en natuurlijk Frederieke. Ik geniet altijd met volle teugen van jullie vriendschap. Dank voor de koffietjes, etentjes, belletjes en stedentrips! Ik ben een geluksvogel met zulke leuke en lieve vrienden!

Mijn ouders en schoonouders ben ik veel dank verschuldigd: Papa en mama dank voor alle mogelijkheden die jullie me hebben geboden waardoor ik ben waar ik nu ben. Mike en Berosh, dank voor jullie steun en hulp bij het draaiend houden van ons gezin.

Lieve zusjes, Lieve, Merel, Bregje en Jet, wat een rijkdom om jullie als mijn vier zusjes te hebben. Met elkaar groeien we van de ene fase in de andere, met alle ups en downs die daarbij horen. Ik hou van jullie!!

Mijn liefste Janesh, dank voor jouw onvoorwaardelijke steun in de afgelopen periode. Je was een onmisbaar onderdeel van mijn leven als promovendus, niet alleen omdat je meelas of luisterde naar een van mijn betogen tegen research waste. Je was vooral mijn steun en toeverlaat waardoor het ons lukte onze carrières te combineren met de drukte van een jong gezin. I love you.

Natuurlijk ben ik trots op het boekwerk wat ik heb gemaakt, maar dat valt in het niet bij de trots die ik als moeder voel voor de liefste kinderen van de wereld. Lieve Noah, Belén en Josie, het is een genot om jullie moeder te zijn. xxx

CURRICULUM VITAE

Puck van der Wouden was born on the 25th of June 1983 in Amsterdam, the Netherlands. She grew up in greater Rotterdam. After finishing her secondary school, Erasmiaans Gymnasium in Rotterdam, in 2001, she studied dentistry at the Academic Centre for Dentistry Amsterdam (ACTA). After graduation in 2007, Puck worked as a dentist in different practices. From 2009, she combined her work as a dentist with clinical teaching in the master clinic of ACTA.

As a dentist, she experienced a lack of transparency and clarity towards patients due to an absence of clinical guidelines. This experience increased her interest in dental research, more specifically the societal impact of research.

From 2011 to 2015 Puck followed the post-graduate master of epidemiology at Epidm (Amsterdam UMC). The subject of her thesis was the prediction of dental caries. After completion of her post-graduate master in 2015, Puck was granted a PhD training position at the department of Oral Public Health at ACTA. During her PhD, she focused on agenda-setting for research in oral health care. Puck was able to fully use her exceptional organizational skills as well as her skills to connect people from different backgrounds, stakeholder groups and perspectives. Consequently, Puck set up a collaboration with the Athena institute to include the perspective of patients in the research agenda, as well as a collaboration with Professor Peter van den Besselaar, to use bibliometric data on oral health research as context for research agenda-setting.

In addition, Puck taught different courses (statistics and evidence-based dentistry) to bachelor dental students at ACTA, and supervised students during their bachelor and master internships.

In July 2021, Puck has started as an educational coordinator at the master clinic at ACTA.

Puck lives with her husband Janesh Pillay and their three children, Noah, Belén, and Josie, in Amsterdam.

Puck van der Wouden