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### Specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands: Lessons learned in an attempt to improve healthcare

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# Availability and accessibility of healthcare for deaf and hard of hearing patients

Anika S. Smeijers

# **Availability and accessibility of healthcare for deaf and hard of hearing patients**

Anika S. Smeijers

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FOR DEAF AND HARD OF HEARING PATIENTS  
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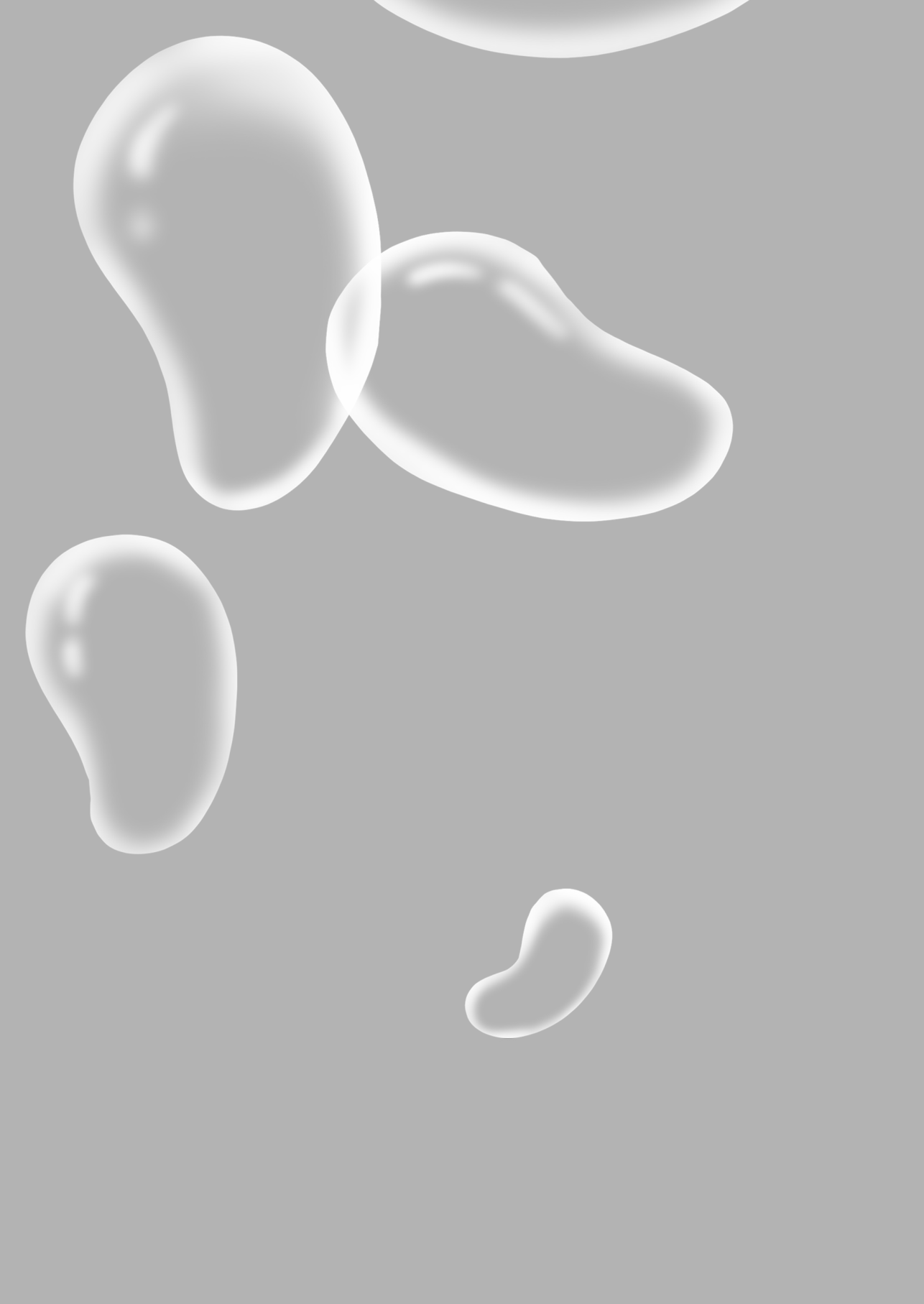
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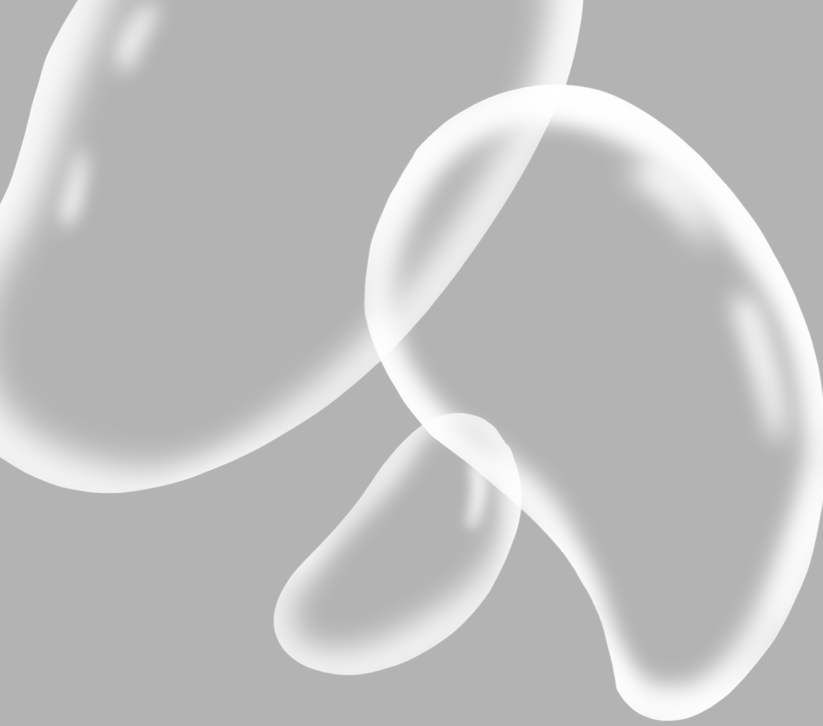






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# 5.2

## Specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands: Lessons learned in an attempt to improve healthcare

Submitted article:

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# Abstract

In 2013 a group of organizations and individuals in the Netherlands got together to attempt to improve access to healthcare and health education for deaf and hard of hearing (DHH) patients in the country. The result was the start of a specialized outpatient clinic named PoliDOSH. An independent research group was set up to evaluate the effect of this specialized clinic. Even though the initiative did not succeed and was closed after only two years, an extensive analysis of the start-up and functioning of the whole process was made. The findings are reported in this paper and advice concerning setting up a similar facility in the future in the Netherlands or elsewhere is given.

**Data collection:** structured and non-structured questionnaires and structured interviews.

**Outcomes:** Only a small group of DHH patients indicated that they felt a need for consultations at the PoliDOSH. However, to ensure that DHH patients are provided with the opportunity to access optimal medical care it is essential that the possibility to visit specialized healthcare facilities exists. There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for 1) the DHH persons themselves and 2) healthcare professionals, concerning the specific needs and problems of this patient group. To ensure successful functioning of a specialized facility the **team members should include a representative group of DHH members**. All key functions should be filled by top experts in the relevant fields as well as an expert in communication and needs of the target group. It is essential that regular healthcare workers who look after the target group are frequently informed about the existence and possibilities of these facilities.

**Thorough market research prior to start up is needed to enable the facility to connect with the needs of patients. The start-up period** should allow sufficient time for the project to become known and for patients to become familiar with it and trust it. Charting the availability of medical and paramedical care available for DHH people in the whole country can help to concentrate the care in various regions and strengthen the already present expertise.

## Introduction

Ideally a healthcare system should be easily available to all who need it. However, Deaf and Hard of Hearing (DHH) patients often report that they experience feelings of fear, mistrust and frustration during contact with healthcare professionals (Barnett & Franks, 2002; Steinberg, Barnett, Meador, Wiggins, & Zazove, 2006; "United States District Court Georgia. Sign language interpreters: US court says hospital discriminated against deaf patient," 2008). They feel that physicians do not understand them (Bat-Chava, Martin, & Kosciw, 2005; McEwen & Anton-Culver, 1988; Schein & Delk, 1980). Good communication with DHH patients is essential because poor communication may lead to wrong diagnoses and misguided therapy (Hochman, 2000; "US Department of Justice: Communicating with people who are deaf or hard of hearing in hospital setting," 2015; Woodroffe, Gorenflo, Meador, & Zazove, 1998; Zazove et al., 1993). It has been shown that many physicians are not sufficiently trained for caring for DHH patients, since academic curricula do not provide the necessary skills to meet the needs of this population (Barnett & Franks, 2002). However, various services and technical support systems have been developed to attempt to improve access to medical care for these patients.

There are several reasons why DHH patients' access to healthcare facilities is difficult (Arulogun, Titiloye, Afolabi, Oyewole, & Nwaorgu, 2013; Barnett & Franks, 2002; Bentes, Vidal, & Maia, 2011; Royal Institute for Deaf People, 2004; Folkins et al., 2005; Hochman, 2000; Jones, Renger, & Firestone, 2005; Kritzinger, Schneider, Swartz, & Braathen, 2014; Maddalena, O'Shea, & Murphy, 2012; Parsons, 2013; Peinkofer, 1994; Pereira & Fortes, 2010; Steinberg, Wiggins, Barmada, & Sullivan, 2002; Tedesco & Junges, 2013; Ubido, Huntington, & Warburton, 2002; Zazove et al., 1993). Communication is the greatest barrier, as availability and use of sign language (SL) mediation by interpreters is restricted and medical information in SL is scarce in many countries (Folkins et al., 2005; Kritzinger et al., 2014). The problem is compounded by the fact that DHH adults have inadequate access to information about health and healthcare and also have less knowledge of these subjects than what is generally considered by others to be common knowledge (Barnett, 1999; Jones et al., 2005; Kleinig & Mohay, 1990; McKee, Paasche-Orlow, & et al., 2015; Pfeinkofer, 1994; Smith, 2014; Vernon & Andrews, 1990). The reasons for this include restricted exposure to many topics during the education of DHH children (Tamaskar et al., 2000) and the fact that most DHH people do not have access to 'ambient information' because they do not overhear conversations or hear radio and television announcements (Barnett, 1999; Jones et al., 2005; Tamaskar et al., 2000). Moreover, low literacy is also a factor and means that information from newspapers, magazines and television captioning is less accessible to them than it is to hearing people (Easterbrooks & Beal-Alvarez, 2012; Napier & Kidd, 2013; Vernon & Andrews, 1990).

Access to healthcare for DHH patients is a worldwide problem and only a few centers have paid specific attention to this. In the Netherlands there is a good network of specialized facilities for mental healthcare for DHH people but none for general practitioner facilities and physical health problems. It was only on June 14th 2016 that the Dutch government signed the United Nations' convention agreement on the rights of persons with a disability which should ensure that special attention should be given to sign language and the rights of DHH people in the Netherlands. Up to then there was no legislation on the rights of persons who were DHH other than that stated in the laws on general equal rights for all. Most general information, also that concerning health and healthcare, is available to DHH people in only a very limited manner. Sign language interpreters or sign-to-text services are commonly not used in medical consultations.

In view of these problems a group of interested organizations and individuals in the Netherlands got together to attempt to improve access to healthcare and health education for DHH patients in the country. The result was a plan to start a specialized outpatient clinic for deaf and hard of hearing patients in the Netherlands which would address many of these problems. This paper describes this endeavor and the lessons learned from it.

### **PoliDOSH initiative**

A plan for a specialized outpatients' clinic for DHH patients (acronym PoliDOSH) was conceived by staff members (with normal hearing) of Royal Dutch Kentalis (Kentalis, 2017). This is a national organization specialized in providing diagnostic, educational and care services to people who are deaf, hard of hearing or deafblind, as well as to people with severe speech/language impairment or autistic spectrum disorders accompanied by severe speech and language difficulties. These hearing professionals decided, both on the grounds of signals from their own practices and research on DHH health issues, that medical care for these patients needed to be improved. The organization of PoliDOSH mirrors that of the specialized outpatient clinics for DHH patients in Austria<sup>1</sup>. Its main purpose was to provide a safety net for patients who, for one reason or another, did not receive adequate appropriate medical care in the regular healthcare system. It aimed to cater primarily to adults with mild to severe hearing loss and an average IQ (>80).

### **Process**

In September 2013 a project proposal was written by a group of hearing individuals, consisting of a physician, project leader and secretary. They contacted various organizations involved in the care of DHH people at the end of 2013. After this the project group was extended by also including DHH members. The official project group was installed on 28

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1 (<http://www.barmherzige-brueder.at/pages/issn/gesundheitszentrumgehoerl>).

January 2014. PoliDOSH was officially opened on World Deaf Day, 27 September 2014. PoliDOSH was set up as a primary care facility, located within a local general hospital. The medical team consisted of one physician (hearing, non-signing, specialized in treating patients with multiple disabilities) and one nurse (suddenly deafened, signing), they were supported by an NGT<sup>2</sup> interpreter (hearing). Consultations were preferably on Friday morning. Consultation fees were covered by all health insurance companies.

The project was planned to be set up for a minimum of 3 years. However, at the beginning of 2016 it became clear that the outpatients' clinic did not attract a sufficient number of patients to be able to evaluate this initiative according to the analysis plan which had been drawn up at the outset. During the 19 months of operation only 23 patients had attended this outpatient facility.

During the preparation of the PoliDOSH it was clear that this new facility would need to be monitored and evaluated. An external independent group (including the authors of this paper) was asked to evaluate the effect of this specialized clinic and a model for evaluation was drawn up. Even though the initiative did not succeed and was closed after only two years the evaluation group carried out an extensive analysis of the start-up and functioning of the whole process. The findings are reported in this paper and advice concerning setting up a similar facility in the future in the Netherlands or elsewhere is given.

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2 NGT (Nederlandse Gebarentaal) means Sign Language of the Netherlands.

## Methods

Data collected in three different manners were used to evaluate how the PoliDOSH functioned.

A questionnaire was completed by PoliDOSH patients (2.1)

- Structured interviews were carried out with professionals of the PoliDOSH and those directly concerned with its running (2.2)
- A questionnaire for members of the Deaf community was made available online (2.3).

### **Questionnaire completed by PoliDOSH patients**

All patients who attended the PoliDOSH were asked to complete a questionnaire. This questionnaire included questions on gender and age of the patient, five questions on the referral process and reception at the PoliDOSH, six questions on communication with the physician at the PoliDOSH, seven questions on the content of the consultation and three questions on their general experience with the PoliDOSH. The questionnaire was completed online using Unipark software (Unipark, 2015). The questionnaire can be obtained from the corresponding author. The questions were presented in Sign language of the Netherlands (NGT) and in written Dutch. The secretary of the PoliDOSH sent the invitations to take part in this evaluation, the results were returned directly to the investigator through Unipark allowing these to be analyzed anonymously without the personnel of the PoliDOSH seeing them. The invitations were sent after the patient had attended the PoliDOSH three times, or when consultations ended.

### **Structured interviews**

Ten structured interviews were carried out concerning the start of the PoliDOSH and how it functioned. Eight structured interviews were carried out with personnel of the PoliDOSH and members of the project group. They consisted of one physician (hearing) one nurse (suddenly deafened), one NGT interpreter (hearing) two secretaries (one deaf and one hearing), one project leader (hearing), two advisors (both deaf, one of whom was previously a board member of Dovenschap)<sup>3</sup>.

Three structured interviews were carried out with people who represent interest groups, one sitting board member of Dovenschap<sup>3</sup> (deaf), one ex-board member of Dovenschap (deaf with a double role as this person was also an advisor for PoliDOSH) and one member of the mill organization<sup>4</sup> (hearing).

Eight to 11 open questions were posed in the structured interviews. These concerned the way in which representatives of organizations and personnel were involved in the setting-up and the organization of the PoliDOSH, what their experience was, how they estimated the need for a special PoliDOSH, what they considered as strengths and difficulties and their suggestions for how the PoliDOSH could be improved. The questions are available from the corresponding author.

### **Questionnaire Deaf community**

A short questionnaire was developed in both NGT and written Dutch, based on information from the structured interviews (2.2) and anecdotal information gained from conversations with visitors of the Amsterdam Foundation for the Wellbeing of the Deaf (AKA the Deafclub in Amsterdam). This questionnaire contained 10 questions concerning awareness of the PoliDOSH and the need for this or other types of specialized healthcare (questionnaire available from the corresponding author). The questionnaire was completed online using Unipark software. It was distributed by 14 clubs and organizations for Deaf people in the Netherlands, support organizations, Facebook pages of a Deaf Gain meeting group and the investigators.

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3 Dovenschap is the largest independent interest group for Deaf people in the Netherlands.

4 The mill organization is a collaboration of 7 interest groups/ patient organizations in the Netherlands.



## Results

The results will be discussed per dataset.

### Questionnaire completed by PoliDOSH patients

Twenty-three patients made use of the PoliDOSH. After attending, the questionnaire was completed by 12 patients (52%). Nine patients stated that they found communication with the physician good, one moderately good, no one replied that they considered communication fair or bad and two patients did not answer this question.

Table 1: Communication with the PoliDOSH physician

	Good	Moderate	Fair	Bad	Not answered
How was the communication with the PoliDOSH physician?	9	1	0	0	2

Six patients stated that they were happy with the PoliDOSH, one patient was moderately happy and five patients did not fill out this question.

Table 2: Degree of satisfaction with PoliDOSH

	Yes	Partly	No	Not answered
Do you find PoliDOSH satisfactory?	6	1	0	5

Ten patients indicated that they found that the referral process proceeded smoothly, two patients did not answer this question. No patients offered suggestions for improvement. Statistical analysis or comparative evaluations were not possible in view of the very small number of respondents

### Results of structured interviews

Ten structured interviews were conducted concerning the start-up of PoliDOSH and how it functioned. In the text giving the results, the number of respondents who gave a certain answer is given between brackets and quotes and answers of the interviewees are placed between inverted commas.

### *Involvement in setting up PoliDOSH*

One representative of the mill organizations was indirectly involved in setting up the PoliDOSH. He was not involved with the content before the decision was made to start this initiative, but he functioned as a contact person between PoliDOSH and the various interest support organizations when PoliDOSH became a reality. He provided advice on practical matters such as identifying the target group, approaching patients and reaching interest groups.

Representatives of the support group Dovenschap indicated that they were not involved before the decision had been reached to set up PoliDOSH, but there was some contact after it had started. Dovenschap stated that deaf and hard of hearing individuals mainly experienced communication problems in accessing medical care. They stated that these problems could be solved by providing NGT interpreters or speech to text interpreters. They preferred to concentrate on aiming for the achievement of nationwide availability of interpreters rather than providing specialized medical facilities.

### ***Need for the outpatients' clinic facility***

All the PoliDOSH personnel members indicated that they would not personally seek medical care at a facility like PoliDOSH. Two stated that they would attend the PoliDOSH only if they had attended several other physicians without their problems being resolved. The reason they gave was that they thought that the professionals working at PoliDOSH would spend more time and would explain things better than other physicians. The remaining members stated that they did not need a facility such as PoliDOSH because they were able to communicate well, or if necessary, they would take an interpreter with them to medical appointments. They also added that they were highly educated and assertive enough to ask relevant questions that other patients might not dare to ask.

The personnel members of the PoliDOSH and representatives of interest groups indicated that they knew some people in their surroundings who might probably need facilities such as PoliDOSH. These people were less well educated (3) or less assertive (3). They also thought that these people would be difficult for the PoliDOSH medical team to reach because they were usually less active in interest organizations (2) and more time would be necessary to win their trust. They stated 'the step to attend the PoliDOSH involves changing old habits and this takes a long time' (6).

### ***Description of the target group***

All people who were DHH were officially regarded as the target group at the set-up of the PoliDOSH. Various answers were given to the question of who, in practice, should be regarded as the main target group of PoliDOSH. These answers included 'all deaf and hard of hearing persons', 'all deaf people except those who suddenly lost their hearing as adults', 'elderly deaf and severely hard of hearing persons', 'poorly educated deaf persons'. Almost all the participants gave different answers ranging from 'all deaf and hard of hearing people without regard to their age or educational level' to 'only specific subgroups'.

### ***Strengths of PoliDOSH***

Personnel indicated that, in their view, even though the aim of PoliDOSH had not been reached, the project clearly had not failed. Thanks to the project, some medical information is now available in NGT and a general practice-based nurse specialist especially for DHH patients has been appointed at a general practice in the vicinity of the Gelderhorst, which is the only center in the Netherlands for elderly deaf people. In addition, four personnel members stated that they had learned a lot as a team and that the project had contributed to their personal development.

Team. When asked what went well in the PoliDOSH project, all eight personnel members mentioned the cooperation within the team as the first point. All stated that they had formed a good, close group with team spirit, trust in each other and they had worked well together. The majority of them also indicated that this had not been the case at the beginning. At first it had been seen as a project where 'the hearing were trying to do something good for the deaf' (3). Hearing members had to get used to the working style of deaf members (3), and hearing members had first to gain the trust of the deaf members (5). It is striking that the hearing members experienced the project as containing relatively more 'conflict' while the deaf members found that they 'had had a good discussion'.

The team gradually became more acquainted with the specific (Deaf cultural) aspects of the target group, which led to better communication and information. Examples of this were that information meetings and information folders which were originally organized and written by hearing members were later revised by deaf members who made the language and the information clearer and more succinct (4). Two members emphasized the importance of using a deaf photographer and a deaf website builder, both of whom ensured that the provided information suited the target group better.

Preparation. The three original members of PoliDOSH admitted that the amount of preparation necessary for setting up such an outpatients' facility had been greatly underestimated. Delaying the planned opening date by 10 months ensured that it was properly prepared to start (2).

### ***Points for improvement of PoliDOSH***

The representatives of interest organizations and PoliDOSH personnel offered several possible reasons to account for the fact that POLIDOSH attracted so few patients.

Vicinity of care.

Medical care in the Netherlands is organized in such a manner that almost everyone has one or more general practitioner (GP) practices within walking distance of their home. Inhabitants of the Netherlands are used to not having to travel very far to a hospital either, with most people having a hospital within a radius of 5 km of their home (CBS, 2009). However, almost all patients had to undertake a longer journey to attend PoliDOSH. The interest group representatives and seven personnel members indicated that DHH patients with an average to high education level prefer to access medical care near their home. Even though the representatives of interest organizations stated that their clients regularly encounter communication problems when attending the general practitioner or medical specialist in their area, 'they suppose they will go home with the correct medication'. The three representatives of the interest groups stated that poorly educated DHH persons or DHH persons with other disabilities probably need the specialized care provided by PoliDOSH, but these groups would find it difficult to access this as they generally do not have personal transport and find public transport too expensive. Six personnel members indicated that the location of PoliDOSH was not sited centrally enough in the Netherlands and that the location was difficult to reach by public transport. Two personnel members said that patients were regularly unable to attend before 11 am due to the long distances; patients who came by car did not want to get caught in rush hour traffic and those who came by public transport travelled only in the hours when the prices of travel tickets were reduced outside the rush hours. Personnel gave various arguments for their opinion that it was undesirable to hold the consultations only on Fridays. This was not mentioned by patients. Several personnel members indicated that they considered the travel time to the PoliDOSH too long for some (potential) patients but their views about an acceptable journey time ranged widely.

Three points were proposed for possible improvements:

- 1) A more central location in the country, easily accessible by public transport (2).
- 2) Hold the consultations in turn in four or five locations across the country so the travel time for patients is always less than 90 minutes (3).
- 3) Have a 'mobile' outpatients' facility in a bus or a van so consultations can be carried out all over the country (4).

Duration of the project. Six respondents found that the three year duration of the project was too short to get such a facility set up and running well and that at least twice as much time would be necessary to achieve this. They gave several possible reasons for this. Firstly, a process of consciousness arousal of DHH people is necessary to allow them to become aware of their own higher risk of health problems. This process takes time. Secondly, the deep seated mistrust of some DHH patients towards the medical and paramedical

professions means that it will take time to win their trust. Thirdly, there was no previous experience in the Netherlands with setting up a similar project for DHH patients. The personnel admitted that they later became aware that they had underestimated the complexity and enormity of this project (3).

Communication with the target group. A few of the hearing personnel members stated that it was 'only after the first contacts with e.g. the mill organizations that it became clear that the target group (all deaf and hard of hearing people) was comprised of very diverse subgroups depending on the hearing status, background and age' (2). Many personnel members and representatives of interest groups stated that the individual subgroups within the target group should receive more attention and there should be a designated policy for each subgroup. They remarked 'this makes it more complex but is essential if these subgroups are to be reached'. (5)

More emphasis on health promotion. Before DHH people are prepared to attend a specialized outpatients' clinic or take other steps to improve their health, they must first gain insight into the possibility that their health may be poor or under threat and understand the possible reasons for this (4). The team members had been chosen because of their competency to set up and run a specialized facility. They were not experts in the fields of health promotion/ health communication for DHH people and social media (1). The amount of health information available on the PoliDOSH website<sup>5</sup> is still too limited, more information is necessary (2).

Team. Three of the interviewees indicated that it would be better if there were more DHH team members, which would create a better representation of the different target group in the team. It would also have been better if DHH team members had been involved at an earlier stage of the project. They advised that the initiative for starting a similar project should be taken by DHH people themselves.

Small close knit. Dovenschap indicated that the Deaf community in the Netherlands is small and 'there is a lot of gossip'. Even relatively minor news is generally rapidly spread by WhatsApp and Skype. DHH patients dread meeting acquaintances in the waiting room of a specialized outpatients' facility because, within a few hours, it may be broadcast on social media and their friends and many acquaintances will know that they have attended the facility. The risk of running into DHH acquaintances is much less when they attend the local general practitioner who usually has only one or two DHH patients in the practice.

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5 <http://polidosh.nl>

### The role of Royal Dutch Kentalis.

The original initiative for setting up the PoliDOSH was taken by Royal Dutch Kentalis. The representatives of interest organizations and two personnel members stressed that this organization is regarded by DHH people as caring for them 'from the cradle to the grave', because they are dependent on Kentalis from a very young age. At the start of PoliDOSH there was some resistance to the fact that this facility was also coming from Kentalis. Patient information is sometimes exchanged between various departments of Kentalis and because of this some DHH people were apprehensive about the possibility that their medical information could be made available to more organizations connected to Kentalis. They worried that their medical information might not be safe at PoliDOSH.

### **Evaluation of the online questionnaire among the Deaf community**

The group of patients that PoliDOSH did actually reach was people who are deaf from the prelingual period. Therefore, the questionnaire to evaluate functioning of PoliDOSH was specifically aimed at this target group. A total of 36 respondents completed the questionnaire. Of these, 30 reported that they were deaf, one hard of hearing and five that they were hearing. The questionnaires of the hearing respondents were excluded. The remaining 31 respondents included 10 men and 20 women and one respondent did not answer the question on gender. The age of the respondents was relatively older, with a mean age of 58 years (range 23-77 years).

Twenty-two respondents stated that they were aware of the presence of PoliDOSH and three had visited it (Table 4). These three patients had been satisfied with the care they received. Two-thirds of the respondents stated that they would certainly, or possibly, attend the PoliDOSH should they have physical complaints in the future. The reason they gave was that they expected that they could communicate better with the PoliDOSH physician than with their own physician and/or that they would receive more information there. One respondent indicated that he would attend the PoliDOSH only if a second opinion was needed (Table 6). One-third of the respondents indicated that they would certainly not attend the PoliDOSH. The reason most often given for this was the long distance or travel time. Four respondents gave various reasons why they (as yet) had no faith in the PoliDOSH (Table 7).

Table 3: Awareness of PoliDOSH.

	Yes	No	Not answered
Do you know PoliDOSH exists?	22	9	0

Table 4: Attendance PoliDOSH

	Yes	No	Not answered
Have you attended PoliDOSH?	3	19	0

Table 5: Willingness to attend PoliDOSH

	Yes	No	Maybe	Not answered
Would you attend PoliDOSH if you had physical complaints?	3	11	14	3

Table 6: Reasons given for being prepared to visit PoliDOSH if one has physical complaints

Reason	Number of times given
Good communication	4
Second opinion	1

Table 7: reasons given for not wanting to attend PoliDOSH in the presence of physical complaints.

Reason	Number of times given
Too far away	11
Preference for own general practitioner or hospital specialist	5
Too little information about PoliDOSH, possibly later when PoliDOSH is better known	3
Aversion to institutions connected with Royal Dutch Kentalis, because of fears concerning confidentiality of medical information	1

## Discussion

The plan to set up a special outpatients' clinic in the Netherlands to provide primary healthcare for DHH people with somatic disorders was conceived and executed with great care. It was not foreseen that there would be only limited interest in using these facilities. The analyses of the information gained during evaluation of the process provided some interesting information. On analyzing the results of the structured interviews and the online questionnaire it was striking that some points turned up regularly. Some of these will be discussed here.

### **Distance to care**

Almost all the respondents and some of the DHH interviewees indicated that they considered they would need specialized care only when they felt the need for a second opinion or if the regular medical healthcare system did not succeed in solving their problems. Therefore, it is to be expected that the number of patients who would attend the PoliDOSH would remain limited. However, the interviewees and respondents emphasized that they found it important that such a facility existed.

All the patients who attended PoliDOSH stated that they were happy with the offered care but there were too few answers to be able to draw conclusions. It is important to DHH persons that, just like hearing persons, they are able to receive good medical care without having to travel long distances and this must be taken into account in the future. In the Netherlands only groups with specific care needs seem to be prepared to travel long distances for this care. An example of this are deaf persons with psychiatric problems who did not receive satisfactory care within the regular medical system. They are willing to travel to specialized centers for mental healthcare provision for DHH. Another example is elderly Dutch Deaf people who are willing to move to a specialized center for the elderly, known as 'de Gelderhorst'.

A national specialized center could play an important role in centralizing care and providing information facilities and supporting second opinion consultations. There does not appear to be sufficient need for a specialized outpatients' clinic for primary care for DHH persons in the Netherlands. Throughout the Netherlands there are many individual healthcare providers experienced in caring for DHH patients. These include general practitioners, psychiatrists, physiotherapists, dieticians, psychologists etc. There is no national directory of these healthcare providers, but it could be helpful to compile an overview so that the care for DHH people can be concentrated within different regions and the existing network of care providers strengthened. This network could then be used by DHH people after attending a national centralized specialized facility.



### **Diversity of the target group.**

The target group of DHH persons included a great number of subgroups, each with its own needs. These included persons who are deaf from the pre-lingual period, persons who became deaf at a later age, those with sudden hearing loss, persons with and persons without a cochlear implant and persons who are severely hard of hearing. All these groups have their own communication needs. PoliDOSH mainly reached the prelingually deaf group. If the other subgroups are to become interested in a facility such as PoliDOSH, it is imperative that their communication needs are investigated and met.

One example of differences between sub-groups is that severely hard of hearing persons often do not use NGT but use the Dutch language with signs support, lip reading and /or subtitling. On the PoliDOSH website films were used with information in NGT and written text. This communication method is mainly aimed at prelingually deaf persons. Even though many hard of hearing persons will be able to access this information they will feel that it was not aimed primarily at them and they may lose interest. It is essential that communication is aimed specifically at each subgroup e.g. separate entry portals on the website for persons who are prelingually deaf, persons who became deaf later in life, and hard of hearing persons, as well as for the healthcare providers.

This study showed that preparation for PoliDOSH was not properly planned. Before or during the planning period for PoliDOSH no investigations were carried out to see if there was a need for such a specialized facility. Neither were the interest groups approached to ask what the needs of their target group were and to see whether the aims of PoliDOSH would tie in with their wishes. The inclusion of a contact person for all the mill organizations during the setting up of PoliDOSH was 'too little and too late' and therefore there was a lack of clarity about the interests of the various subgroups and insufficient involvement of the interest organizations. Support for PoliDOSH could possibly have been greater if the interest groups had been involved earlier and not only after the project was started.

### **Awareness of health problems**

Many DHH people stated, in both the structured interviews and the online questionnaires, that they considered PoliDOSH a good initiative, but it was not for them. This was because they considered themselves able to communicate well, were well educated, assertive enough and therefore they expected that they would obtain good medical care without needing PoliDOSH. The statement 'because the body of a deaf person is the same as the body of a hearing person, means I will get the correct tablets' showed how DHH persons regarded the fact that they were deaf or hard of hearing not relevant and seemed unaware of the consequences this could have during a medical consultation. It did not

occur to DHH people that a good reason to attend PoliDOSH would be to ensure that they were well informed about their medical condition and medication. This demonstrated the limited awareness of deaf and hard of hearing people of the fact that information is missed during a consultation.

On one occasion PoliDOSH organized a 'health fair' for deaf and hard of hearing persons with presentations, an information market and discussions about various health subjects (doof.nl, 2016). Many respondents indicated that they found the information meetings and this health fair very useful. The information on the website about frequently occurring disorders was also greatly appreciated. It is probable that this type of health information promotion and psycho-education could lead to more health gain in the short term than the consultative function of PoliDOSH.

### **Providing information for healthcare professionals**

While PoliDOSH focused on promoting the clinic among potential patients, not much efforts were made to inform regular healthcare professionals about the existence of PoliDOSH. This lack of awareness among healthcare workers might exclude potential patients, i.e. DHH with low levels of education who live isolated from the Deaf community and the more highly educated DHH patients who stated they do not need PoliDOSH. Steps must be taken to reach these potential patients. This would probably need an intensive campaign, including presentations at conferences, writing and publishing articles in specialized scientific journals for medics and paramedics as well as hospital newsletters etc.. Interest organizations such as the Dutch organizations for general practitioners, medical specialists and physiotherapists, should be able to advise how their members are best reached.

It may be more effective to concentrate, in the first instance, on providing information for healthcare providers in the region where specialized services for DHH people are available or in regions where relatively more DHH people live.

### **Team**

It is important that the key functions of PoliDOSH are filled by top experts and also include an expert from the target group. For example, when patient information aimed at NGT users is being developed this should be done by a combination of persons with experience in developing patient information and persons with experience with the specific needs of prelingually deaf people. It is essential that the target group is well represented in the team. Young et al. (Young AM, 2000) have stated that teams of service providers comprising deaf and hearing members face enormous challenges in developing effective working relations. These dynamics were also seen within the PoliDOSH team.

## Conclusions

Only a small group of deaf and hard of hearing patients indicated that they felt a need for consultations at the PoliDOSH. However, to ensure that DHH patients are provided with the opportunity to access optimal medical care it is essential that the possibility exists to access a specialized healthcare facility, if desired or if necessary, or to provide an appropriate second opinion.

There is a great need for facilities to collect and disseminate information to and about DHH patients. The information should be aimed at providing psycho-education for 1) the DHH persons themselves and 2) the healthcare professionals concerning the specific needs and problems of this patient group.

## Recommendations

Two categories of advice are given:

- 1) General advice for future international projects for improving medical care for DHH people
- 2) Advice concerning a restart of a DHH medical facility in the Netherlands.

### **General advice**

- When a similar project is being considered it is essential for its success that this is supported by the target group itself, that the needs of the patients are fully assessed and the target group is fully represented in the team.
- This study showed that there is a need for more information concerning health and medical topics. This need may be filled by various means such as setting up a specialized center which produces and disseminates information which can be available online and organizes meetings and informal health information get together sessions.
- Charting the availability of medical and paramedical care available for DHH people in the whole country can help to concentrate the care in various regions and strengthen the already present expertise.
- Special attention must be paid to the specific communication needs and possible medical problems of DHH people during the training of healthcare workers.

### **Advice for a situation when PoliDOSH or a similar project would be restarted in the Netherlands**

A mobile team should be formed, consisting of a physician, nurse and a team of interpreters, and should be available for consultations all over the country, in various locations such as the office of the patient's own general practitioner.

- The start-up period should be sufficient to allow time for the project to become known and for patients to become familiar with it and trust it. It is estimated that it will cost 6-10 years for this to be achieved. No comparable data are available on the precise duration necessary for the start-up.
- All key functions should be filled by top experts in the relevant fields as well as an expert in communication and needs of the target group.
- It is essential that regular healthcare workers who look after the target group are comprehensively informed about these facilities.

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