

ORIGINAL ARTICLE

Establishing the research agenda for oral healthcare using the Dialogue Model—patient involvement in a joint research agenda with practitioners

Puck van der Wouden¹  | Femke Hilverda²  | Geert van der Heijden¹  | Hagay Shemesh³  | Carina Pittens⁴ 

¹ Oral Public Health Department, ACTA, Amsterdam, the Netherlands

² Department of Socio-Medical Sciences, Erasmus School of Health Policy & Management (ESHPM), Rotterdam, the Netherlands

³ Department of Endodontology, ACTA, Amsterdam, the Netherlands

⁴ Athena Institute, Vrije Universiteit, Amsterdam, the Netherlands

Correspondence

Puck van der Wouden, ACTA, Gustav Mahlerlaan 3004, 1081LA Amsterdam, the Netherlands.

Email: p.vd.wouden@acta.nl

Abstract

Engagement of patients in the 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 develop a research agenda for oral health. Experienced challenges and needs with oral health(care) of practitioners and patients formed the 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 practitioners, using a participatory multi-phase approach for research agenda setting (Dialogue Model). Via focus group discussions, 32 research topics were generated. Next, 1495 patients prioritized these topics in an online survey. In a dialogue meeting, a joint research agenda of eight research topics was agreed upon. Many topics 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. Other topics that were prioritized covered affordability and accessibility as well as health system research and organizational issues. By considering different perspectives, this research agenda has uncovered directions for future research that go beyond evident research topics, as many topics are currently underrepresented in oral healthcare research.

KEYWORDS

dental research, patient participation, research and development, research priorities

INTRODUCTION

In many medical research fields, a mismatch between research and practice has been reported. This mismatch concerns a gap between current research topics and the research needs of end-users of research in particular [1,2]. Traditionally, research topics in the oral healthcare field have mainly been based on the established interests from academic research groups,

funding agencies, or the dental industry [3]. As a result, research addressing technical and scientific challenges dominates the current oral healthcare research while research on the effects of prevention, patient-reported outcomes of care, and the quality and organization of oral healthcare remains scarce [4]. The engagement of end-users of oral healthcare research, mainly oral healthcare practitioners (OHPs) and patients, in research planning and programming, for example,

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through the composition of a research agenda which reflects their research needs, is essential to reduce this gap [5,6].

Addressing the needs of the OHPs and patients in research on oral health and oral healthcare increases its societal relevance [5]. 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 impacts on many aspects of life [7]. 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 [8]. Another important argument for involving patients has a normative ground: the research outcomes will impact the health and well-being of patients. Therefore, it is their right to have a voice in research decision-making [9,10]. 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 healthcare 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 healthcare from the perspective of health and well-being. The information needs of the users of oral healthcare research—OHPs and patients—form the basis of the research topics on the agenda. The aim of this paper is twofold: we first aim to reflect on the establishment of the research priorities of patients. Next, we reflect on the integration of the research priorities of patients with the previously established research priorities of OHPs through a dialogue meeting. The research priorities of OHPs are published elsewhere [11]. The Consolidated Criteria for Reporting Qualitative Studies (COREQ) checklist has been followed in the reporting of this research [12,13].

MATERIAL AND METHODS

Methodology

This research agenda-setting project was initiated by the Department of Oral Public Health of the Academic Center for Dentistry Amsterdam (ACTA). The principal investigators with a background in epidemiological and dental research collaborated with researchers from the Athena Institute of the Vrije Universiteit Amsterdam, who have extensive experience in patient involvement in health research.

To develop a joint research agenda, we followed the methodology of the Dialogue Model [6]. 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 [14].

The use of the Dialogue Model is guided by six principles: (i) active involvement of end-users (including OHPs and patients), (ii) adaptation to social conditions, (iii) respect for experiential knowledge of end-users, (iv) dialogue and partnership, (v) emergent and flexible design, and (vi) 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 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 into 10 categories.

Next, in the prioritization phase, the 84 research topics were prioritized in an online survey, and two topics per category were chosen. The 20 chosen topics were presented and respondents were asked to rank the top 5. Two hundred thirty-five OHPs filled in this online survey. These research topics were sorted by the product of their frequency of endorsement and priority. This resulted in the identification of the top 10 research priorities. The development of the research priorities of OHPs has been described in detail previously [11].

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 1).

Data were collected from April 2018 to January 2019 in the Netherlands, proceeding through the four phases of exploration, consultation, prioritization, and integration, described separately in the paragraphs below.

Exploration

Patient involvement in this project was not obvious. The oral healthcare 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

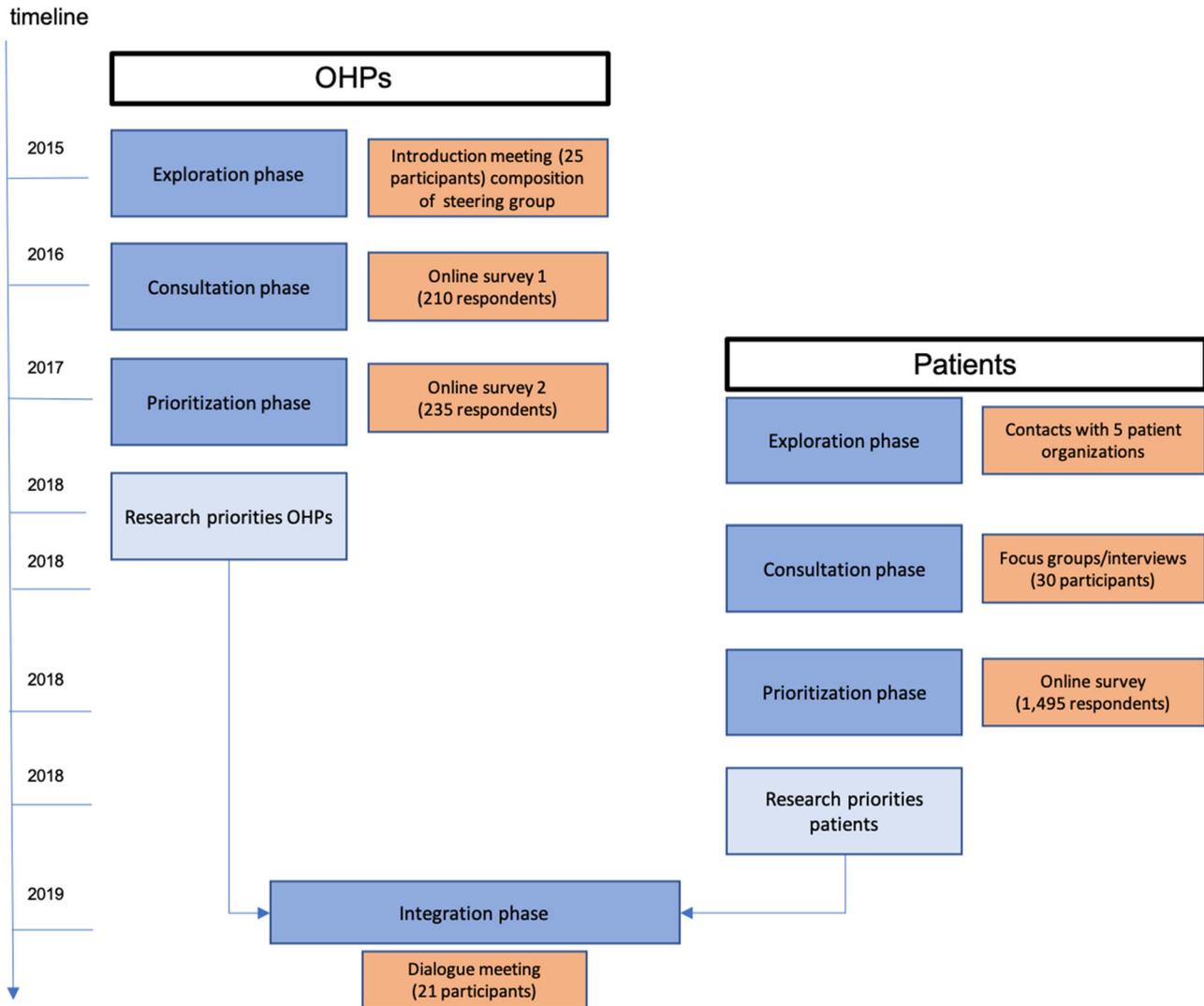


FIGURE 1 The timeline of the research agenda-setting project. The orange boxes display the activities for each phase of the project, per stakeholder group. The study that describes the development of research priorities of OHPs in detail has been published previously [11]

found of the number of participants and demographics per patient group.

Prioritization

In the prioritization phase, the research topics collected in the consultation phase were prioritized through a survey study. Thereby, the results from the small number of representatives in the consultation phase were validated among a larger sample of patients.

The survey was distributed amongst the patient panel of the Netherlands Patient Federation (NPF). This federation represents over 200 patient organizations [22]. The NPF panel consists of over 20,000 volunteers with different medical backgrounds. 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 sub-

sequent invitation to the survey in a separate mail distributed by the NPF. Approximately 3000 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 focus group discussion 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 32 research topics categorized into five research themes and presented in the survey as such. We used Qualtrics software (Version 2018; Qualtrics) 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 were collected on demographic characteristics, notably age and gender, as well

TABLE 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	Endodontist
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		

as on the presence of any disease. If respondents were interested in participating 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 list of the top 10 research topics of patients was determined.

Integration

In the previous phases, the research topics of both patients and OHPs were obtained from representatives and prioritized among a larger group. The prioritized topics that resulted from these phases form the basis of the dialogue meeting. 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 21 participants represented the patients and OHPs during the dialogue meeting, of which 11 were patients and patient representatives and 10 were OHPs. We aimed for an equal distribution of participants from both patients and professionals to ensure equal representation. The participating patients had different backgrounds 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 3, the characteristics of each participant are described. Five of the participating OHPs had attended previous meetings during the project to establish the top 10 research topics of OHPs.

We invited patients based on two criteria. First, at least two out of three prioritized topics of the participant had to be included in the patients' top 10 list. Thereby, we ensured that topics prioritized by each participant were represented at the meeting. Second, 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 [23]. After explaining the aim of the meeting, the top 10 research topics list of OHPs and the top 10 research topics list of patients with diseases were presented. We stratified the results of the prioritization survey for respondents without chronic disease. Four topics were prioritized by this group that were not found in the top 10 list of all patients. These four topics were added as a starting point for the consensus meeting since these topics could be of importance to 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 (dialogue meeting groups), in which professionals and patients were evenly distributed. The aim of the dialogue meeting groups 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 dialogue meeting group was chaired by a moderator to ensure an equal contribution in the dialogue for both patients and professionals.

The dialogue meeting group started with each participant naming his or her three 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 dialogue meeting group participants insight into each other's perspectives. Next, each dialogue meeting group was asked to establish an integrated top 10 through constructive dialogue. During this dialogue flexibility for rephrasing and adding topics was allowed if consensus could thereby be obtained. The results of each dialogue meeting group 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 on the results, an integrated topic 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 were encouraged.

The data that emerged up through the integration phase were then analyzed by the researchers through the three steps of consultation, prioritization, and integration, described successively below.

Data analysis consultation

All focus group discussions 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). Topics that were collected on sight during the focus group discussions 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 focus group discussions that overlapped or were strongly related were merged into research topics. The research topics were grouped into five overarching research themes after all focus group discussions 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 focus group discussion was discussed in depth.

Data analysis prioritization

Survey data were analyzed by SPSS version 26.0 (2019, IBM). Selected research topics were sorted by the product of their frequency of endorsement and weight to determine their ranked position.

Integration

The moderators of the dialogue meeting groups clarified and discussed the results of their integrated top 10 topic list with each other and the project team. Specifically, topics that required rephrasing or merging, according to the participants of the dialogue meeting group, were discussed and interpreted. The research topics prioritized by the dialogue meeting groups were used for individual voting. The individual top three 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 February 15, 2018). Under the Medical Research Involving Human Subjects Act (WMO), Health Services Research projects are not considered as medical-scientific research [24]. 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 focus group discussions 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 [25].

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 [11]. 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 prioritized research topics. Last, the results of the integration phase, the dialogue meeting, are described.

Consultation phase

Focus group discussion 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 (i) oral symptoms, (ii) lack of information on oral health(care), (iii) problems in daily life, (iv) organization and design of (oral) healthcare, and (v) the role of (oral) healthcare professionals.

In this manuscript, 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 4). All topics in this section

TABLE 4 Research topics per theme

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

Abbreviation: OHP, oral healthcare practitioner.

are indicated by a number that refers to the topic number in the survey as found in Table 4 (example: 1-3 refers to the third item, 'Dry mouth,' under the theme '1. Oral symptoms' in the Table).

Oral symptoms

In total, eight topics concerning oral symptoms were mentioned during the focus group discussions and interviews.

Some of these were unique for certain patient groups, such as oral fungus (1-1) for lung disease patients and painful jaws (1-2) for patients with rheumatic disorders. Other oral symptoms were mentioned in different focus group discussions. For example, problems due to a dry mouth (1-3) (diabetes mellitus, depression, lung disease) and inflammation of the gums (1-4) (rheumatic disorders, diabetes mellitus). Next to these, dental caries (1-5), periodontitis (1-6), problems with dental implants (1-7), and sleep apnea (1-8) 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 (2-1). Participant 3 from the diabetes mellitus focus group discussion stated:

I think it is very important that the OHP 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 healthcare treatments (2-2). Participant 3 from the heart disease focus group discussion noted the following.

Sometimes you have to make treatment decisions, and I think OHPs are often reluctant to give sufficient information.

In the focus group discussion of patients with lung disease, there was a discussion on which medical information should be shared with your OHPs (2-3). 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 (2-4). As Participant 5 of the heart disease focus group discussion stated:

I feel like the Internet is like a fallen bookcase. You are just not sure the right books are on top.

Many focus group discussion participants expressed they value the exchange of experiences and information with other people suffering from similar conditions, but are unaware of possibilities regarding this (2-5).

Some participants also missed information on how they could contribute to scientific oral healthcare research (2-6).

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, diabetes mellitus)

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

sought for solutions to cope with these problems and limit the impact. For example, Participant 4 of the diabetes mellitus focus group discussion had brought his charcoal toothpaste, which he had purchased after a thorough Internet search on how to reduce his gum problems. Other participants chose adaptation 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' (3-1).

Many participants experiencing oral symptoms tried to find effective oral care products (3-2). In the focus group discussion 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 focus group discussion for patients with rheumatic disorders reported problems with the use of oral care products, for example, 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' (3-3).

Other problems that patients encountered were a lack of motivation to take care of their oral health. For some, this applied to daily care (3-4):

..... because of 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, diabetes mellitus)

While others encountered a lack of motivation to visit an OHP (3-5):

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) healthcare

Many participants encountered problems with the oral healthcare system, mostly because they experience it as an insular system with limited connection to other healthcare domains. Furthermore, many found oral healthcare 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 healthcare providers as there is little integration between oral healthcare and other healthcare fields (4-1). Participant 6 in the focus group discussion 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 for additional expenses required for maintaining oral health (4-2). Third, for some participants, the one-size-fits-all experience in oral healthcare was reflected in the fact that some oral healthcare practices are not adequately designed for people with chronic conditions (4-3). Participant 4 from the focus group discussion 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 (4-4). A quote from Participant 3 of the focus group discussion 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 healthcare and dental treatments are not tailored to their specific situation (4-5). As Participant 1 from the lung disease focus group discussion 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) healthcare professionals

The seven topics in this theme all concern the role and responsibility of OHPs and other healthcare professionals. For the most part, these topics reflect a lack of knowledge and communication issues. Participants encountered ignorance on different occasions and levels. Some found their OHP as well as their other healthcare providers ignorant of the effect of their condition on their oral health as reflected in the topics 'Increasing the knowledge of other healthcare professionals about the effect of my condition on oral health' (5-1) and 'Increasing the knowledge of oral healthcare professionals about the effect of my condition on oral health' (5-2). As Participant 7 of the focus group discussion 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 previous 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 (5-3).

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, diabetes mellitus)

Moreover, participants experienced problems in communication between professionals. Only limited information exchange on oral health problems between OHPs with other healthcare providers takes place (5-4). Another topic concerned the need to improve communication between the OHP and the patient (5-5):

Well, that downplaying of the oral problems by my dentist makes me feel like I am not being taken seriously and that I'm not getting the right information. (Participant 5, rheumatic disorders)

A recurrent subject in each focus group discussion was how OHPs create and update their medical files (5-6). 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 healthcare was discussed. One participant stated the following:

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 4 were presented for prioritization in an online survey. In total, 1495 patients participated via the patient panel of NPF and social media and returned a complete survey. Characteristics of the participants of the survey are displayed in Table 5. Of the respondents, 321 had no (chronic) disease. Six hundred sixty-six respondents indicated they (also) had other diseases than diabetes mellitus,

TABLE 5 Respondents of the survey in the prioritization phase

Demographic characteristics		N (%)
Gender	Male	588 (40)
	Female	897 (60)
	Total*	1485 (100)
Age	Mean (sd)	61 (12)
Level of education	Low	125 (8)
	Middle	501 (34)
	High	852 (58)
	Total ^a	1478 (100)
Condition	Rheumatic disorder	452 (22)
	Heart disease	270 (13)
	Diabetes I/II	225 (11)
	Depression	125 (6)
	Lung Disease	308 (15)
	Other	666 (33)
	Total ^b	2046
	None	321
Visit OHP	Yes	1389 (93)
	No/missing	106 (7)
	Total	1495

^aNot all respondents completed the demographic data.

^bMultiple answers were allowed, therefore the percentages indicate the proportion of a certain condition based on the total amount of all conditions rather than the percentage of participants having a certain condition.

cardiovascular diseases, depression, rheumatic disorders, or lung diseases. Diseases that were often mentioned were cancer, physical disabilities, multiple sclerosis, different types of bowel diseases, and mental illnesses.

Table 6 presents the top 10 research topics sorted by the product of their frequency of endorsement and priority. Along with the rank of each topic, the theme from which the topic originated from is given. Topics concerning oral symptoms (#3 and #4 in Table 6) and (financial) access to oral healthcare were highly prioritized. The most important topic for patients was the possibility to add oral healthcare to the standard basic healthcare insurance benefits package for people with chronic diseases. In total, 667 respondents chose this particular topic among their top three priorities, of which 304 respondents listed this as their first choice. The topic that ranked as second most important was effective products for oral health self-care (#2 in Table 6), which was chosen among the top 3 by 375 respondents, of which 108 respondents listed this as their first choice.

When we stratified the results of respondents with one of the initially targeted chronic diseases, we saw substantial differences between the prioritized topics. Only 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-

TABLE 6 Top10 research topics of patients

Research topic			
I would like to see research done into:	Research theme	Ranksum	
1. The possibility to include oral healthcare in the basic insurance system	Organization and design of (oral) healthcare	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 healthcare that is attuned to my condition.	Impact of oral health(care) problems on daily life	388	
6. Expanding the knowledge of (oral) healthcare professionals beyond their own expertise.	The role of (oral) healthcare professionals	352	
7. How patients can participate in decisions on their oral healthcare treatments.	Information on oral health supplied to patients	319	
8. How access of oral healthcare practices can be improved for people with a physical disability.	Organization and design of (oral) healthcare	307	
9. How my oral healthcare professional can improve interaction with my medical professionals	Organization and design of (oral) healthcare	299	
10. Increasing the knowledge of oral healthcare professionals about the effect of my condition on oral health.	The role of (oral) healthcare professionals	282	

specific topics in the top 10 of a specific patient category. For patients with rheumatic diseases, the topic problems and pain in the jaws was highly prioritized, for heart disease this was sleep apnea, for diabetes mellitus it was motivation for self-care, and for depression it was motivation to visit an OHP. In the top 10 of lung disease patients, problems with implants were prioritized.

TABLE 7 The top 10 research topics of OHPs

1. What's the most effective method to change behavior to improve oral health?
2. Oral healthcare 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?

Topics that were suggested by respondents and were not included in the survey covered privacy issues in oral healthcare, oral healthcare for patients with dental anxiety, and oral healthcare 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 healthcare research'; 'To improve access to oral healthcare 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 increase the representation of patients without (chronic) diseases.

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 7) and the 14 topics of patients.

Dialogue meeting groups

All four dialogue meeting groups succeeded in reaching consensus over a list of prioritized topics. Among the four groups, the discussions resulted in considerable variability on the

TABLE 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 healthcare professional can improve interaction with my medical professionals	6 (2 / 4)
4	Oral healthcare that is attuned to my condition.	5 (4 / 1)
5	The possibility to add oral healthcare to the basic insurance system	5 (4 / 1)
6	Oral healthcare for the geriatric patient: What are the implications for the treatment plan and treatment?	4 (2 / 2)
7	Expanding the knowledge of (oral) healthcare professionals beyond their own expertise.	4 (3 / 1)
8	How patients can participate in decisions on their oral healthcare 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 healthcare professionals about the influence of my condition on my oral health.	2 (1 / 1)
11	To improve access to oral healthcare professionals	2 (2 / 0)
12	How patients can participate in scientific oral healthcare 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 healthcare 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)

Note. The top 8 research topics listed above were agreed upon as the joint research agenda for oral healthcare.

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 dialogue meeting group 2 and with the topic 'How to motivate myself to take good care of my oral health' in dialogue meeting group 3. The participants of dialogue meeting group 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 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 (merged into the topic on behavior change, #1 in Table 8), the relation between nutrition and oral health (also merged into the topic on behavior change, #1), and how the time between OHP appointments should be adjusted to provide adequate care (merged into the topic 'How patients can participate in decisions on their oral healthcare treatments', #8). The topic on adjusting time between appointments was merged with the topic on participating in decisions on oral healthcare (#8). 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 eight topics, there was strong support from participants from both stakeholder groups while there was limited support for the remaining nine. 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 healthcare (items #1–#8 in Table 8).

Of the eight highest prioritized topics, five topics originate from the top 10 of patients and three 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 healthcare in the basic healthcare insurance. The final votes of OHPs showed clear convergence: topics #1, #2, and #3 received nine, eight, and four votes from OHPs, respectively. The other five topics of the eight highest prioritized topics received only one or two votes from OHPs. The voting of patients was much more differentiated. All eight highest prioritized topics received between two and four votes, and no 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 dialogue meeting groups, 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.

The 17 research topics used for prioritization during the dialogue meeting are displayed in Table 8.

Consensus through the dialogue resulted in topics that were found important to both patients and professionals. These were not self-evident as the highest-ranked topics from one or the other 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. On the other hand, the topic 'How my oral healthcare 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.

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. Many topics 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. The research agenda covers a wide range of topics from prevention and treatment of oral disorders to health system research and personalized (oral) healthcare. Some of the topics on the research agenda represent existing knowledge gaps regarding oral healthcare as still many issues about treatment, prevention, and oral healthcare services remain unanswered [26–28].

In our study, the use of the perspective of patients and OHPs has provided important insights into their knowledge gaps. The articulated and prioritized research needs 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 research topics that are often overlooked [1,29].

In a recent study [30], we found that the current dental research portfolio is influenced by academic drift. For the dental research field, the mission of academic excellence has resulted in a science system that incentivizes publications within high impact, often basic science journals, and less in application-oriented journals. This academic drift has resulted in a research portfolio that moves away from research that serves oral health care. Moreover, the interests of OHPs and patients are implicitly dismissed in this science system, as it currently functions as a reputation system. As a consequence, the topics on the agenda identified in the

current study are underrepresented in the current dental research portfolio.

Despite being underrepresented in the current dental research portfolio, the topics identified in this study do align with conclusions from important policy reports and opinion papers. These report that there is an urgent need to reform oral healthcare systems by a better integration with primary healthcare and universal health coverage. Also, a more preventive and upstream focus of interventions is needed to respond to population oral health needs and equity [31–34]. It is well known that the burden of oral disorders for the individual as well as the socio-economic burden is high due to its high prevalence—dental caries and periodontitis rank among the most prevalent diseases worldwide [35]. However, the people suffering from and treating oral disorders, to whom the results from research often apply, are rarely consulted in the process of setting research agenda.

To uncover the topics on the research agenda identified in this study, it was essential to engage OHPs as well as patients. The inclusive and widespread consultation, where every one of interest had been offered the opportunity to contribute, has resulted in a research agenda that represents the research priorities of a large patient group and a wide diversity of OHPs [11]. Previously, OHPs have been consulted to identify research priorities in the field of oral healthcare, but these concerned prioritized topics that were defined a priori, notably on oral diseases, conditions, symptoms, or medical specialization [36,37]. Projects in which OHPs and patients are both consulted are rare [38].

Interestingly, while this research agenda-setting project was running in the Netherlands, a Priority Setting Partnership (PSP) was executed in the UK [39]. 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 focus group discussions. 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, Table 8) in our research agenda, while the PSP does not contain such topics. Possibly, the consultation via focus group discussions allowed for more in-depth topic analysis than an online survey, which has resulted in the inclusion of these topics. 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 not only succeeded 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.

The involvement of patients and OHPs in the field of oral healthcare was not self-evident [21,29]. 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 patient. This carried the risk that people would not feel addressed, with low engagement as a possible result. Through our approach of consulting specific patient groups [based on (chronic) diseases] that evidentially encounter oral health(care) problems, and a survey thereafter, this barrier was bypassed.

Also, we consulted both stakeholder groups individually, and we explicitly used the consultation phase to stimulate the sensitization of OHPs and the empowerment of patients. This process of preparing both stakeholder groups prior to the dialogue meeting enhanced the integration during the dialogue meeting. Also, 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 to establish a joint research agenda [23].

Through our approach, we included a fragmented group of patients. As a result, many of the topics collected in the consultation phase were very disease-specific. Through thematic analysis, we defined broader research topics based on common denominators. With regards to the fragmented group of patients, the results of the prioritization phase of patients were surprising. There was a clear conversion for the two highest-ranked topics (in Table 6: #1, ‘The possibility to add oral healthcare to the basic insurance system’, and #2, ‘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, by using the votes of both patients and OHPs a clear top eight research topics were revealed, diluting the effect of the heterogeneity. In the final voting, five out of eight topics originated from the top 10 identified by 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 using a fragmented patient group 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 affected the generalizability to a larger public. In the prioritization phase, the findings in the consultation phase were validated among a large group of patients. In this phase, there were no restrictions for respondents. In the prioritization phase, 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 to a larger public. Two of these four topics (access to

oral healthcare and participation 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.

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 including 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 [5].

The authors would like to stress that through our approach, the perspective of children and adolescents was underrepresented. Some topics that were prioritized might be relevant for patients of all age groups, for example, the topic on behavior change and the prediction of caries. However, it is important that for this specific patient group, a separate research agenda be developed.

The reported research agenda concerns the research priorities shared by patients and OHPs regarding oral health(care) from the perspective of health and well-being. It covers a wide range of topics, of which most topics originated from the patients' topic list, 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. The research needs of patients and OHPs are currently underrepresented in the research portfolio. Therefore, we urge researchers, research policymakers, and research funders to design new research based on the topics on the research agenda.

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CONFLICTS OF INTERESTS

The authors have no conflicts of interest to declare.

AUTHOR CONTRIBUTIONS

Conceptualization: Puck van der Wouden, Femke Hilverda, Carina Pittens. **Investigation:** Puck van der Wouden, Femke

Hilverda. **Formal analysis:** Puck van der Wouden, Femke Hilverda, Carina Pittens. **Writing—original draft:** Puck van der Wouden, Femke Hilverda. **Writing—review and editing:** Hagay Shemesh, Geert van der Heijden, Carina Pittens. **Supervision:** Geert van der Heijden, Carina Pittens.

ORCID

Puck van der Wouden  <https://orcid.org/0000-0003-2721-9670>

Femke Hilverda  <https://orcid.org/0000-0002-7542-4508>

Geert van der Heijden  <https://orcid.org/0000-0003-4979-2099>

Hagay Shemesh  <https://orcid.org/0000-0002-4840-048X>

Carina Pittens  <https://orcid.org/0000-0002-2795-4790>

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