Online coverage of innovative Parkinson's disease treatments:

A comprehensive overview & categorization of websites, and assessment of references to clinical evidence & subjective language of online Parkinson's disease information

Master Thesis

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Voorwoord

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Abstract

Worldwide, the internet has become an important source of finding health information for patients. However, inadequate or misleading information is a common problem with online health information. Nevertheless, information may be scientifically correct, but lack references to clinical evidence (i.e. proven effects in humans) and the information can be written in a subjective way. Not reporting clinical evidence may increase false hope and confusion among patients. The present study investigated the online coverage of a common chronic disease, Parkinson's disease, and evaluated the references to clinical evidence and subjective language in the online information. Regarding RQ1, this study provides a comprehensive overview of 83 websites where patients can find information about Parkinson's disease innovative treatments. Subsequently, regarding RQ2 and RQ3, online articles about Parkinson's disease innovative treatments were analyzed on references to clinical evidence and the extent of subjectivity (superlative words and references to first- and second person). Out of all 240 analyzed articles, 33% referred to clinical evidence and 18% contained superlatives. 48% of all articles contained references to first person and 17% referred to second person. There is more use of subjective language when an article did not report any clinical evidence (RQ4). Future experimental studies should investigate the extent of influence health information could have on patients.

1. Introduction

Patients are no longer restricted to healthcare professionals to get access to health information. The internet has become a popular and convenient source of information for patients (Best, Muzaffar & Mitchell-Innes, 2015; Fox & Duggan, 2013). In a 2013 survey carried out by the Pew Internet Project, 72% of the people responded using the internet to seek for health information, their topics mostly focused on specific diseases or conditions, treatments or procedures (Fox & Duggan, 2013). In the Netherlands, more than 93% of the population are internet users (Internet live stats, 2016). A study of Solvo found that 7 out of 10 Dutch people seek online for health information (Emerce, 2017).

Although this development encourages patient independency and self-education, there is also a risk of misinformation. Inadequate or misleading medical reporting is common (Dentzer, 2009) and patients can be exposed to inaccurate and/or harmful information (McGrath & Kapadia, 2009). People turn to the media when making health decisions and while the internet is a convenient source of information for patients, the information is only helpful if patients can understand it and if the information is scientifically correct (Kelly et al., 2010). Yet, even though the information may be scientifically correct, research results in early developmental phases (e.g. in vivo studies) do not guarantee safe future treatment for humans. This means that when patients read articles about innovative treatments in developmental phases, it does not necessarily guarantee the patients could use these treatments. Only a few innovative developments reach the phase of safety assessment in patients (Thomas et al., 2016). The empirical evidence that proves positive effects in humans is called 'clinical efficacy'. Reporting news or rumors about medical innovations that lack referral to clinical efficacy may increase false hope and confusion among patients. For example, several websites state that so called 'superfoods' that supposedly prevent or ease symptoms of chronic diseases like Parkinson's disease or Alzheimer (Superfoodleven, 2013; Energieke Vrouwen Academie, 2015; Leef Nu Gezonder, 2015). These speculations are based on mere rumors or researches in early development phases, because no references to scientific research or medical professionals are mentioned in the articles. Reported news such as this could lead to misinterpretation and contribute to possible hopeful reactions with people.

The present research explored the online information of a common chronic disease: Parkinson's disease. This study focused on finding the online places where the Parkinson's disease patient can gather information about innovative Parkinson's disease treatments and the presented references to clinical effects and the degree of subjectivity of the online information were analyzed.

1.1 Online health-seekers

Worldwide, most online health seekers search for health information on specific health conditions when they, or a relative or friend, are diagnosed with a medical condition (Fox & Duggan, 2013; Fiksdal et al., 2014). Reasons for online health information searching include learning more about (superficial) symptoms and getting more detailed information to help identify underlying causes (Fiksdal et al., 2014), practical reasons like time and money (Fiksdal et al., 2014; Fox & Duggan, 2013), better communication with health professionals (Kinnane & Milne, 2010), not wanting to bother health professionals with their questions (Caiata-Zufferey, Abraham, Sommerhalder & Schulz, 2010), to verify the obtained information and searching for alternative treatments (Caiata-Zuffery et al., 2010) and searching for health information online also has positive effects on medicine adherence (Samal et al., 2011). The basic needs for searching for health information online include reducing doubt, being reassured and gaining the perspective to get better (Caiata-Zuffery et al., 2010).

However, there are also negative consequences of searching for health information on the internet. The amount of information provided could be overwhelming. For instance, I performed a Google search for the term "Parkinson" information in March 2017 which resulted in 52,800,000 results. It can be problematic to find the facts you are looking for in this sea of information. Besides, literally anyone can publish health information online, which means the quality and credibility of the information is at stake. It can be difficult for health-seekers to distinguish between relevant and inaccurate information (Morahan-Martin & Anderson, 2000). Eysenbach, Powell, Kuss and Eun-Ryoung (2002) reviewed 79 studies about web quality of health information and almost 70% of these studies concluded that there is a problem with the quality of online health information. Subsequent studies on specific diseases also found that the quality and accuracy of health information on the internet vary widely (Lorence & Abraham, 2008; Kitchens, Harle & Li, 2014; Best, Muzaffar & Mitchell-Innes, 2015; Cardel et al., 2016; Joury et al., 2016)**.**

Altogether, many patients seek health information online, especially when they or a close relative/friend was diagnosed with a (chronic) medical condition. This study aimed to evaluate the online information of a common chronic disease: Parkinson's disease.

1.2 Online information coverage of Parkinson's disease

Worldwide, 0,3% of the general population is afflicted with Parkinson's disease (PD). The disease occurs in about 1% in people aged 60 years or older and increases to 4-5% in individuals aged 85 or older (Lew, 2007). It is the second most common chronic neurodegenerative disease (Alzheimer comes first) and leads to cardinal motor symptoms like akinesia, rigidity and tremor (Lew, 2007). Like all chronic diseases, patient education is essential to improve patient understanding of the condition and its treatment. The first description of Parkinson's disease was published almost 200 years ago, but there is still a lack of understanding of the causes of PD. Although there is no cure for PD, there are several different treatments available for managing the motor and nonmotor symptoms. Continuing research develops new insights into the disease and innovative treatments like pharmacologic therapy or deep brain stimulation are some of the innovative treatments nowadays. Patients receive information from their health professionals but many patients also seek information about their condition, innovative treatments and medicine online. No published estimates of internet usage by PD patients are available. Nevertheless, a part of the PD patients regularly uses the internet because some demonstrate participation in internet gambling and other pathological gambling (Wong et al., 2007; Larner, 2006). The study of Fitzsimmons, Michael, Hulley & Scott (2010) identified the 100 highest ranked consumer-orientated Parkinson's disease webpages and determined the webpage readability. They found that the majority (60-89%) of consumer orientated PD information was not comprehensible to the average PD patient and none of the websites complied with the recommended readability level (sixth grade level). A previous smaller study regarding online consumer orientated PD information found similar results (Barton, 2009).

During the current study, the content of PD information of innovative treatments on the internet was analyzed. Therefore, an overview of the most probable websites used by the average (Dutch) PD patients was created. However, there are many different kind of websites containing health information available online. News about innovative treatments of PD are likely to be found on news websites, but also on the website of a hospital or a website where PD patients share their experiences. These diverse websites may lead to different content and therefore the websites were categorized. This leads to the following research question:

RQ1: Which website and website categories containing Dutch information about innovative ways to treat Parkinson's disease are likely to be found by PD patients who perform a search for new treatments?

Other studies point out that people who need health information the most (patients with chronic diseases, the elderly and people with low socio-economic status) have insufficient health literacy (Nielsen-Bohlman & Panzer, 2004) which leads to incomprehensibility of the information and harmful or life-threatening situations (Lorence & Abraham, 2008). Most studies regarding the poor online health literacy are foreign studies (Fitzsimmons et al., 2010). It is hard for people with poor health literacy to find trustworthy, relevant and understandable health information. The incomprehensibility of the information may be related to people who are reporting this information: the editors. There may be a rapid growth in using the internet to obtain health news, this information is only beneficial if patients can understand it. Therefore, the next section describes the important role the editors play regarding health information.

1.3. Reporting online health information

News media are regularly cited by people as a primary source for their health information and patients often take particular actions after reading health news that suggest advantage of this behavior. There is a need for journalists that accurately report on medical research, especially because the media influence is prevalent among people with lower education levels (Hinnant, Jenkins & Subramanian, 2015). Medical research is complex information which needs to be told with context such as background stories and explanations of difficult medical terms to create a comprehensive story. Health information in the media can influence the behavior of patients and therefore it is important that journalists understand how important their role as healthcare messengers is (Dentzer, 2009). Inaccurate coverage of health news and medical studies thus may lead to wrong assumptions or inappropriate / harmful behavior of patients (McGrath & Kapadia, 2009). There are several explanations for such inaccuracies. Firstly, the lack of scientific expertise or medical training of the journalists (Dentzer, 2009). Health journalists solemnly rely on expert sources. McGrath and Kapadia (2009) recommend that journalists undergo training in science and medical topics in order to understand and report medical innovations in an accurate and comprehensible way. Secondly, sensationalism and exaggeration in terms of invalid causal claims and resulting advice (Sumner et al., 2014) as well as misleading descriptions of costs, benefits, and other aspects of innovative treatments may also contribute to the inaccurate news coverage of health information. As McGrath & Kapadia (2009) explain in their research, the media has different interests to look after, with consequences: "The news media is pressured to publish tomorrow's news today. When the media gets it right, people and patients can benefit, but when they get it wrong, patients can

be exposed to inaccurate, or worse, harmful information" (McGrath and Kapadia 2009, 16). However, even though the information may be scientifically correct, reporting about medical innovations without evidence for guaranteed human treatments may not always be in favor of the patient. The next chapter will explain more about importance of evidence provided in health news.

1.3.1. Reporting on the clinical efficacy in online health information

Significant research results in early developmental phases do not guarantee a successful future treatment application for human patients and reporting about these early development phases may contribute to false hopeful reactions among patients. For one thing, just a few "hopeful" research results are qualified enough to be tested in laboratories (Thomas et al., 2016). Even less of these developments achieve the phase of a safety assessment in patients and eventually only 9,6% of drug development programs successfully make it to the market (Thomas et al., 2016). Proven positive effects in humans are of great importance, because a successful medicine tested on, for example, mice does not guarantee the same effect on humans. The positive effects of medicine/treatments in humans is referred to as the "clinical efficacy". Positive clinical effects must be demonstrated in at least a small group of patients before the theory behind a medical intervention may be accepted (Vehof, 2017). Quantitative evidence on this developmental phase of published scientific innovations in a common chronic disease such as PD is lacking. If a great amount of health information about innovative news of PD lack referral to proven clinical effects, this may possibly cause confusion and false hope among patients. This introduces the following research question:

RQ2: To what extent are references to clinical effects on patients mentioned in online information about innovative ways to treat Parkinson's disease?

Like mentioned before, websites with different characteristics have various kinds of content and different goals concerning distributing PD news as well. For example, news websites have the objective to report about the latest news, but fellow PD patients probably have a different intention to share their news, perhaps to discuss various kind of treatments with other PD patients. Because all these article editors have different interests in providing PD information, references to clinical effects in online PD news may also vary per website category. Thus, this leads to the next research question:

RQ2b: Does the degree of referencing to clinical effects in online information about innovative ways to treat Parkinson's disease differ between website categories?

1.3.2. The extent of subjectivity in online health information

As mentioned before, media have the power to influence people (Dentzer, 2009). There has been increasing characterization by journalists, in terms of ways they 'personalize' the news by adding their own impressions (Vis, 2011) meaning they report news in a more subjective way. In scientific context, subjectivity suggests that a claim is not trustworthy and not objective because it's not based on empirical evidence (Vis, 2011). The role of the journalist is also an important factor to analyze because the writers of the online information are the source of the information. However, not all sources of online information are 'professional journalists', hospital websites and patients' associations are not owned by news media and have different ways of reporting news. For that reason, the authors of the online PD information will be referred to as 'editors' instead of 'journalists'. It is important that health news is reported in an objective way and exaggeration and sensationalism (Sumner et al., 2014) or misleading health information are factors that do not match with the definition of objectivity. For the present research, this results in the following research question:

RQ3: To what extent does online information about innovative ways to treat Parkinson's disease contain subjective information?

Like mentioned before, all the websites have different editors and goals regarding distributing PD news. For example, fellow sufferers of PD may express their insights on PD in a more subjective way because of the emotional and personal level. Scientists would probably refer to PD research in a more professional and objective way. For this research, I want to analyze if websites add a personal opinion or interpretation, i.e. subjectivity, to the news. This brings up the next research question:

RQ3b: Does the ratio of subjective online information about innovative ways to treat Parkinson's disease differ between website categories?

Considering RQ2 and RQ3, the question arises if there may be a connection between references to clinical evidence and subjectivity in the online information about PD. It is a possibility that editors may use more subjective language to express their joy/enthusiasm

when the clinical evidence is confirmed in a research. These suggestions lead to the following research question:

RQ4: Is there a relationship between references to clinical effects on patients and subjectivity in online information about innovative ways to treat Parkinson's disease?

1.4 Recap & goal of the study

Patients seek health information online, especially people with a specific (chronic) medical condition. The current study is a quantitative research of online information about a chronic medical condition, namely Parkinson's disease. An overview of websites where the PD patient can find news about their disease was created and these websites were categorized. Results from Fitzsimmons et al. (2015) show that PD foreign websites are not comprehensible for patients. Poor health literacy of patients may lead to great health risks (Lorence & Abraham, 2008) and the lack of context in reporting (Dentzer, 2009; Hinnant et al., 2015) and the possible lack of references to clinical effects, could all lead to confusion and false hope among patients. This study is an attempt to address this issue. Because, do the PD innovations that are described by websites actually work? The goal in collecting this quantitative data is to gain better insight in the evidence of clinical efficacy in online Parkinson's disease information and the difference of the clinical evidence and subjectivity between various kind of websites. These results will provide useful information for communication scientists, medical institutions, and consequently the patients as well. The next part describes the methods for analyzation.

2. Method

Following the research questions, this section explains how these questions were answered. Regarding RQ1, a description of the online searching method to find the websites and search terms that are likely to be used by PD patients is given and the procedure of the website categorization. Following RQ2, the coding procedure to determine clinical effects in the online information is explained. Finally, the coding procedure of the journalistic subjectivity indicators is described, following RQ3. As mentioned earlier, this is a cross-sectional study where understanding the behavior and choices of the health seeker, the PD patient, is central. Therefore, taking the perspective of the patient is the guide line for this research.

2.1 Material

A qualitative research of Eysenbach and Kohler (2002) found health information seeking patients use search engines as a starting point, none of the health seeking participants in their study started searching at medical websites. Other studies confirm that health-seekers start their inquiries at a search engine (Fox & Duggan, 2013; Dubbeldam, 2016). A search engine is a database of webpages, a way for finding webpages and indexing them, and a method to search this database (Malaga, 2008). To determine which search engine is currently the most commonly used in The Netherlands, the statistics from StatCounter were consulted. StatCounter is an online tool with statistics that gathers data provided by 15 billion page views for more that 3 million websites and is updated every 4 hours. This data indicated that Google is the most commonly used search engine in The Netherlands (86,21%) from June 2016 to June 2017, while the second most used search engine, Bing, is used far less frequently (3,7%) whether on a desktop or a mobile browser (StatCounter, 2017). People used tabs function of web browsers to compare multiple websites at once and thus "get as much information as you can" (Fiksdal et al, 2014). Since the aim of the present study is to perform a health search in a PD patients' mindset, Google was used as the search engine to look for Parkinson related information. A first time installed browser (Firefox) was used to prevent any chance of saved settings or account properties, such as "cookies" from previous searches that might influence search results. Cookies track and record browsing behaviour and could possibly alter the Google results due to previous visited Parkinson websites. Previous studies on assessing online health information applied the same method to verify "fresh" results (Kitchens, Harle & Li, 2014; Joury et al., 2016).

2.1.1. Search terms

To determine the most exhaustive list of search terms, results from several studies were combined to put together a comprehensive method for the present study.

Firstly, Dubbeldam (2016) conducted a study to investigate any patterns in the information behavior of women who have been referred to a cervical polyclinic as a result of a deviant pap smear for further investigation and possible treatment(s). The results put forward that the women used very specific keywords as a search strategy and made use of the auto-completion function of search engines. Secondly, health seekers tend to use less sophisticated vocabulary to start their searches, frequently with misspellings that are corrected by "auto-completion" features available universally in all web search engines (Jadhav et al, 2014). The study of Jadhav et al. (2014) on health search queries on the web showed that the average search query length consisted of 2.90 words and most queries (> 70%) have 1-2 nouns. Thus, for the present study very specific 2 to 3 keywords that definitely contained a noun were used for the web searches. The applied method of the auto-completion function of search engines is explained below.

Web searches were performed in April 2017, via the Google search engine (www.google.com). The original set of search terms were generated using Google's auto-complete auto completion. Using Google, the word "Parkinson" was inserted, firstly following the letter "A", "B", "C", etc to observe the Google suggestions. These suggestions hold the most popular and relevant keywords used by individuals on Google and, like mentioned before, patients also use the auto-completion function as a search strategy. So, this search strategy is according to the patients' line of thinking. Only suggestions that were related to innovative treatments or news of Parkinson's disease were selected. An example of Parkinson" and the letter "n" in the Google search engine can be found in figure 1. In this example, "Parkinson nederland" was not selected, meanwhile "Parkinson nieuws" was.

Figure 1.   A search query for "Parkinson n…" in Google in April 2017.
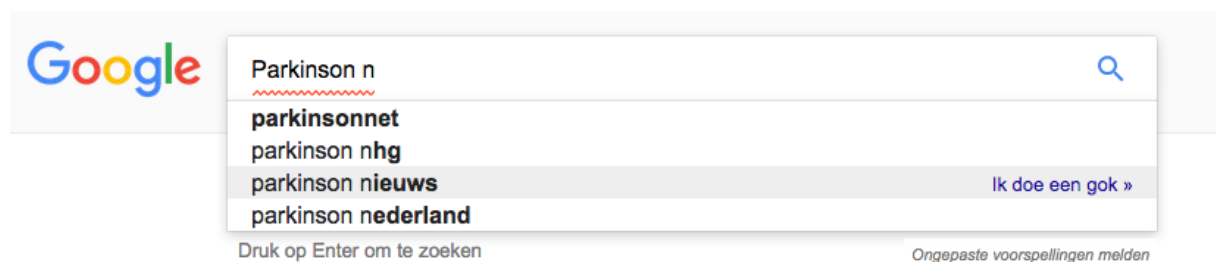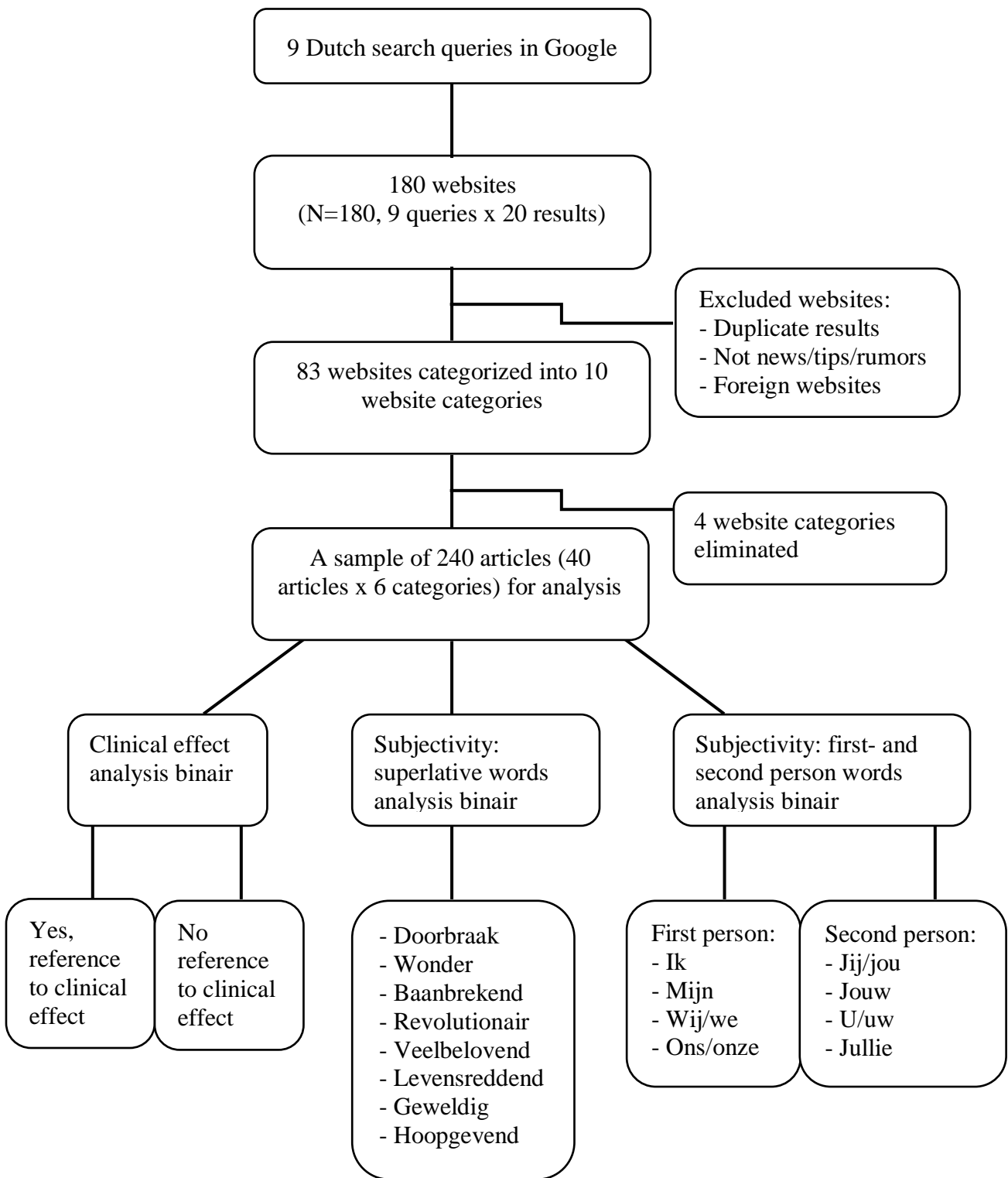
Thereafter the frequent use of these collected terms was verified by searching and finding them in a list of very frequently used words in a database with 11,800 online PD forum messages. By this method, the nine strings that are most likely used by the general PD population were established: *"Parkinson nieuws", "Parkinson nieuwe behandeling", "Parkinson nieuwe medicijnen", "Parkinson nieuwe medicatie", "Parkinson nieuwe therapie", "Parkinson ontwikkeling", "Parkinson onderzoek", "Parkinson studie" and "Parkinson innovatie".* The results from the nine strings partly overlapped, but this method created a very complete overview of websites with innovative PD information. The most important and crucial websites will surely be included in the database this way.

2.1.2. Retrieval of websites

The first 20 Google results that appeared of each of the nine search strings were included in a database. The amount 20 was chosen because prior studies have shown that people seldom go beyond the first two result pages (one page is 10 results, excluding advertisements) (Morahan-Martin, 2004; Fox & Duggan, 2013; Fiksdal et al., 2014, Eysenbach, Powell, Kuss, Sa, 2002). A participant of the qualitative research of Fiksdal et al (2014) on consumers research methods explained: "If you go down the 17th, 20th, 30th option under Google, you find that what you are looking for is the 30th degree of separation. It is just not as relevant to what it is you are trying to research anymore". After performing each query, and collecting these 180 websites (N = 180, 9 search strings x 20 results), the websites were selected for analysis on the condition that the web page indeed contained any news, tips, rumors or recommendations for innovative treatment of PD or its symptoms. A website is a group of World Wide Web pages usually containing hyperlinks to each other and made available online by an individual, company, educational institution, government or organization (Merriam-Webster, 2017). Foreign websites were excluded, only articles in Dutch were selected which means websites originated from Belgium were also included in the analysis. Duplicate websites were excluded in the analysis in order to solemnly collect unique webpages. Additionally, it has been previously established that when performing an online health search, people do not click on the sponsored links (Fiksdal et al., 2014). Therefore, sponsored links were also excluded from the analysis. After screening all the websites on these conditions, out of 180 webpages 83 unique webpages remained for categorization. Figure 2 shows the complete extended method of the present study step by step.

Figure 2.   Flowchart diagram of the websites and analyses included in the present study.

| 9 Dutch search queries in Google |

180 websites
(N=180, 9 queries x 20 results)

Excluded websites:
- Duplicate results
- Not news/tips/rumors
- Foreign websites

83 websites categorized into 10 website categories

4 website categories eliminated

A sample of 240 articles (40 articles x 6 categories) for analysis

Clinical effect analysis binair

Subjectivity: superlative words analysis binair

Subjectivity: first- and second person words analysis binair

Yes, reference to clinical effect

No reference to clinical effect

- Doorbraak
- Wonder
- Baanbrekend
- Revolutionair
- Veelbelovend
- Levensreddend
- Geweldig
- Hoopgevend

First person:
- Ik
- Mijn
- Wij/we
- Ons/onze

Second person:
- Jij/jou
- Jouw
- U/uw
- Jullie

2.2 Procedure

When the most frequently found websites by PD patients were collected, these websites were sorted into "website categories" to answer RQ1 and to distinguish the variety of online information so the differences in online information of various websites were analyzed. After that, the coding procedure of the news of innovative treatments on the websites was conducted. The online information was evaluated on accuracy of the information related to clinical effects and the subjectivity of the journalist. Detailed description of the coding procedures can be read below.

2.2.1. Coding procedure of the websites

Websites were categorized based on the owner/host of the website. These categories are based on the study of Dubbeldam (2016) and are as follows: health institution/professional, funds, publisher, profession, wiki, research/government, commercial organization, fellow sufferers/experience experts. After a pre-evaluation of some of the PD websites generated by the queries, the category 'publisher' was distinguished in two categories: news publisher and medical news publisher and the category 'individual medical information providers ("quacks")' was created. After the 83 websites were categorized, four website categories, wiki, funds, commercial organization and individual medical information providers ("quacks"), were eliminated for further analyzation (the analyses for references to clinical evidence and subjectivity) because not enough webpages could be sorted into these categories, resulting in six analysis website categories. In short, 10 categories were used for categorizing the 83 websites and 6 categories were used for the clinical evidence and subjectivity analyses. Figure 3 shows the complete categorization process. Table 1 shows the categorization of the 83 websites along with examples of each website category (n=10).

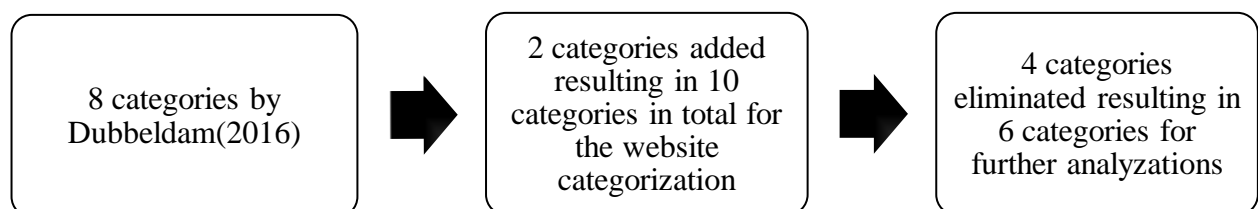Figure 3. The categorization process of the websites (n=83).

Table 1. Categorization of the 83 webpages based on the type of owner/host of the website.

Website category	Website meaning	Website example
Health institution/-professional	Website of a physical place where patients can get treatment for Parkinson's disease, like hospitals or clinics.	Radboud Ziekenhuis, hospital.
News publisher	Online and websites of offline newspapers that publish the latest news.	De Volkskrant, a national newspaper.
Medical news publisher	Website that only publishes medical related news.	Gezondheidsnet, latest news on health and nutrition.
Profession	Publishes the latest news for professionals (doctors, physiotherapists, etc).	Apothekernieuws news for and by pharmacists.
Research/government	Website of institutions that carry out Parkinson's disease research.	Zonmw, finances and reports about health research and treatments.
Funds	An organization that manages a capital for a certain purpose (in this case; Parkinson).	Parkinson Fonds, main financer for Parkinson's disease research.
Wiki	Wikipedia association, content made by public.	Wikipedia, free encyclopedia.
Fellow sufferers/ experience experts	Other Parkinson patients or family/friends who are sharing their knowledge and experiences.	Parkinson Vereniging, an association for and by people with Parkinson's disease and their personal caregiver.
Commercial organization	Websites with commercial purposes, to sell products to consumers.	Smarthealth, a company that specializes in digital care technology and its use by consumers.
Individual medical information providers ("quacks")	Individuals who make medical assumptions despite not being medical specialists.	Infowebweistra, a website providing information/rumors for various kinds of diseases.

After the categorization of the websites, samples of 40 articles per category were collected to create a database that was used for further analyses. These articles were obtained by visiting the main domain of the tophits found by the Google search queries. Subsequently, the "news" section of the website was used to find articles about PD and in most cases, the search function of the website with the search query "Parkinson" or "Parkinson nieuws" was used to find relevant articles. Like for the webpages, only articles that contained any news, tips, rumors or recommendations for innovative treatment of PD or its symptoms were selected for further analysis. In total, 240 (n=240, 40 articles x 6 categories) online articles about innovative ways to treat PD were selected for analyzation. Three categories, health institution/-professional, research/government and profession, could not meet the terms of 40 articles for their category. For that reason, these categories were completed by creating a search query in Google that consisted of one of the nine search strings and the name of the category. Figure 4 shows an example of the search string "Parkinson nieuwe medicijnen" and "health institution/-professional". By doing this, all categories contained the sample of 40 articles.

Figure 4.   A search query in Google for "Parkinson nieuwe medicijnen" and the category "health institution/-professional".
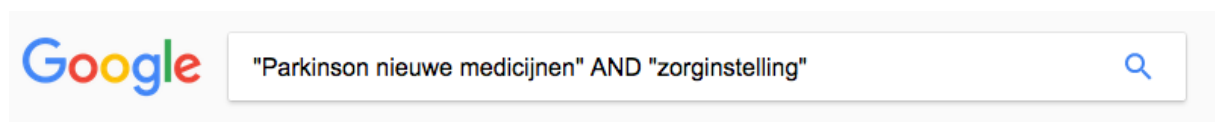
2.2.2. Coding procedure of the clinical effects

A binary measure, as presented in the study of Vehof et al. (2017), will be applied to code for the in-article determination of references to detect clinical effects found in a scientific setting. Information was coded as "yes" for *references to clinical effects are provided* when two conditions were fulfilled:

- The found information contained a reference to a positive effect on one or more Parkinson's disease outcomes in one or more Parkinson's disease patients. Example: *22 patients showed improvements in their motor abilities after cannabis treatment.*
- The found information contained a reference to specified science. Specified is described as containing the name of a science institute, a scientist, a study or research program, or an academic journal (including references to academic journals).

Companies who performed medical studies using scientific methods were also considered as a specified science. Doctors or "experts" were not considered as scientists except if it was clear that they carried out the research themselves. Examples: *researchers at the Tel Aviv University* or *a quote from Dr. Fox.*

This coding procedure was assessed by two coders independently and the interrater reliability of the variable 'references to clinical effects' was good κ = .81, *p* <.001.

2.2.3. Coding procedure of subjectivity

To analyze the subjectivity of the articles, three binary measures for subjectivity indicators were created. The relevancy of the indicators and practicability for this study was taken into account when the indicators were selected. Based on Vis (2011) the representation of self and interactivity with the addressee were chosen as subjectivity indicators because both were considered as very personal if an article about a medical research refers to a first- or second person.

Abola & Prasad (2016) investigated the use of modest and superlative indicators in news articles regarding cancer drugs by searching 10 superlative terms in conjunction with "cancer drug" in the Google news section. They found that words like "game changers" or "breakthroughs" are common words used in news about medical researches. Therefore, these words, called "superlatives", were relevant to this study to analyze. The indicators with their corresponding words, are described in table 2. These words are based on Abola & Prasat (2015) and complemented with Dutch words.

Table 2.   The three indicators of subjectivity based on Vis (2011) and Abola & Prasat, (2015).

Indicators of subjectivity	Corresponding words
Representation of self: first person pronouns	Ik, mijn, wij/we, onze/ons
Interactivity with the addressee: second person pronouns	Jij/jou, jouw, u/uw, jullie
Superlatives	Doorbraak, wonder, baanbrekend, revolutionair, veelbelovend, super, levensreddend, geweldig, hoopgevend,

An automatized analysis was performed on 240 articles using the programming code Python (regex). To do this properly, the content of the articles was pasted into a text file. This way, only the text of the article (no HTML codes or text not related to the article, such as advertisements) was obtained. Subsequently, Python was programmed to search for specific words. Then, for each of the indicators, a binary measure was constructed that expressed if the article contained subjective elements.

2.4 Data analysis

Statistical analyses were performed using SPSS. An analysis of variance showed that the articles of the six categories all have the same amount of text. If the articles did not have the same length, a correction to make sure the articles could be compared fairly should have been applied. In this case, statistical analyses were carried out without having to correct the length of the articles. Seven Chi-square tests were performed to test four research questions, as presented in table 3.

Table 3.   All statistical analysis performed for this research.

Research question	Variable 1		Variable 2
RQ2+RQ2b	Website categories	x	References to clinical evidence
RQ3+RQ3b	Website categories	x	Superlatives
RQ3+RQ3b	Website categories	x	References to first person
RQ3+RQ3b	Website categories	x	References to second person
RQ4	Superlatives	x	References to clinical evidence
RQ4	References to first person	x	References to clinical evidence
RQ4	References to second person	x	References to clinical evidence

3. Results

3.1 Website categories

In order to answer RQ1 (which website and website categories containing information about innovative ways to treat Parkinson's disease are likely to be found by PD patients who perform a search for new treatments?) 83 unique webpages were found using Google. An overview of these webpages can be found in Appendix I. As previously explained in the method, these categories were sorted into different categories, based on Dubbeldam (2016). The categories were adjusted after a pre-evaluation of the websites, resulting in the following 10 categories: health institution/professional, news publisher, medical news publisher, profession, research/government, wiki, funds, individual medical information providers ("quacks"), commercial organization and fellow sufferers/experience experts. These website categories hold the websites that are likely to be found by PD patients who perform a Google search for information about innovative treatments of PD. As shown in Appendix I, Google returned websites that were categorized, but were not further analyzed on references to clinical effects and subjectivity because there were not enough websites to create an appropriate sample. These categories, along with the amount of websites in parentheses, were: wiki (1), commercial organization (3), funds (3) and individual medical information providers ("quacks") (2). From the remaining six categories the sample of 240 articles was drawn (40 per category) to answer RQ2 and RQ3. An overview of the links to all 240 articles used for the analyzation of RQ2 and RQ3 can be found in Appendix II.

3.2 Reference to clinical effects

In total, 33% of all online information on PD innovative treatments referred to clinical effects (table 4). A Chi-square test showed a marginal trend toward a significant relation between references to clinical effects in online information and website categories ($\chi^2 (5) = 10.71$, $p =.$ 057). Articles from the category health institution/-professional contain the least references to clinical effects (20%) and the category profession hold the most articles with references to clinical evidence (48%). This answers RQ2 (to what extent are references to clinical effects on patients mentioned in online information about innovative ways to treat Parkinson's disease?) and RQ2b (how does the degree of references to clinical effects in online information about innovative ways to treat Parkinson's disease differ between website categories?).

Table 4.   Amount of references to clinical effects in all online articles (n=240) and per category (n=6).

Category	Reference to clinical effect
Health institution/-professional (n=40)	20%
News publisher (n=40)	28%
Medical news publisher (n=40)	40%
Profession (n=40)	48%
Research/government (n=40)	23%
Fellow sufferers/experience experts (n=40)	38%
Total	33%*

* p =.057

3.3 Subjective language

To answer RQ3 (What is the ratio of subjective online information about innovative ways to treat Parkinson's disease?) and RQ3b (How does the ratio of subjective online information about innovative ways to treat Parkinson's disease differ between website categories?), the subjective language in online information of PD was measured in two ways (superlatives and references to first- and second person). These indicators measure different variables and therefore, the results for both subjective indicators will be divided into two sections so an individual statement about both indicators can be made.

3.3.1 Superlatives

18% of all the online articles reporting on PD innovations contained superlatives. A Chi-square test showed no significant relation between superlatives and website categories (χ^2 (5) = 7.24, p =. 204). There are no particular differences in the amount of superlatives between categories.

Table 5.   Proportion of articles (n=240) containing one or more superlatives

Category	Superlatives
Health institution/-professional (n=40)	10%
News publisher (n=40)	30%
Medical news publisher (n=40)	23%
Profession (n=40)	20%
Research/government (n=40)	15%
Fellow sufferers/experience experts (n=40)	13%
Total	18%*

*p =.204

3.3.2. References to first- and second person

A Chi-square test showed a significant relation between the use of referring to first person in online information and website categories (χ^2 (5) = 15.84, p =. 007). In total, 48% of all online articles contained references to first person (table 6). The category 'health institution/-professional' contained the most references to first person (68%).

Table 6.   Proportions of references to first person in all articles (n=240) per category (n=6).

Category	References to first person
Health institution/-professional (n=40)	68%
News publisher (n=40)	60%
Medical news publisher (n=40)	30%
Profession (n=40)	38%

Research/government (n=40)	43%
Fellow sufferers/experience experts (n=40)	48%
Total (n=240)	48%*

*p =.007

A Chi-square test showed a strong trend between references to second person in online information and website categories (χ^2 (5) = 9.96, $p =$. 076). 17% of all online articles contained references to second person (table 7). The category 'health institution/-professional' contained the most references to second person (33%).

Table 7.   Proportions of references to second person in all articles (n=240) per category (n=6).

Category	Use of second person references
Health institution/-professional (n=40)	33%
News publisher (n=40)	15%
Medical news publisher (n=40)	18%
Profession (n=40)	10%
Research/government (n=40)	10%
Fellow sufferers/experience experts (n=40)	15%
Total (n=240)	17%*

*p =.076

3.4 Relation between clinical evidence and subjectivity

Regarding RQ4 (to what extent is there a relationship between references to clinical effects on patients and subjectivity in online information about innovative ways to treat Parkinson's disease?), a Chi-square test showed a significant relation between references to clinical effects

in online information and superlatives (χ^2 (1) = 5.04, p =. 025). There are more superlatives in the online PD information when there are less references to clinical effects (table 8).

Table 8.   References to clinical effects and superlatives in articles (n=240)

	Superlatives	No superlatives
Clinical effect	8	70
No clinical effect	36	126

To test the second part of the subjectivity measure (references to first- and second person), two Chi-square tests were carried out. A Chi-square test was performed and showed a significant relation between references to self in online PD information and clinical effect (χ^2 (1) = 7,69, p =. 006). Articles that contain more references to first person have less references to clinical evidence (table 9).

Table 9.   References to clinical effects and references to first person in articles (n=240)

	Reference to self	No reference to self
Clinical effect	27	51
No clinical effect	87	75

A Chi-square test was performed and showed a significant relation between references to second person in online PD information and clinical effect (χ^2 (1) = 6,70 p =. 010). Articles that contain more references to second person have less references to clinical evidence (table 10).

Table 10.   References to clinical effects and references to second person in articles (n=240)

	Reference to second person	No reference to second person
Clinical effect	6	72

| No clinical effect | 34 | 128 |

These results are consistent with the results for superlatives and references to clinical effects. There is more subjective language (reference to first person and superlatives) when there is no reference to clinical effect in online information of innovative treatments to treat Parkinson's disease.

4. Conclusion

The main goal of this study was to find the websites Parkinson's disease patients use to search for information about innovative ways to treat Parkinson's disease and assess the clinical evidence and subjectivity in this online information. The key findings were that, 83 unique webpages with news, tips or rumours about Parkinson's disease innovations were found. These 83 webpages fitted the categories health institution/-professional, news publisher, medical news publisher, research/government, profession, commercial organization, funds, wiki, fellow sufferers/experience experts and individual medical information provider. In an extended sample of 240 articles, 67% of all this online information did not contain references to clinical evidence. In addition, 18% of all these articles consist of language with superlatives, 48% contained references to first person and 17% referred to second person. Besides, there are less references to clinical evidence when the information contained superlatives and references to first- and second person. There is more use of subjective language when there are no references to clinical evidence.

5. Discussion

5.1 Research questions

For RQ1 the method was compiled by combining information from different kinds of literature and methods of other studies. By using the knowledge of these studies, the best possible method to find the websites used by PD patients was created. The categorization of the websites was based on Dubbeldam (2016) and was also the most logical categorization process for this kind of online information. The tophits from Google also provided websites that in the first place were categorized, but not further analyzed because of the insufficient sample size of the category. However, these websites did show up in the first 10 Google results which means it is likely PD patients could indeed find these places. Since RQ1 focused on locating the websites where PD patients could gather information on innovative treatments, a full raw data table with the 83 Google tophits is thus presented in Appendix I. In addition to this, a full raw data table with the links to the 240 articles used for the analyzations regarding RQ2, RQ3 and RQ4 is provided in Appendix II. When comparing the sizes of the categories with each other, it can be argued the category "fellow sufferers/experience experts" also could have been eliminated during the process of choosing the categories that would be used for further analyzation. As can be seen in Appendix I, this category holds just three unique websites, but the informed decision was made to include this category for further analyzation because this category includes the website "Parkinson Vereniging" and this website occurred regularly in the Google results with several unique webpages. This website ranked the first tophits of Google with all nine search strings and it would have been unwise to eliminate such an essential website.

Furthermore, I expected to find more PD news online. Finding information that met the requirements was not an uncomplicated path.

Regarding RQ2 and RQ2b, the articles from the category health institution/-professional contain the least references to clinical effects (20%). A possible explanation for this is that this category consisted of several articles about ongoing investigations. These studies explore new treatments and medicine for Parkinson's disease but do not (yet) have clinical effects and are therefore marked as "no clinical effects" in this study.

Overall, 33% of all information of PD innovative treatments referred to clinical effect. In comparison, the study of Vehof (2017) found that 19% of newspapers articles reporting on innovative diabetes treatments referred to clinical evidence. The reason that the present research found considerably more references to clinical effects could be related to the nature

of the disease. Diabetes and PD are dissimilar diseases. Type II Diabetes is strongly associated with lifestyle factors (Vehof, 2017). Data from Vehof's study shows that nutrition is a key subject in topics about diabetes treatments. The data from the present study shows that almost all the PD articles were written with a professional approach, and even though most articles did not refer to clinical evidence, generally these articles had a scientific angle. As opposed to the topics about diabetes treatments, these articles contained less personal lifestyle stories. The approach of diabetes and PD is different and this could explain the difference in the references to clinical evidence.

Firstly, regarding RQ3 and RQ3b, there were differences between the use of references to first- and second person in the PD articles. The most references to first- and second person occurred in the category "Health institution/-profession". A possible explanation is, like mentioned before, that this category included a lot of articles about ongoing investigations. These articles contained sentences like "U kunt zich hier voor dit onderzoek inschrijven (You can sign up for this research here)" and "Mijn onderzoek gaat over ergotherapie (My research is about ergo therapy)". Underlined are the words refer to first- and second person. As can be seen in these sentences, articles contained information about participation in researches and scientists who tell about their studies. It is therefore understandable why references to first- and second person score the highest in this category.

I expected the category "fellow sufferers/experience experts" to contain the most references to first person because these articles are written from personal experiences. However, this category did not contain more first person references than other categories (it contained the same amount as the average for all categories, 48%). This may be related to the fact that this category consisted of websites that indeed had fellow sufferers as an audience and the articles were also written by fellow sufferers, but most of these websites also represented the general Dutch Parkinson association. This association has a professional role and hence, the articles were written in a more "professional" way, contained a lot of scientific topics and almost no information about own experiences. Examples of these kind of websites are "Parkinson Vereniging" and "Parkinson Plaza" (for detailed information, see Appendix I).

Besides, as Vis (2011) states in her research, referring to first person can be divided into two parts: when the editor writes the article and uses references to first person or when the editor quotes someone (i.e. a doctor or scientist). For more detailed statements on first person references, further research should distinguish between "quote-self" or "non-quote-self". This could not be applied to this research due to the practicability.

Secondly, there were no significant differences between the use of superlatives between the categories. The category "news publisher" uses the most superlatives, perhaps because sensationalism and exaggeration are common in journalistic reporting (Sumner et al., 2014), which could possibly result in using more subjective language.

Lastly, concerning RQ4, there are less references to clinical effects when there are superlatives and references to first- and second person in the online information. This means editors use words like "doorbraak (breakthrough)" and "baanbrekend (ground-breaking)" when writing about researches that do not (yet) have clinical evidence. They write about a breakthrough when there is, in fact, no real breakthrough for patients, because no clinical evidence means no guarantees that the treatment would be safe to use on humans. Patients could read about a "ground-breaking medicine" that is only successfully tested on mice and might never be marketed. In this case, false hope among patients could be raised. It is preferable that editors use superlative words in their articles when there is an actual breakthrough in treatments or medicine for patients.

5.2 Strengths and limitations

A strength of this research is the comprehensive method that was created to establish an overview of the websites where PD could find information about innovative treatments of PD and the categorization of these websites. Valid methods of other studies and necessary self-invented ways were combined, which made it possible to carry out this part of the study.

The second strength is the result of the first method: a focus on a broad range of online websites with different audiences, from scientific researches to stories of an experience expert. Besides, because the patient perspective was the main direction in the method of this study, the found results are comparable with real life results. Because of this, a complete and comprehensive overview of online information about innovative PD treatments could be created.

The last strength of this study is that this is the first time anyone assessed the use of references to actual clinical evidence in online information about PD. The measurement of clinical evidence was previously done by Vehof (2017) for diabetes in printed newspapers. This study

showed this method was also applicable to online information and to Parkinson's disease.

A limitation of this research is that finding references to clinical evidence in online information does not guarantee successful innovative treatments. The final outcome of developments is not yet known and therefore there is no promise a medicine or treatment is successful. Clinical trials could still show that the innovative treatment is not suitable for humans. Therefore, also articles that do contain references to clinical effects may eventually contribute to false hope or confusion.

5.4 Future studies
Due to the differences in referring to clinical effects in diabetes (Vehof, 2017) and PD, other diseases should also be investigated. This way, differences between various kinds of diseases can be measured and implications can be made.

This study investigated online information of PD. Vehof's research (2017) analyzed innovative diabetes treatments in newspaper articles. In future studies, the information of PD in newspapers could be analyzed on references to clinical effects and subjectivity so a comparison can be made. Consequently, conclusions can be drawn on the differences between online and offline media reporting about PD.

As mentioned several times before, lack of references to clinical effects in articles could possibly lead to potential false hope of confusion among patients. This study established the references to clinical effects in online PD. There is no indication known from literature that PD patients may be confused or have false hope by reading the online articles. Future experimental studies should investigate whether different kinds of health information can have an influence on patients. Possible consequences of health news written in different angles on patients could be investigated.

5.3 Final conclusion & implications
The internet is one huge sea of cheap and easily accessible information. More and more people are using it to find health information. Results from this study show that PD information on the internet often not contains references to clinical effects, the empirical evidence that proves if innovative treatments can be used on humans. This study successfully measured this evidence in online innovative PD information. Only one third out of all online

information presented the patients with references to clinical evidence. These results are contradicting with serious consequences like false hope and confusion among PD patients. Future experimental studies on this subject should be conducted to find out to what extent these consequences play a critical role. In addition, the articles that did not contain references to clinical evidence, were written in using a more subjective language. This way, editors can make wrong assumptions and this could also contribute to more confusion among readers. As patients continue to use health information gathered from the internet, organizations would do well to write and monitor their articles with the welfare of the patient in mind. After all, the patient's well-being is paramount.

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Appendix I. Dataset of the 83 top Google ranking webpages per category.

	Health institution/-professional
1	http://www.catharinaziekenhuis.nl/nieuws/359-parkinson-compensatie-in-het-brein-als-basis-voor-nieuwe-behandeling.html
2	http://www.dezorgpraktijk.nl/acupunctuur/laatste-ontwikkelingen-bij-behandeling-m-parkinson/
3	http://www.imedlevante.com/nl/actualidad/imed-levante-is-voorzien-van-een-nieuwe-therapie-om-de-aanpak-te-verbeteren-bij-geavanceerde-parkinson/
4	http://www.lumc.nl/org/neurologie/research/propark-research/onderzoek-bij-mensen-met-parkinson/
5	http://www.parkinsonnet.nl/nieuws
6	http://www.parkinsonnet.nl/nieuws/cheval-studie
7	http://www.parkinsonnet.nl/nieuws/otip-studie
8	http://www.parkinsonnet.nl/onderzoek/vumc/cheval-studie
9	http://www.parkinsonnet.nl/otip
10	http://www.parkinsonnet.nl/parkinson/diagnose
11	http://www.parkinsonwestbrabant.nl/innovatie/
12	http://www.puntvoorparkinson.nl/nieuws/
13	http://www.puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
14	http://www.revalidatie.nl/revalideren/nieuws-r/parkinsonapp-cue2walk-genomineerd-voor-innovatieprijs-van-parksinonnet

15	http://www.vumc.nl/afdelingen/PCD/8968823/bewegingsklachten/
16	http://www.vumc.nl/afdelingen/PCD/centrumneuropsychiatrieparkinson/onderzoek/lopend-onderzoek/impulscontrole/
17	http://www.vumc.nl/onderzoek/nieuws/nca/
News publisher	
18	http://www.ad.nl/rotterdam/wereldrecordpoging-dansen-met-parkinson-bij-hofplein~a51314db/
19	http://www.degoednieuwskrant.nl/nieuws/gezondheid/1373-nieuwe-hoop-op-behandeling-parkinson
20	http://www.drimble.nl/nieuws/ziekte-van-parkinson/
21	http://www.eoswetenschap.eu/gezondheid/nieuwe-behandeling-voor-parkinson-onderweg
22	http://www.goedgevoel.be/gg/nl/148/Parkinson/actua/index.dhtml
23	http://www.goedgevoel.be/gg/nl/148/Parkinson/article/detail/1019247/2009/10/22/Nieuw-medicijn-vertraagt-gevolgen-Parkinson.dhtml
24	http://www.goedgevoel.be/gg/nl/148/Parkinson/article/detail/1237493/2011/03/17/Nieuwe-hoop-voor-patienten-Parkinson-dankzij-doorbraak.dhtml
25	http://www.hln.be/hln/nl/1/home/12634/Parkinson/actua/index.dhtml
26	http://www.kijkmagazine.nl/mens/begint-ziekte-parkinson-darmen/
27	http://www.nemokennislink.nl/publicaties/gentherapie-parkinson-werpt-vruchten-af
28	http://www.nu.nl/gezondheid/2521572/bacterie-veroorzaker-parkinson.html
29	http://www.nu.nl/tag/parkinson
30	http://www.nu.nl/wetenschap/2107413/medicijn-vertraagt-gevolgen-parkinson.html

31	http://www.omroepgelderland.nl/nieuws/2117830/Wereldwijde-primeur-voor-Nijmegen-grootschalig-Parkinson-onderzoek-met-behoud-privacy
32	http://www.plusmagazine.knack.be/gezondheid/nieuwe-hoop-op-behandeling-parkinson/article-normal-660341.html
33	http://www.spiksplinternieuws.nl/parkinson-genezen/
34	http://www.tmgonlinemedia.nl/consent/consent/?return=http%3A%2F%2F
35	http://www.volkskrant.nl/alle-nieuws-over-parkinson/
36	http://www.volkskrant.nl/wetenschap/twijfelachtige-parkinsonstudie-heeft-mogelijk-kwalijke-gevolgen~a4228382/
Medical news publisher	
37	http://www.fmtgezondheidszorg.nl/nieuwe-innovatie-eit-digital-gericht-op-verbeteren-levenskwaliteit-parkinsonpatienten/
38	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=21157
39	http://www.gezondheidsweb.eu/parkinson/mogelijk-nieuwe-methode-veelbelovende-methode-ontwikkeld-om-alzheimer-en-parkinson-te-best
40	http://www.icthealth.nl/nieuws/nieuwsitem/article/EIT-Digital-ontwikkelt-digitale-innovatie-om-leven-parkinsonpatienten-te-verbeteren.html
41	http://www.orthokennis.nl/nieuws/ubiquinol-bij-parkinson
42	http://www.ziekenhuis.nl/nieuws/mogelijk-nieuwe-behandeling-ziekte-van-parkinson/item25650
Profession	
43	http://www.fysioactueel.nl/artikel/18813/nieuwe-revalidatiefysiotherapie-bij-ziekte-van-parkinson/
44	http://www.medicalfacts.nl/2016/09/30/grootschalig-onderzoek-naar-de-ziekte-van-

	parkinson/
45	http://www.tvbzorg.com/technologie/technische-innovatie-voor-betere-behandeling-parkinson/
46	http://www.utwente.nl/nieuws/!/2016/4/201116/nieuw-licht-op-oorzaak-bewegingsstoornissen-parkinson
47	http://www.zorginnovatie.nl/innovaties/begeleiding-parkinson-met-mems
48	http://www.zorgvisie.nl/ict/nieuws/2016/9/groot-big-data-onderzoek-radboud-en-verily-over-parkinson/
Research/government	
49	http://www.bprc.nl/nl/parkinson/
50	http://www.investamc.nl/
51	http://www.leapamc.nl/
52	http://www.nivel.nl/sites/default/files/bestanden/1000477.pdf?
53	http://www.nwo.nl/actueel/nieuws/2016/cw/twee-miljoen-voor-chemische-innovaties.html
54	http://www.parkinsonopmaat.nl/
55	http://www.zonmw.nl/nl/onderzoek-resultaten/kwaliteit-van-zorg/programmas/project-detail/kennisbeleid-kwaliteit-curatieve-zorg/innovatie-en-snelle-ontwikkeling-van-een-multidisciplinaire-richtlijn-voor-de-
56	http://www.zonmw.nl/nl/onderzoek-resultaten/preventie/programmas/project-detail/sport/bewegen-met-parkinson-de-park-in-shapestudie/verslagen/
Funds	
57	http://www.hersenstichting.nl/alles-over-hersenen/hersenaandoeningen/parkinson

58	http://www.parkinsonfonds.nl/nieuws/
59	http://www.parkinsonfonds.nl/nieuws/onderzoek/mogelijk-nieuwe-behandeling-ziekte-van-parkinson/
60	http://www.parkinsonfonds.nl/onderzoek/
61	http://www.parkinsonfonds.nl/onderzoek/het-effect-van-lichttherapie-bij-parkinson-patienten/
62	http://www.parkinsonfonds.nl/over-de-ziekte-van-parkinson/behandelingen-voor-parkinson/toekomst-met-parkinson/
63	http://www.parkinsonfonds.nl/over-de-ziekte-van-parkinson/wat-is-de-ziekte-van-parkinson/hoe-verloopt-de-ziekte-van-parkinson/
64	http://www.wetenschap.hersenstichting.nl/onderzoek/onderzoeken/mogelijke-nieuwe-behandeling-voor-ziekte-van-parkinson
Wiki	
65	http://www.nl.medipedia.be/parkinson/geneesmiddelen/artikels_ontwikkeling-afremmen_180
Fellow sufferers/experience experts	
66	http://www.parkinson-vereniging.nl/actueel/archief-nieuwsberichten/nieuws-archief-2013/subsidie-voor-innovatie-die-langer-thuis-wonen-met-parkinson-mogelijk-maakt
67	http://www.parkinson-vereniging.nl/onderzoek-en-ontwikkeling
68	http://www.parkinson-vereniging.nl/onderzoek-en-ontwikkeling/wetenschappelijk-nieuws
69	http://www.parkinson-vereniging.nl/onderzoek-en-ontwikkeling/wetenschappelijk-nieuws/nieuw-licht-op-oorzaak-bewegingsstoornissen-parkinson
70	http://www.parkinson-vereniging.nl/onderzoek-en-ontwikkeling/wetenschappelijk-nieuws/nieuw-medicijn-zorgt-voor-minder-tijd-bij-mensen-met-de-ziekte-van-parkinson

71	http://www.parkinson-vereniging.nl/onderzoek-en-ontwikkeling/wetenschappelijk-nieuws/tweede-vaccin-tegen-de-ziekte-van-parkinson-ontwikkeling
72	http://www.parkinson-vereniging.nl/parkinsonismen/wat-zijn-parkinsonismen/diagnose
73	http://www.parkinsoncafelelystad.nl/nieuws.htm
74	http://www.parkinsonplaza.nl/
75	http://www.parkinsonplaza.nl/assets/Algemeen/PDF/
76	http://www.parkinsonplaza.nl/category/nieuws/onderzoek/
77	http://www.parkinsonplaza.nl/nieuwe-behandelingsrichtlijn/
78	http://www.parkinsonplaza.nl/sparking-boxing-wint-innovatie-award-in-strijd-tegen-parkinson/
Commercial organization	
79	http://www.care-iq.com/nl/portugese-innovatie-voor-parkinsonrevalidatie/
80	http://www.innofab.nl/producten/parkinson_smart_watch/
81	http://www.smarthealth.nl/trendition/2015/02/25/innovaties-voor-chronisch-zieken-cue2walk-app/
Individual medical information providers	
82	http://www.infowebweistra.eu/parkinson-alternatief.htm
83	http://www.parkinsonhuis.nl/onderzoek/richt.htm

Appendix II. Dataset of the websites used for the clinical evidence and subjectivity analyses.

	Health institution/-professional
1	http://www.parkinsonnet.nl/nieuws/doctorbeat-muziek-nodigt-uit-tot-bewegen
2	http://www.parkinsonnet.nl/nieuws/otip-studie
3	http://www.parkinsonnet.nl/nieuws/cheval-studie
4	https://www.vumc.nl/afdelingen/PCD/centrumneuropsychiatrieparkinson/onderzoek/lopend-onderzoek/beware/
5	https://www.vumc.nl/afdelingen/PCD/8968823/bewegingsklachten/
6	https://www.vumc.nl/afdelingen/PCD/centrumneuropsychiatrieparkinson/onderzoek/lopend-onderzoek/beloop-psychische-klachten/
7	https://www.vumc.nl/afdelingen/PCD/centrumneuropsychiatrieparkinson/onderzoek/lopend-onderzoek/impulscontrole/
8	https://www.vumc.nl/afdelingen/PCD/8968823/stemming-en-slaap/
9	https://www.vumc.nl/4978246/57232/5267088/5267329/nca
10	https://www.vumc.nl/verwijzers/nieuwsberichten/wereld-parkinson-dag-2017/
11	https://www.vumc.nl/verwijzers/nieuwsberichten/wereld-parkinson-dag-2017/
12	https://www.vumc.nl/verwijzers/nieuwsberichten/wereld-parkinson-dag-2017/
13	https://www.vumc.nl/afdelingen/neurologie/nieuws/subsidie_ipf/
14	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
15	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf

16	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
17	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
18	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
19	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
20	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
21	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
22	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
23	http://puntvoorparkinson.nl/wp-content/uploads/2016/04/Parkinson-onderzoek-UMCG-2016.pdf
24	https://www.catharinaziekenhuis.nl/nieuws/359-parkinson-compensatie-in-het-brein-als-basis-voor-nieuwe-bemanualeling.html
25	https://www.dezorgpraktijk.nl/acupunctuur/laatste-ontwikkelingen-bij-behandeling-m-parkinson/
26	http://www.imedlevante.com/nl/actualidad/imed-levante-is-voorzien-van-een-nieuwe-therapie-om-de-aanpak-te-verbeteren-bij-geavanceerde-parkinson/
27	https://www.revalidatie.nl/revalideren/nieuws-r/parkinsonapp-cue2walk-genomineerd-voor-innovatieprijs-van-parksinonnet
28	https://www.zel.nl/rgm-zet-het-brein-in-beweging/

29	https://www.ysl.nl/het-ziekenhuis/nieuws/nieuwsberichten/nieuwsitem/?tx_ttnews%5Btt_news%5D=262&cHash=2fe501327a8d16b16d3a32011e076645
30	http://radboudumc-neurologie.nl/2015/07/07/oudere-met-creatief-beroep-heeft-minder-kans-op-parkinson/#more-1350
31	http://www.fysiotherapiemeerzicht.nl/nieuws/ziekte-van-parkinson-ontstaat-mogelijk-in-de-darm/
32	https://www.mumc.nl/actueel/nieuws/brein-van-parkinsonpatienten-vertoont-compensatievermogen
33	https://www.mumc.nl/actueel/nieuws/onderzoek-naar-de-invloed-van-omgevingsfactoren-op-ontstaan-ziekte-van-parkinson
34	https://neurologie.mumc.nl/ziekte-van-parkinson-0
35	https://neurologie.mumc.nl/ziekte-van-parkinson-0
36	http://movementdisordersgroningen.com/nl/20-overzicht-lopende-studies/141-fdg-pet-patronen-bij-de-diagnose-van-parkinson-en-andere-neurodegeneratieve-ziekten-glimps-project
37	ttp://movementdisordersgroningen.com/nl/20-overzicht-lopende-studies/422-apomorfine-hallucinaties
38	http://www.fysiovanhoof.nl/?s=parkinson
39	http://www.fysio-op-maat.nl/nieuws/63-pwr-powertraining-voor-parkinson.html?highlight=WyJwYXJraW5zb24iXQ==
40	https://www.uzleuven.be/nl/neurologie/news/16/04/08/parkinson-op-uw-40e-niet-onmogelijk
News publisher	
41	http://www.nu.nl/gezondheid/4455756/bloedtest-kan-uitwijzen-of-iemand-

	parkinson-heeft.html
42	http://www.nu.nl/gezondheid/4369519/apparaat-kan-zeventien-ziektes-aantonen-adem-analyseren.html
43	http://www.nu.nl/gezondheid/4359729/ziekte-van-parkinson-ontstaat-mogelijk-in-darm.html
44	http://www.nu.nl/gezondheid/4081040/minder-kans-parkinson-met-creatief-beroep.html
45	http://www.nu.nl/tech/3851561/intel-gaat-wearables-inzetten-parkinson-bestrijden.html?redirect=1
46	http://www.nu.nl/gezondheid/3747926/parkinsonpatient-heeft-baat-bij-ergotherapie.html
47	http://www.nu.nl/gezondheid/3598317/doorbraak-in-onderzoek-alzheimer.html?redirect=1
48	http://www.goedgevoel.be/gg/nl/9/Gezondheid/article/detail/2218402/2015/02/14/Bier-beschermt-tegen-Alzheimer-en-Parkinson.dhtml
49	http://www.goedgevoel.be/gg/nl/9/Gezondheid/article/detail/1720347/2013/10/10/Hoop-op-simpele-pil-tegen-Alzheimer-na-doorbraak.dhtml
50	http://www.goedgevoel.be/gg/nl/9/Gezondheid/article/detail/1666373/2013/07/09/Mindfulness-helpt-Parkinsonpatienten.dhtml
51	http://www.goedgevoel.be/gg/nl/148/Parkinson/article/detail/1539969/2012/11/26/Hoe-fietsen-de-symptomen-van-Parkinson-kan-verlichten.dhtml
52	http://www.goedgevoel.be/gg/nl/148/Parkinson/article/detail/1237493/2011/03/17/Nieuwe-hoop-voor-patienten-Parkinson-dankzij-doorbraak.dhtml
53	http://www.goedgevoel.be/gg/nl/230/Pijnstillers/article/detail/1230924/2011/03/03/Ibuprofen-verkleint-kans-op-Parkinson.dhtml

54	http://www.goedgevoel.be/gg/nl/148/Parkinson/article/detail/1222442/2011/02/14/B essen-eten-verlaagt-kans-op-ziekte-van-Parkinson.dhtml
55	http://www.volkskrant.nl/wetenschap/microbubbels-slechten-krachtveld-van-het-brein~a4184238/
56	http://www.volkskrant.nl/wetenschap/experts-enthousiast-over-nieuwe-aanpak-alzheimer~a3525121/
57	http://www.volkskrant.nl/wetenschap/verkleint-een-creatief-beroep-de-kans-op-parkinson~a4096309/
58	http://www.volkskrant.nl/wetenschap/herprogrammering-huidcellen-gekraakt~a3808351/
59	http://www.volkskrant.nl/wetenschap/binnenkort-op-uw-arm-de-elektrische-pleister~a3625652/
60	http://www.volkskrant.nl/archief/human-beatbox~a3613345/
61	http://www.volkskrant.nl/wetenschap/tijdens-slaap-wordt-het-brein-gewassen~a3529266/
62	http://www.volkskrant.nl/magazine/lepel-voor-parkinsonpatienten-compenseert-trillingen~a3496788/
63	http://www.volkskrant.nl/archief/parkinsonpatient-heeft-baat-bij-lichttherapie~a3444444/
64	http://www.ad.nl/rotterdam/wereldrecord-dansen-met-parkinson-verbroken~afb8d1e7/
65	http://www.ad.nl/rotterdam/nieuw-deodorant-op-basis-van-wiet~a6726d33/
66	http://www.ad.nl/dordrecht/sneller-revalideren-door-het-neusje-van-de-zalm~a91908c5/
67	http://www.ad.nl/enschede/ut-onderzoekster-werpt-nieuw-licht-op-oorzaak-

	parkinson~ad613861/
68	http://www.ad.nl/economie/koffie-ongezond-juist-goed-voor-hart-lever-en-hersenen~a3d34f10/
69	http://degoednieuwskrant.nl/index.php/nieuws/gezondheid/2764-nieuwe-revolutionaire-ontdekking-powerstrips
70	http://degoednieuwskrant.nl/index.php/nieuws/gezondheid/2564-waar-is-kaneel-goed-voor
71	http://degoednieuwskrant.nl/index.php/nieuws/gezondheid/1726-wernard-bruining-mediwiet-olie-het-ideale-volksmedicijn
72	http://degoednieuwskrant.nl/index.php/nieuws/gezondheid/1373-nieuwe-hoop-op-bemanualeling-parkinson
73	http://degoednieuwskrant.nl/index.php/nieuws/gezondheid/1151-wat-zijn-anti-oxidanten
74	http://www.telegraaf.nl/gezondheid/24230270/__Creatieveling_heeft_minder_kans_op_Parkinson__.html
75	http://www.telegraaf.nl/gezondheid/e-health/23064799/__App_detecteert_Parkinson-symptomen__.html
76	http://www.telegraaf.nl/gezondheid/22499069/__Ergotherapie_nuttig_bij_Parkinson__.html
77	http://www.telegraaf.nl/binnenland/21295324/__Elektroden_bij_parkinson__.html
78	http://www.hln.be/hln/nl/961/Wetenschap/article/detail/3138394/2017/04/20/Veelbelovende-ontdekking-bestaande-medicijnen-kunnen-dementie-of-alzheimer-halt-toeroepen.dhtml
79	http://www.hln.be/hln/nl/14/Nina/article/detail/2908792/2016/10/08/Stress-nog-slechter-voor-je-lijf-dan-gedacht.dhtml

80	http://www.rd.nl/vandaag/binnenland/groene-thee-helpt-bij-alzheimer-1.431408
Medical news publisher	
81	https://www.ziekenhuis.nl/nieuws/mogelijk-nieuwe-bemanualeling-ziekte-van-parkinson/item25650
82	https://www.ziekenhuis.nl/nieuws/elektrische-pleister-geeft-medicijnen-af/item25660
83	https://www.ziekenhuis.nl/nieuws/bessen-beschermen-mannen-tegen-parkinson/item9960
84	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=21157
85	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=19364
86	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=18561
87	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=17940
88	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=15938
89	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=15910
90	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=14308
91	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=3928
92	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=5724
93	http://www.gezondheid.be/index.cfm?fuseaction=art&art_id=14703
94	http://www.gezondheidsweb.eu/gezondleven/parkinson/stimulering-hersenen-nuttig-bij-bestrijding-van-parkinson
95	http://www.gezondheidsweb.eu/voedingssupplementen/creatine-kan-gezondheid-postief-beïnvloeden

96	http://www.gezondheidsweb.eu/parkinson/hogere-concentratie-van-natuurlijke-antioxidant-kan-parkinson-vertragen
97	http://www.gezondheidsweb.eu/parkinson/mogelijk-nieuwe-methode-veelbelovende-methode-ontwikkeld-om-alzheimer-en-parkinson-te-best
98	http://www.gezondheidsweb.eu/parkinson/bessen-kunnen-risico's-op-ziekte-van-parkinson-doen-afnemen
99	http://www.gezondheidsweb.eu/gezondleven/parkinson/revolutionaire-doorbraak-strijd-tegen-parkinson-op-komst
100	https://www.fmtgezondheidszorg.nl/nieuwe-innovatie-eit-digital-gericht-op-verbeteren-levenskwaliteit-parkinsonpatienten/
101	https://www.fmtgezondheidszorg.nl/kwart-miljoen-voor-onderzoek-diepe-hersenstimulatie-bij-parkinson/
102	https://www.fmtgezondheidszorg.nl/minder-kans-op-parkinson-vopor-oudere-met-creatief-beroep/
103	https://www.fmtgezondheidszorg.nl/oudere-valt-minder-met-virtuele-looptraining/
104	https://www.fmtgezondheidszorg.nl/minister-schippers-opent-cyclotronfaciliteit-radboudumc/
105	https://www.icthealth.nl/nieuws/nieuwsitem/article/dansen-goed-voor-parkinson-patienten.html
106	https://www.icthealth.nl/nieuws/nieuwsitem/article/Nieuwe-oogtest-ontdekt-Parkinson-voordat-symptomen-zichtbaar-zijn.html
107	https://www.icthealth.nl/nieuws/nieuwsitem/article/Schoenen-met-laserlicht-tegen-bevriezen-van-Parkinson-patienten.html
108	https://www.icthealth.nl/nieuws/nieuwsitem/article/EIT-Digital-ontwikkelt-digitale-innovatie-om-leven-parkinsonpatienten-te-verbeteren.html

109	https://www.icthealth.nl/nieuws/nieuwsitem/article/ZonMW-geeft-Off-Road-subsidies-aan-innovatieve-onderzoeksprojecten-Radboudumc.html
110	https://www.icthealth.nl/nieuws/nieuwsitem/article/IBM-kunstmatige-intelligentie-voorspelt-geestelijke-gezondheid-via-onze-taal.html
111	https://www.icthealth.nl/nieuws/nieuwsitem/article/Ouderen-vallen-minder-na-looptraining-met-virtual-reality.html
112	http://www.orthokennis.nl/artikelen/nieuwe-studies-met-co-enzym-q10
113	http://www.orthokennis.nl/artikelen/ashwagandha-koninklijk-kruid-uit-india
114	http://www.orthokennis.nl/nieuws/ubiquinol-bij-parkinson
115	http://www.orthokennis.nl/artikelen/rode-gist-rijst
116	http://www.orthokennis.nl/artikelen/Curcumine
117	https://www.gezondheidsnet.nl/fietsen-helpt-bij-parkinson
118	https://www.gezondheidsnet.nl/parkinson/bewegen-met-parkinson
119	https://www.gezondheidsnet.nl/sporten-helpt-bij-ziekte-van-parkinson
120	https://www.gezondheidsnet.nl/parkinson/minder-kans-op-parkinson-met-creatief-beroep
Beroeps	
121	https://www.fysioactueel.nl/artikel/21181/grootschalig-onderzoek-naar-de-ziekte-van-parkinson/
122	https://www.fysioactueel.nl/artikel/20244/oudere-valt-minder-vaak-met-virtuele-looptraining/
123	https://www.fysioactueel.nl/artikel/18813/nieuwe-revalidatiefysiotherapie-bij-ziekte-van-parkinson/

124	https://www.fysioactueel.nl/artikel/6527/samenwerking-bij-het-bestrijden-van-de-ziekte-van-parkinson/
125	https://www.fysioactueel.nl/artikel/3753/parkinsonpatient-heeft-baat-bij-ergotherapie/
126	https://www.fysioactueel.nl/artikel/1961/revalideren-op-interactieve-loopband/
127	https://www.fysioactueel.nl/artikel/1079/slimme-bril-moet-parkinsonpatient-helpen-lopen/
128	https://www.medicalfacts.nl/2016/09/30/grootschalig-onderzoek-naar-de-ziekte-van-parkinson/
129	https://www.medicalfacts.nl/2015/11/17/stamceltransplantatie-voor-de-ziekte-van-parkinson-behoeft-verdere-optimalisatie/
130	https://www.medicalfacts.nl/2016/04/21/meander-medisch-centrum-maakt-grote-stappen-parkinsonrevalidatie/
131	https://www.medicalfacts.nl/2015/07/03/oudere-met-creatief-beroep-heeft-minder-kans-op-parkinson/
132	https://www.medicalfacts.nl/2014/11/05/verbetering-cognitie-van-parkinsonpatienten-met-elektrische-stroompjes/
133	https://www.medicalfacts.nl/2013/10/14/smart-glasses-kunnen-loopbeweging-parkinsonpatient-verbeteren/
134	https://www.medicalfacts.nl/2012/12/17/umcg-onderzoekt-of-sensor-pen-vroegtijdig-parkinson-kan-aantonen/
135	https://www.medicalfacts.nl/2012/07/24/meer-licht-op-stemming-en-slaap-bij-parkinson/
136	https://www.medicalfacts.nl/2011/03/18/gentherapie-voor-parkinson-hoopvol/
137	https://www.medicalfacts.nl/2011/03/04/minder-kans-op-parkinson-door-ibuprofen/

138	http://www.tvbzorg.com/varia/nieuw-traploop-hulpmiddel/
139	http://www.tvbzorg.com/technologie/technische-innovatie-voor-betere-bemanualeling-parkinson/
140	https://www.zorginnovatie.nl/innovaties/begeleiding-parkinson-met-mems
141	https://www.zorginnovatie.nl/innovaties/upright
142	https://www.zorginnovatie.nl/innovaties/psyche-cognitie
143	http://www.apothekersnieuws.nl/5460/compensatie-in-het-brein-bij-parkinson-soms-gunstig-soms-niet/
144	http://www.apothekersnieuws.nl/4568/parkinsonpatient-baat-bij-nieuw-medicijn/
145	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/20362
146	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/10746
147	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/10707
148	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/10645
149	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/10644
150	http://neuro.venvn.nl/Nieuws/Nieuwsarchief/ctl/ArticleView/mid/3692/articleId/10637
151	https://www.medischcontact.nl/nieuws/laatste-nieuws/artikel/symptoom-bestrijding-ziekte-van-parkinson.htm
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