

**Identification of user requirements for
prosthetic devices by means of text
mining in online user fora**

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Abstract

Identification of user requirements for prosthetic devices by means of text mining in online user fora

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Identifying user requirements is difficult for manufacturers of prosthetic devices. This is a result from the fitting process happening under doctor-patient-confidentiality, limiting access to amputees for the industrial partner. User needs were thus traditionally derived from experience, by interviewing amputees directly and the involvement of lead users. Product innovations were often also technology driven, making these approaches difficult and limited in their value.

Exploring new avenues to generate insight into (unsolved) user needs is thus a major task for the (prosthetic) industry. This thesis investigated the idea to extract unmet and unknown user needs from relevant online user fora. The underlying hypothesis is that amputees communicate unmet needs as well as unresolved usability issues in online user groups and that text mining can be utilized to identify these needs.

Data from relevant user fora were extracted and analysed by means of commercially available tools. webLyzard was used to identify number of posts and sentiment for defined research questions. Relevant associations were also recorded and analysed. Results were discussed with experts in the field (certified prosthetists, product managers, experienced developers).

The results confirmed existing knowledge about user needs and usability of current prostheses. The results also demonstrated that amputees think in prosthetic systems and not in the components that make up such systems. Finally the results identified several areas of interest that need to be considered in more detail in future product developments.

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Affidavit

I hereby affirm that this Masters Thesis represents my own written work and that I have used no sources and aids other than those indicated. All passages quoted from publications or paraphrased from these sources are properly cited and attributed.

The thesis was not submitted in the same or in a substantially similar version, not even partially, to another examination board and was not published elsewhere.

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“Science may be described as the art of systematic over – simplification.”

Karl Popper (1902 – 1994)

Chapter 1

Introduction and Motivation

1.1 Product development in the medical device industry

The development, manufacturing and sales - together with the after-sales service - of medical devices is a strictly regulated business. Currently the medical device regulation in its version released in 2017 (MDR)¹ is to be applied to all new product developments, together with a number of further internationally recognized standards such as IEC-60601, ISO-13485 and ISO-14971 to name just a few. These standards motivate (or rather force) companies to follow a well defined operating model for product development. In most cases a stage-gate approach is used in product development [Pietzsch et al., 2009]. Often, this stage-gate development process describes a linear number of steps,

¹Regulation (EU) 2017/745 on medical devices

without loops returning to earlier stages of the process. This linear approach is in the interest of the development organization since any loop in the development process increases effort and time spent on development. As a result user-requirements and technical requirements of any new product are defined early on in the process. The definition of the correct user requirements though will generally markedly influence later success of any product.

Defining the correct requirements and identifying the really unsolved user needs is of particular interest as well as of considerable difficulty in the medical device industry. In this thesis one specific branch of the medical device industry shall be investigated. The author has fifteen years experience in research and development in the area of prosthetic devices, namely neuro-prostheses such as functional electrical stimulation devices and prostheses that are used following amputation of a limb. Especially the area of leg prostheses, and here again the segment of high-end knee prostheses are key areas of the author's daily work. The author works at Ottobock, a privately owned company that currently is the world leader in this area of prosthetic devices. Compared to other industries the market is somewhat limited globally. The overall numbers of amputees that are fitted with such a device are rather low (i.e. in the range of 10,000 to 20,000 systems per year for above knee amputations that are fitted with a high-end prosthesis and approximately a factor ten less following hand and arm amputations). Globally, two companies dominate this market, Ossur (based in Iceland) and Ottobock (based in Germany).

In most industries one would assume that companies of such size as these two global players find it rather easy to assess and define user

requirements. Years and years of experience together with strong links to users should lead to a continuous stream of ideas and unsolved user needs. In reality the situation is very different. Prostheses are used in the process of a medical intervention (called fitting), most often following a traumatic event such as an accident. Medical interventions are usually covered by medical confidentiality of all parties involved. Otto-bock, Ossur or any other supplier do generally not directly participate in this process, but merely deliver the prosthesis that is used in the fitting process. In practically all cases the affected person undergoes amputation surgery in a hospital and is fitted by the (local) certified prosthetist with a suitable device. Since these high-end prostheses are very expensive (prices for an above-knee fitting range into the area of several ten-thousand Euros) this is in most cases paid for by the health insurance of the person. As a result of the fitting process even the two globally acting manufacturers do not have direct contact to amputees. Moreover, and most interesting during the development of prosthesis the interests of as much as three customers need to be fulfilled.

The interests of these three parties are not necessarily in alignment:

- **End-user or amputee** The end-user generally wants a device that fulfils all his or her daily unsolved needs. These may vary widely between different users. Ultimately any company aims at fulfilling the end-users' needs first, but must also consider the needs of the other stake-holders (see below). As mentioned above, access to end-users is often limited for companies.
- **Certified prosthetist and orthetist, CPO** Certified prosthetists play a crucial part in the fitting process of prostheses.

They chose the prosthesis that is being fitted and work with the end-user (or amputee) in setting up the fitting. Most crucially they manufacture the so called socket. The socket is the interface to a patient's stump and crucially influences the overall performance of the fitting. Moreover the prosthetist sets-up the prosthesis for the end-user. A prosthetist is often motivated by two factors, one being the outcome that can be achieved for the end-user and the second one being the financial income they can generate for themselves. Since the quality of a fitting (and the satisfaction of the end-user) is difficult to assess and is not considered in the reimbursement the latter often takes priority over the first. A prosthesis thus is interested in a device that is easy to set-up in order to provide the best possible outcome for the amputee, requires limited work with the end-user, is covered by reimbursement (codes) and provides a (good) profit.

- **Health-insurance** In the first world - which is the primary market for high-end prostheses - prostheses are in general paid for by health insurance. In practically all nations of commercial interest this process is again highly regulated. Most often fittings, including all relevant steps taken along the fitting process are listed in so called reimbursement catalogues under specific reimbursement codes. Commercial success of a device in practically any market depends on eligibility for one or more reimbursement codes. Especially in times of economic pressure health insurances generally do not issue new reimbursement codes for new devices and are interested to limit their overall spending. They are thus interested in the cheapest device they can get for a certain ailment.

To summarize, manufacturers of high-end prostheses (but also other medical devices) frequently find it difficult to get access to their end-users (the amputees) and need to fulfil differing requirements. These stem from the different stake-holders that are involved in the process of selling, fitting, using and paying for a prosthesis. In order to limit the scope of this thesis - and also considering that the requirements of prosthetists and health-insurance providers are rather well defined - this work will concentrate on the requirements of the end-user (the amputee) and how these can be gathered.

In order to gain a more complete overall picture the process followed during the development of a high-end prosthesis will also be explained. As mentioned earlier, the development of medical products is strictly regulated. In Europe and the USA a number of applicable standards have to be adhered to. Together with other internationally accepted standards the process as well as the technical requirements are defined through these regulations. Despite this plethora of standards each manufacturer still needs to implement its own set of rules and processes. This is usually done in the companies' quality management system and is approved by a notified body. Most often the later applied process model is defined by standard operating procedures, process description and templates for documents. [Pietzsch et al., 2009] detailed the usual steps taken in the development of medical products and developed and presented a stage-gate process suitable for medical products. Although the stage-gate process in most companies will differ from the process presented in the paper it nevertheless gives a good overview. Moreover, the paper showcases the medical device industry in general. It also lists a number of other requirements that are important in the

development of medical devices. In their paper they describe a “Phase 0 - Predevelopment Activities”. In this phase clinical requirements (or rather user requirements in the case of prostheses) are being collected and analysed.

The inclusion of end-users in the development process has been of increasing interest in recent years, not only in the medical device industry, but in a wide range of industries. The medical device regulation focuses on usability of medical devices, their documentation and also enforces the implementation of post-market surveillance systems. All of these are aimed at improving usability and safety of devices. In addition IEC-60601 and more recently IEC-62366 specifically detail the requirements for home-use of devices. Despite all these standards and the regulatory need and focus to concentrate on the end-user-needs it is not always simple and easily legally possible to approach end-users as a manufacturer of medical devices.

The following introduction will investigate a few traditional approaches to collect user requirements and user needs. Finally it will also introduce the proposed novel approach that will ultimately be investigated in this thesis.

1.2 End-users and product development

Apart from the regulatory necessity to include and consider end-users in the development process in the medical domain there also is growing interest in industry in general to include end-users into product development. In addition end-users themselves are also interested in

“developing” their own product or at least participating in the development. This should come as no surprise as they are the ones ultimately using a device on a daily basis. Depending on the product in question the involvement of end-users is more practical and more or less frequent. To give just an example. The development of software and especially modern apps can relatively easily involve end-users. This is based on the short update cycles and the established update model of such products. In contrast to this model there are products that take years to develop or have very long usage times. Example therefore are cars or medical products. Both are “updated” very infrequently (if at all) and have very long development processes (generally in the range of years rather than months or weeks).

Nevertheless, or especially because of this fact the involvement of end-users is crucial, since end-users know their needs best [Cooper and Kleinschmidt, 1995]. Early testing with end-users can also improve usability and safety, as well as improve functional outcomes of a device or product. [Kristensson et al., 2004] have shown that users generate more original ideas than professional developers, while the latter generated the more realizable ideas.

Over the years a number of different approaches to integrate end-users into the development process have emerged. [Steen et al., 2007, Money et al., 2011] mention the following methods to gain user insights:

- **Focus groups** are generally group discussions of eight to ten end-users. Focus groups are relatively common throughout the development life-cycle. Most often they are guided and facilitated by a moderator [Money et al., 2011].

- **Interviews** are a very common approach. They can quickly be deployed and enable the engineer to access a broad range of opinions [Money et al., 2011].
- **Usability Testing** is usually performed at a later stage of the development cycle. Its focus frequently is to assess effectiveness, efficiency and satisfaction (of the end-user) [Money et al., 2011].
- **Heuristic Evaluation** often is a pre-stage of *Usability Testing*. “Developers step through the device features and functionality and check the extent to which it complies with pre-determined list of characteristics...”. [Money et al., 2011].
- **Participatory Design** “Participatory Design is about providing people who will be using a system a voice in the process of design, evaluation and implementation of a system which they will be using.” [Steen et al., 2007]. End-users and their knowledge are treated as experts, and they work together with designers to jointly improve the product.
- **Ethnographic Fieldwork** “The ethnographic move is about researchers and designers going into the field often to work places to better understand people via observations and interviews.” [Steen et al., 2007]. Ethnographic fieldwork is similar to the Participatory design approach but requires the designer or engineer to go into the field to experience the end-user in their environment. Observing what the end-user does in daily practice may generate valuable knowledge.
- **Contextual Design** is similar to - or rather a more systematic version of ethnographic fieldwork. Again the end-user is observed

during their daily routine by members of the design team. Their findings are then transferred into the design process. Often their findings are organized “along different perspectives, such as what end-users do; how they communicate; the roles that power and culture play; the artefacts which they use; the physical environment in which activities take place.” [Steen et al., 2007].

- **Lead User** are users who have two distinguishing characteristics: “... they are ahead of the majority of users in their populations with respect to an important market trend, and they expect to gain relatively high benefits from a solution to the needs they have encountered there.” [von Hippel, 2005]. As a result other users will in future also experience or develop the same or similar needs and the solutions provided will also benefit them, respectively will have a relatively high appeal on the market. Most often the developed solutions are pragmatic in nature and oriented towards commercial goals [Steen et al., 2007]. Identification of lead user is in practice not always straightforward. [Bilgram et al., 2008] have investigated the usability of web 2.0 applications to identify lead-users.
- **Empathic Design** “Empathic design is about attempts to find inspiration in the end-users practice and to fuel creativity by empathising with end-users.” [Steen et al., 2007]. In Empathic Design designers or engineers try to *experience* the daily life of the end-user, rather than observe it, as in Participatory Design.
- **Co-designing or Co-creation** attempts to bring end-users and designers and/or engineers to jointly *create*. “The focus is on

jointly articulating ideas, on playing with concepts, on making and evaluating sketches, on jointly tinkering with mock-ups and prototypes.” [Steen et al., 2007]. Co-designing is also described as a mixture or combination of Participatory Design and Empathic Design.

As can be seen above, a number of different approaches exist and have already been used in product development in a number of industries. Not all methods appear suitable to all industries. In some industries this may be related to the rather innovative nature of the products. Asking user about their assumptions and needs with relation to yet unknown product features may not yield usable results. Even well established world-leading companies at times miss new trends when they are new and disruptive. To give just one example, Nokia misjudged the importance of smartphones completely. In the medical device industry the uptake of user-centric design methods has been rather slow.

In product development often a differentiation between functional and non-functional requirements is made. [Gausepohl, 2008] mentions a number of interesting facts in her master thesis in relation to these types of requirements. Functional requirements describe what a system or product needs to do, while non-functional requirements specify how well a system or products needs to perform its functions. In addition, when stakeholder needs are identified it may be difficult to understand the context-of-use as well as conflicting stakeholder needs. Martin et al investigated the challenges of capturing user requirements in medical devices in a number of papers [Martin et al., 2006, Martin et al., 2008, Martin et al., 2012]. A number of the methods mentioned above are difficult to perform in the healthcare setting. Amongst the concerns

mentioned are “time, financial, ethical and practical factors as well as commercial confidentiality” [Martin et al., 2006]. Moreover it may be difficult to access end-users in the healthcare sectors, respectively it may require ethical approval, which in many cases is a time consuming procedure and does not fall into the standard domain of knowledge of a medical device company. In order to overcome some of these aspects sometimes proxies are being used. A typical proxy could be a clinician instead of end-users. In this case the clinician (the proxy) would be seen as representing at least the knowledge, needs and requirements of several end-users. Sometimes (experienced) engineers may act as proxies themselves. This is often the case in early testing, but poses the risk that results may “be fraught with bias and should never completely replace testing with representatives of the target users” [Martin et al., 2006]. Another issue identified is the fact that more than one set of end-users may exist [Martin et al., 2008].

In the domain of prosthetic devices one may argue that up to three user-groups exist (as listed earlier). [Martin et al., 2008] mention that “Certain regulations must be met before devices can be tested by real users and, once a device has met regulations, developers can be reluctant to make changes that would require re-submission, given the time and financial cost of putting devices through regulatory assessment.” It is the author’s own experience that amendments to clinical studies performed with non CE-marked devices may take up to six months, a time period that may be prohibitive when compared to fast developing technology.

But there are more aspects to consider. [Martin et al., 2008] also mention context and sampling, the fact that field research may be

inappropriate, that it may be difficult to obtain access to users in certain phases of product development and that eventually more than one research method should be used. These aspects may be seen as further challenges related to user requirement studies. Context and sampling refer to the different users that one product may have, the difficulty to obtain users in certain phases relates to the inability of certain groups to express their needs (e.g.: children or mentally impaired users) or the fact that especially early stage prototypes may still be confidential in nature (and not yet protected by intellectual property). In contrast to some areas such as software development the prosthetic device industry faces a further major challenge. Due to the nature of the products it is basically impossible to evaluate the function with (early) prototypes. A device needs to be almost completely finished before it can be evaluated by the end user. Not fully developed devices are frequently too heavy, or have issues with the control or are too noisy. All of these aspects seriously affect the impression the end-user will perceive. It is evident that this would influence perception of effectiveness, efficiency and satisfaction that were mentioned earlier. Moreover medical devices “are frequently technology driven rather than resulting from an identified unmet need”, which may exacerbate this issue [Martin et al., 2008].

In their 2012 paper [Martin et al., 2012] investigate the medical device industry perspective on user-centered requirement elicitation. They mention that often assumptions are made for user requirements, because real users are not accessed for time and financial constraints. Unfortunately these assumptions are often not correct. Developers then often spend considerable time and effort to identify and recover

from these wrong assumptions. In their work they propose a method of brainstorming and interviews to gather requirements in a number of areas. Based on a real-world example the study found that “a broad and wide-ranging approach to data collection, followed by a focused analysis and reporting process produced data that the developers found accessible and actionable.”

This triggers the question about success factors in products and especially in medical products. [Brown et al., 2008] investigated the “success factors in New Product Development in the medical device industry”. They found that especially end-user involvement in the development process showed a correlation to market success. They also found that technological innovation often lead that products that surpassed companies‘ expectations. [Loch, 2000] investigated the product and project portfolio in a single company and identified different new product development processes at work at the same time. In the introduction he highlighted the fact that project success of new product development processes is influenced by customer orientation. This view is also supported by [Cooper and Kleinschmidt, 1995], who call it homework or performing the pre-development activities.

Concluding, it has been shown that on the one hand user-centric design is an important success factor. On the other hand we have also established that end-users are very difficult to access in the prosthetic device industry. Shah et al provide an overview over user involvement in the medical device industry, showing similar results as discussed earlier in a series of papers [Shah and Robinson, 2007, Shah et al., 2009, Shah and Robinson, 2006]. [Lettl, 2007] investigated the different dimensions that need to be considered when integrating users into the development

process.

Despite all these difficulties, modern communication and recent developments may have opened up a new source of information that waits to be explored. Similar to many other areas of modern life also amputees exchange their ideas and concerns online and have established user-groups, discussion platforms and user-fora. Albeit being largely unstructured (as is the nature of such data) it must be assumed that these fora contain useful information with respect to user-requirements and unresolved needs and pains. It most likely will also contain information on usability issues with existing devices and other yet unknown criticism. This thesis will therefore investigate whether this information can be made accessible via automated data processing tools.

1.3 Text mining of user fora

Modern technology and communication means such as online-fora or discussion-groups allow users to exchange their ideas and concerns in a reasonable structured, yet quickly accessible format. It may come as no surprise that user-fora related to almost all areas of daily life (and beyond) have been formed. Similarly interest groups on Facebook and Reddit are already available for a huge number of topics (and continue to be formed for new areas of interest). Amputees - despite globally being a rather small group of people - have also established user-fora and relevant groups on Facebook and Reddit. Perhaps the small number of amputees even contributed to this format, since an online presence allows amputees to communicate with peers even if that was not possible in real life.

How powerful text-mining can be is described by [Fan et al., 2006] in an example. In their paper they mention the integration of Dow Chemical and Union Carbide Corp.. In this example text mining was used to integrate 35,000 research reports from one into the other company. Their paper cites time-savings of approximately 50% and a reduction in error rate of 10-15%.

In 2009 [Gupta and Lehal, 2009] provided an overview over text-mining techniques. Gupta and Fan similarly define text-mining as a process of discovering new (previously unknown) information automatically from written resources. The “.. goal is to discover unknown information, something that no one yet knows ...” [Gupta and Lehal, 2009]. An important aspect relates to the data that is available. In contrast to data-mining when the data is already structured, text and the available resources are most often unstructured. The unstructured nature of the data, generally written as free texts, emails or discussion entries in online fora is difficult to understand for a machine. Despite all the developments of recent years, computers are still limited in their ability to understand human speech. Gupta mentions limitations such as slang, spelling and context, which are difficult to process. Humans - in contrast - are able to do just that, yet lack the ability to process large amounts of data quickly.

In text-mining therefore a structured approach is commonly applied. [Gupta and Lehal, 2009] describes the following possible techniques in relation with text mining:

- **Data retrieval** Before any text mining can start it is necessary to prepare and clean the data from non-relevant information that

can easily be identified, such as data and time in emails or sender and receiver information.

- **Information extraction** identifies key-phrases and relationships within the text.
- **Topic tracking** tries to predict which documents are of interest based on key-words that were chosen. In a similar process key-words can be extracted from a data source and be used to give an overview over the document.
- **Summarization** attempts to identify the meaning of a text. Since computers lack the understanding of text like humans do, summarization can be performed in different ways. These can include statistical methods, search for headings, may concentrate on the syntactic level or include the semantics level too.
- **Categorization** identifies the main themes of a manuscript or text and places the text into pre-defined topics. Often this is done by counting words and does not attempt to process the actual information (compare information extraction).
- **Clustering** may be compared to categorization, but rather than using pre-defined topics documents are clustered on the fly.
- **Concept linkage** connects related documents by identifying their commonly shared concepts. Especially in the biomedical field this allows to link different literature to each other.
- **Information Visualization** is a tool to improve browsing and visual analysis of documents or texts.

- **Question Answering** attempts to answer given questions.
- **Association Rule Mining** attempts to discover relationships amongst a large set of variables within a data-set.

But text mining does not only offer a number of different methods to analyse text, it also has been used for a number of applications already. Of particular interest for this work is the use of text-mining or data-analysis with respect to user centric design in a wider and requirement extraction in a more narrow context. [Botzenhardt et al., 2011] have proposed a text mining tool to extract the voice of the customer. A first prototype was tested in a software-development setting. [Bank and Mattes, 2009] have developed an algorithm identifying user comments in flat internet fora. [Casamayor et al., 2012] reviewed the state of the art in text mining to assist architectural software-design. [Collier et al., 2008] describe BioCaster, a system to detect public health hazards using a Web-based text crawler. [Guzman et al., 2017] used Twitter to identify improvement request for software based on three real-world examples. Similar work was done by [McGarry and McDonald, 2017] in order to identify user experience issues in a gaming forum. In another approach - but related to requirements in more general terms - [Sateli et al., 2012] demonstrated the use of text mining to improve requirement specifications. [Tigerlaar et al., 2010] presented a tool set to automatically summarize the contents of discussion fora. [Mostafa, 2013] investigated the ability of text mining to analyse sentiment towards brands.

In a different approach [Hecking et al., 2015] used network analysis tools to identify emerging themes in an online forum. [Isah et al., 2014]

presented a framework to discover adverse effects of drugs via data from Facebook and Twitter. A completely different area of research concentrates on text-mining in biomedical applications, most often in connection with protein structures, medical records or the biomedical domain in general [Huang and Lu, 2016, Hahn et al., 2002, Lee et al., 2020, Zweigenbaum et al., 2007, Pereira et al., 2015].

Natural language processing (NLP) is a modern approach to analyse the content of data that has limited structure or form. For example, medical records are often relatively formalized documents, that have a comparable structure, contain similar data entries and use a formalized language. In contrast, user generated content such as posts in online fora lack most if not all of these “features”. NLP is described as an important branch of artificial intelligence (AI). In their recent review [Zhou et al., 2020] describe the history of NLP. Over the years NLP has developed from rule-based systems, that were manually coded, via statistical methods to deep learning approaches. The latest development is called neural network-based NLP or “neural NLP” and represents the current state-of-the-art.

In their review [Zhou et al., 2020] mention “fundamental neural network-based modelling paradigms, such as word-embedding, sentence embedding and sequence-to sequence modelling”. In short “word/sentence embedding attempts to map words and sentences from a discrete space into a semantic space, in which the semantically similar words/sentences have similar embedding vectors.” In contrast “sequence-to-sequence modelling attempts to generate one sequence with another sequence as input”. In word-embedding words are characterized “by the company it keeps”, while “sentence embedding can be used for sentence-level

tasks, such as sentiment analysis and paraphrase classification”.

NLP and word-embedding has also been the interest of ongoing research. Word-embedding in itself has drawn interest with respect to its ability to find medical terms in relevant literature or documents [Wang et al., 2018]. It has been shown that training word-embedding with relevant records and data improves performance compared to training word-embedding with non-relevant content. Combining elements from NLP, information retrieval and semantic fields improved results, yet are not viable for real-time use due to excessive computing times [Plu, 2016]. With respect to clinical notes [Luo, 2017] investigated the influence of using recurrent neural networks (Long Short-Term Memory). They found similar results to state-of-the-art previously published results, but without manual feature engineering. [Hassanzadeh et al., 2018] investigated the transferability of neural networks to other sources of data (e.g.: to clinical notes from other hospital in their specific case). The academic activity in this field demonstrate that NLP has a very active community and potential in the analysis of unstructured text. Clinical documents in general are one area of interest.

NLP is also readily available in commercial tools. One such powerful tool is webLyzard², which in the past has been used for various commercial applications that can be found on the webpage. Of interest is the fact that webLyzard has been used to extract knowledge from the Web and Social Media Channels [Scharl et al., 2013, Scharl et al., 2012]. In wider reaching work the webLyzard platform was used to analyse emotional values associated with different brands and companies. For this affective knowledge as well as factual knowledge was combined [We-

²www.weblyzard.com

ichselbraun et al., 2017]. The team developing webLyzard has also introduced tools for data acquisition such as the extensible web retrieval toolkit (eWRT) [Weichselbraun et al., 2013].

As shown above, text mining has been used for a number of different applications in recent years. In addition numerous algorithms have been developed and have been deployed, again in a number of different applications. Yet - to the best knowledge of the author - the elicitation of

- unknown user requirements,
- unknown usability issues with existing devices and/or
- performance issues with existing devices

in the context of prosthetic devices has not been attempted. The following chapters of this thesis will therefore attempt to answer the following two hypotheses:

1. It is possible to identify (currently unknown) user demands or user needs for high-end prosthetic devices from online-sources generated by amputees.
2. It is further possible to identify (currently unknown) usability issues and/or performance issues that amputees may have with existing high-end prostheses.

More specifically these hypotheses will be approached via a number of research questions. Some of these are based on issues that are frequently mentioned by amputees. Others try to expand the focus of the analysis beyond these common areas of interest.

- **Pain:** Is pain or phantom pain really a dominating issue for amputees, regardless of their amputation level? Is pain related to the used prosthetic device? Does a consensus exist how pain can be alleviated?
- **Socket & Comfort:** Are sockets and their fit a common topic amongst amputees? Is comfort a topic that is regularly addressed amongst amputees?
- **Activities of daily living:** Which activities of daily living are most often mentioned amongst amputees? Is there a common activity of daily living that is not addressed by modern prosthetic devices?
- **Usability:** Is usability of prosthetic devices (regardless of a specific product) mentioned amongst amputees?
- **Performance:** Are there common performance issues that are discussed amongst amputees? Are specific topics such as battery lifetime, size or weight discussed amongst amputees?
- **General topics:** Is it possible to identify further frequently mentioned topics that are not covered by the above questions?

“Great products are engineered when product managers truly understand the desired outcomes by actively listening to people, not users.”

Michael Fountain - Head of Product at Apptentive

Chapter 2

Material and Methods

The following section describes the material used and the methods applied in this thesis. As stated earlier - and as a brief reminder - this thesis aims to investigate the following hypotheses:

1. It is possible to identify (currently unknown) user demands or user needs for high-end prosthetic devices from online-sources generated by amputees.
2. It is further possible to identify (currently unknown) usability issues and/or performance issues that amputees may have with existing high-end prostheses.

As discussed in the introduction to this thesis, online user fora as well as Facebook and Reddit discussion groups and other online sources would appear to be suitable data sources worthwhile to be analysed in the following chapters.

2.1 Characteristics of online users

The total number of amputees is limited worldwide. It therefore appears meaningful to not differentiate posts based on the type of amputation in the first steps already. Nevertheless it is important to note that an amputation can occur at the upper and lower extremity and also at different locations. The following list will give an overview of the most common amputation levels organized by extremity and moving from more distal to more proximal amputation levels. A graphical representation can be found in figure 2.1.

- **Amputations of the upper extremity**

- fingers: most often this type of amputation does not result in (functional) prosthetic fittings.
- below the elbow are called transradial and are frequently fitted with prosthetic systems.
- at the elbow are called elbow disarticulation.
- above the elbow are called transhumeral amputations and result in relatively complex prosthetic fittings.
- at the shoulder joint are called shoulder disarticulation and result in very complex fittings, if at all possible.

- **Amputations of the lower extremity**

- toes: most often this type of amputation does not result in (functional) prosthetic fittings.

- below the knee are called transtibial and are frequently fitted with prosthetic systems. These fittings often lead to relatively good outcomes.
- at the knee are called knee disarticulation.
- above the knee amputations are called transfemoral amputations and often lead to prosthetic fittings. Compared to the upper extremity the outcomes are much better. This is caused by the much simpler nature of movement of the lower extremity when compared to the upper extremity. Moreover these amputees would most likely be wheelchair-bound if no fitting can be achieved.
- at the hip joint are called hip disarticulation and result in very complex fittings, if at all possible.

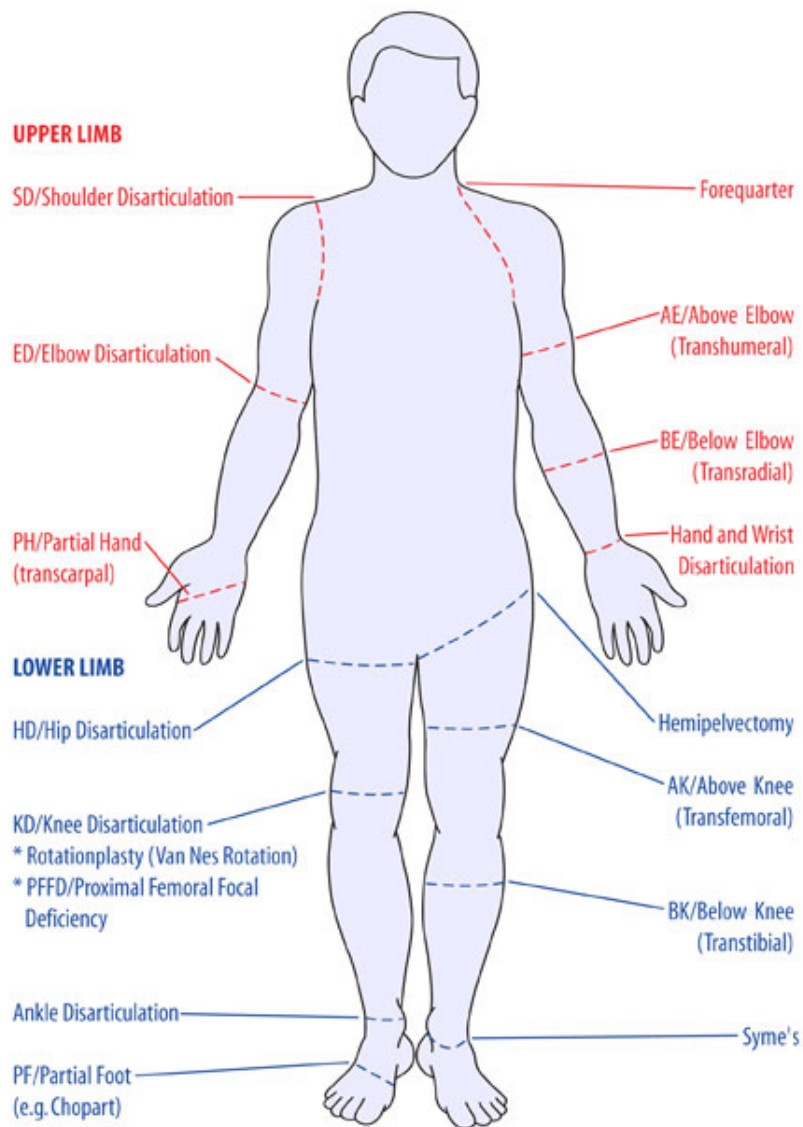


Figure 2.1: Amputation levels, accessed online at “<https://www.physio-pedia.com/Amputations>” on the 11th of September 2020.

In general the site of the amputation is often referred to as the amputation level, whereas the term *low amputation level* refers to below knee and below elbow amputations, and *high amputation levels* coincide with above elbow and above knee amputations for the upper and lower extremity respectively. It can moreover be noted that the incidence decreases with higher amputation levels in both upper and lower extremity. Finally it should be noted that the technical complexity increases with the level of amputation, meaning that high amputation levels are technically and functionally more challenging to fit than low amputation levels.

Due to the nature of online fora no information on the extremity and the amputation level of the author will generally be available. This thesis attempts to identify new and yet unknown user needs. Posts may also stem from people with different amputation levels and extremities affected. They may use the same terms and thus results may be unspecific. Should the extremity and amputation level become of relevance for the understanding of the data a detailed analysis of the underlying posts will be required. Therefore no attempt will be made in the early analysis to differentiate with respect to the amputation level or extremity in the data available.

2.2 Data flow

Throughout the work the following steps are followed (details are provided in the following sections):

- **Identification of data sources:** In this step suitable data-

sources are first identified and then checked for validity.

- **Data extraction:** The data-sources identified are reviewed with respect to content and structure and suitable methods to extract raw data are identified. Finally raw data are extracted for further analysis.
- **Data evaluation:** In the next step data are prepared for further evaluation and analysis in webLyzard. Data may be provided from the data-extraction step or may be read into webLyzard directly where suitable.
- **Data analysis:** The pre-processed data-sets are analysed by means of webLyzard with respect to finding new user needs, user requirements or yet unknown usability-issues, as identified in the hypotheses.

The Methods listed above will be described in more detail below. Following these steps results and a conclusive discussion will be presented in later chapters.

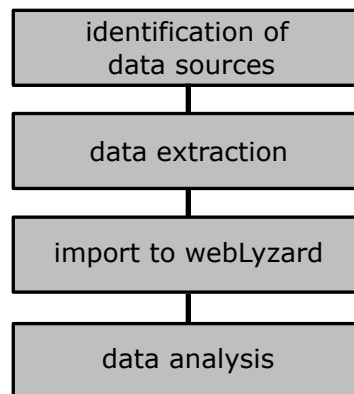


Figure 2.2: Graphical representation of the data-flow applied in this thesis.

2.3 Identification of online data sources

Given the fact that the number of users is limited worldwide and assuming that not all of these will also actively participate in respective online user groups it is paramount to identify as many sources as possible for the following analysis.

In a first step three different online search engines (Bing, Yahoo and Google) were used to identify meaningful online user fora. Using the terms *user-forum amputee(s)*, *user forum amputee(s)* and *online forum amputees(s)* yielded very similar results in all three search engines. The highest ranked results will be compared and manually checked.

In a second step Facebook and Reddit were searched for groups containing the terms *amputee* or *prosthetic*. Public groups were joined in order to identify suitable sources and groups with an active user base. Private groups were if possible accessed via a request for membership. If granted groups were again reviewed for activity and content. Denied requests were not followed up, as this thesis concentrates on freely available resources.

In a further step the author personally contacted product managers in the company, both in the area of upper and lower extremity, in order to find online data sources that are utilized regularly by them. Moreover the author also contacted certified prosthetists working for the company with the same request. Finally the social media team was also contacted to identify the data-sources used for their analysis. This was performed to identify further sources that might not have been found via the previous avenues.

Following identification of sources, unusable results will be removed

and discarded. Reasons to remove sources are:

- **invalid link** found in search engines. Links may no longer be valid or may not direct to a user forum at all.
- **kind of forum or online resource** link provided does not identify a user-forum, but rather links to (offline) community-based user-groups
- **lack of activity** Groups or fora that did not show regular activity were not included.
- **lack of focus** Groups that did not concentrate on Prosthesis were omitted. Several online sources were found that were related to prosthesis but dealt with other aspects that are not relevant for this thesis, e.g. search for a relationship.
- **limited or no user interaction** This was the case when fora or sources were mainly used as information channel from one party to numerous other parties.
- **access not possible** especially in Facebook a number of groups are peer-to-peer groups only. These groups did not grant access to their community upon request.

2.4 Data sources identified

Various online sources were identified for this thesis. In all areas that were investigated search results were returned. The search moreover also returned results that were omitted. The reasons to omit sources have been defined previously.

2.4.1 Search results of online search

It is interesting to note that the online search for online fora or user fora was less productive than anticipated. All three search engines delivered results, mainly of comparable quality but differing in quantity. While Yahoo did not specify the number of pages found there were 345,000 and 4,110,000 results for Bing and Google respectively. Subsequent analysis showed that only a very small number of search-results were meaningful for the purpose of this thesis. It could also be noted that the “quality of the ranking” was comparable between the search engines for the term *online forum amputee*. Interestingly the term *user forum amputee* yielded worse results, especially on Bing. Results referring to Facebook-pages or groups were under-represented in the online search engines, or at least not highly ranked. Overall it should be noted that there seems to be no global online-forum that emerged from this search. It may also be noted that there seems to be no obvious (more) localized structure either. Finally it is also worth noting that amputees do not seem to be organized in online fora in a larger context.

The relevant search on Facebook resulted in a number of Facebook groups or discussion groups. On Reddit the names of results already indicated that a number of entries were not relevant. Groups such as “Amputeedevotees” or “amputeedating” were not considered. On Facebook the terms “amputee” or “prosthesis” did not yield a relevant global group. The term “Prosthetics” yielded only one result. Interestingly the term “Prothesen” was more productive. So it appears that the most relevant Facebook groups were German based. Again - as noted before - it is interesting to observe that no global community seems to exist. Further Facebook groups were also highlighted by col-

leagues via personal contact. Most Facebook groups are closed groups and require registration into the group. This was not always granted since several groups are peer-to-peer groups only.

Table 2.1 gives an overview over the online sources that are of relevance for the following sections on data extraction and analysis. As shown in the table, most online fora contained a landing page linking to a number of sub-fora. Several of these sub-fora were not considered for this thesis for a lack of focus or limited relevance for the research questions posed. The Heather-Mills Forum contains sub-fora for topics such as *Travelling with Special Needs*, *Amputee Happenings* and *Amputee News Stories* to name but a few. The Amputee Discussion and Support Forum contains similar sub-fora such as *Share your Story*, *Found in the News* and *Sexuality and Relationships*.

type	name	URL	data	# members	# posts
RE	Reddit - Amputee	www.reddit.com/r/amputee/	OK	3,707	unknown
RE	Reddit - Prosthetics	www.reddit.com/r/Prosthetics/	OK	3,310	unknown
OF	The Amputee Discussion & Support Forum	amputees.proboards.com/		unknown	4,500+
SF	Prosthetics	LINK/board/12/prosthetics	OK	unknown	1,147
OF	Heather Mills - Amputee Forum	forum.heathermills.org		unknown	70,000+
SF	General Forum	LINK/forum/7-general-forum/	OK	unknown	30,000+
SF	Prosthetics and Related	LINK/forum/4-prosthetics-and-related/	OK	unknown	10,000+
SF	Tips and Tricks	LINK/forum/17-tips-and-tricks/	OK	unknown	4,000+
FB	Welt der Prothesenträger	/groups/27829667102	OK	unknown	unknown
FB	Prothesenwelt	/groups/117543168593424	OK	unknown	unknown

Table 2.1: Online Sources identified for further analysis. The following abbreviations are used in the table: RE .. Reddit-forum, FB .. Facebook group (URL stated must be preceded by www.facebook.com), OF .. online forum, SF .. relevant sub-forum, LINK .. refers to the URL of the related online forum. Data valid 20th June 2020.

2.4.2 Data extraction

Following manual inspection of the site structure and the information available for each data source a method to extract raw-data was developed. Depending on the structure of the web page different approaches had to be developed. Defining the extraction method requires knowledge of the data-sources identified. Therefore the names of the online-sources are given below. More detailed results for each online-source and the sources in general can be found in chapter Results (chapter 3 on page 44). The steps applied for the extraction of data-fields for each data-source are defined below.

2.4.2.1 Facebook groups

Several private and public Facebook groups were identified. Extracting data from Facebook had to be performed manually since possible web-crawling tools failed to identify posts and comments reliably. The following data-field were extracted:

- user name of post originator
- date of post
- original post
- relevant comments

Irrelevant threads were ignored. Threads were typically ignored consisted of a welcome message upon joining the forum followed by polite welcome replies from other group members. Also posts that merely

showcased information that was found on the internet with the typical replies were not extracted. Instead, posts that resulted in a discussion and/or tried to start a discussion mentioning or asking a specific question in the original post were included. Data were stored in an Excel file so that export to a csv (comma separated values)-file could be conducted at any time .

2.4.2.2 Reddit fora

Data in Reddit fora are provided as a list with a headline, or the title of the post, together with (parts of) the original post. Moreover the number of replies is also directly displayed. Extracting complete and meaningful data from this main page proved unreliable. In a first step “Instant Data Scraper”¹ a Chrome Extension was therefore used to scrape this information from Reddit. Instant Data Scraper automatically performs the required scrolling to advance the forum and retrieve further entries. Data extraction at this stage was manually stopped once data from more than twelve months were collected. Typically further fields were identified automatically at this stage. Data was stored in an Excel-file as well as into a csv-file for further use. From the files stored the URL-links (URL: Uniform Resource Locator) for each post identified were extracted for further processing. The list of URLs was then provided to Octoparse². Octoparse can apply the same operation to a number of URLs. These URLs can be provided when creating a new job. Using the “Advanced Mode” of Octoparse a suitable task was defined that extracted the username of the Originator, the original

¹offered by webrobots.io - <https://webrobots.io/instantdata>

²<https://www.octoparse.com/>

post and comments to the original post. Identification of posts and comments had to be performed manually when defining the task. The number of replies was therefore limited to no more than ten replies for each post. Since most threads had less than ten replies this was seen as an acceptable omission of data. Data extracted from this setup was again stored as an Excel-file and csv-file. If threads from some URLs could not be automatically extracted during the process they were not followed up. Reasons for not extracting data from some posts were not investigated. The number of lost posts was relatively small compared to the overall number of posts.

2.4.2.3 Heather Mills Amputee Fora

Similar to Reddit fora also data in the Heather Mills fora was extracted following a two step process. In contrast to the Reddit fora the first step was also performed in Octoparse. Since automatic detection (as well as manual identification) of the “NEXT” button failed it was not possible to step through the index pages of the forum automatically. This shortcoming could be circumvented by supplying the single URLs of all relevant index pages to Octoparse. In the first step a file was created that again contained one URL pointing to one individual thread of the forum. Again, just as for Reddit then a second job was defined in Octoparse that extracted the post together with the originator and up to ten comments. Number of entries searched in the first step was limited to no more than 500 posts. Again automatic extraction of posts resulted in some posts not being identified correctly. Since 500 posts in general spanned a time frame of several years and the loss of posts was not very high, these lost posts were not recovered manually. Reasons

for not extracting some posts were not investigated, but may be related to the structure of single threads. Some threads contained videos and images and no original post, which may have resulted in these posts not being retrieved correctly.

2.4.2.4 Amputee Discussion & Support Forum

Data from the Amputee Discussion and Support Forum were treated comparable to the Heather Mills user fora. Again data was extracted in two steps, both performed in Octoparse, as described above. Again data were saved into Excel files for later analysis.

2.5 Data evaluation

Evaluation and further analysis of data can be summarized under the term “social media intelligence”. In 2012 [Omand et al., 2012] discussed the impact and possibilities of Social Media Intelligence in the context of crime, safety, security and privacy, yet it is obvious that the general discussion also applies to other fields of data and their use. Social media intelligence in general refers to the systematic analysis of social data, such as those posted on Facebook, with the aim to deduct meaningful trends and stories from these data-sets.

Numerous software tools have been developed in recent years that concentrate on online data-sources. Online data are generally easily and quickly accessible, yet - as mentioned earlier - are usually unstructured and non-uniform in language and style. These tools have often developed their own algorithms to address these challenges. The use of

artificial intelligence is regularly advertised in connection with these software packages. Detailed comparison and description of the available software packages is beyond the scope of this thesis. Nevertheless it should also be mentioned that social media intelligence is often conducted with the aim to bolster a companies' social media appearance or improve sales number through optimized social media appearance. It has been mentioned earlier that text-mining seems not to have been used to extract user-needs from online sources. Again - to the best knowledge of the author - this statement may be expanded into the domain of social media intelligence, which tools are also not regularly used in this context.

The online platform webLyzard³ was chosen for data evaluation and analysis in this thesis. This was based on the opportunity to gain full access to webLyzard through the Department of New Media Technology at the Modul University. webLyzard offers a comprehensive toolset to access, collect, analyse and visualize online data in one application. It has been used by a number of international organizations such as the United Nations in the past, e.g.: United Nations Environment Programme (UNEP). But also governmental institutions such as the National Oceanic and Atmospheric Administration (NOAA) have used webLyzard. webLyzard offers tools such as Story Detection and Visualisation, Geographic Maps, Word Trees, Relations Tracker and Trend Charts amongst others.

In the context of the present work webLyzard was used to import the previously extracted posts into the webLyzard database. For this posts were converted into json files that were subsequently imported. Data

³<https://www.weblyzard.com/>

was anonymized as no username was imported, moreover time and date were neither imported. All available posts were imported into webLyzard.

2.6 Data analysis

Keywords that are related to the research questions were used to search the complete data-set. Moreover more generalized terms were used to characterize and cross-check the validity of the available data. The results obtained will then be used to accept or reject the hypotheses stated.

Search terms related to the research questions are given below (a complete list of terms is given in the results section of this thesis starting on page 44):

- **Pain:** stump AND pain, painful, phantom AND pain, pain, hurting, socket AND pain
- **Socket & Comfort:** Discomfort/uncomfortable, sweat, skin, fitting, adjust, Comfort/comfortable, adjustable and so on
- **Activities of daily living (ADL) :** falling/fall, sitting, showering, walking, biking, running, ramps, driving and so on
- **Usability:** doffing, take off (all words), putting on (all words), put on (all words), taking off (all words), complicated, simple, donning
- **Performance:** noise/loud, weight, missing, size, battery, height, design, waterproof and so on

- **General topics:** brands, different devices, information on amputated extremities, level of amputation and so on

Analysis was performed by means of the webLyzard graphical user interface (GUI), as shown in figure 2.3. Search items were entered in the search field and data for sentiment were then read from the *Metadata* area.

For each search term the number of posts with positive, neutral and negative sentiment were recorded and the percentage of each was calculated. Outliers in terms of unexpected results were singled out for further evaluation and analysis. In such a case a more detailed analysis of the associations and the key-words was performed. Moreover, in such cases also single posts were read in more detail.

Results were also listed as *Sentences* in the *Word List* view in the webLyzard interface. An appropriate level of detail was chosen depending on the number of results returned. For easier identification of context the list was coloured according to sentiment. The *Sentences*-view was used to cross-read through the underlying posts in order to obtain deeper insight and identify further topics that might be of interest.

The *keyword-graph* was used to identify the most relevant associations related to the specific search term with positive and negative sentiment. In some circumstances also other associations were selected from the *associations* in order to gain quick insight into related topics of relevance.

Results obtained in the context of *General Topics* were used to cross-check the data basis available. Search terms such as *leg* and *arm* were compared. In commercial practice there is approximately a 10:1 relationship between leg and arm amputees. It may thus be expected that a similar relationship may also be found in the number of posts for these terms. Similarly the popularity of single brands or single devices can be assessed as well. Since the database is largely uncontrolled these checks can only serve as a very rough estimate, but one would expect that the relatively large number of posts available would allow such an assessment (see the results section for the number of posts analysed).

2.7 Data validation/verification

During the manual extraction of the Facebook user groups a number of posts were identified that either announced a study of a master student, or called for participation in a clinical trial. Interestingly these posts in general received little to no attention and had few comments. In the context of this thesis it would thus appear to generate limited value to attempt to verify the findings made here within the online user groups again.

In this thesis it was therefore chosen to discuss the findings made with experts in the field. These experts are available within the author's organisation, which is the world leading manufacturer of prosthetic devices. As stated in the hypothesis the aim was to identify (a) "unmet user needs" and (b) "unknown performance issues". It seems obvious that these two aspects are of real interest for the organisation and therefore knowledge concerning these two questions will already

be available. Within the company there are a number of employees that have frequent access and contact to end-users. The first group are the certified prosthetists and orthotists (CPO). They are employed in the department of *Orthopedic Technology* and routinely fit devices to end-users. Devices in this context are either prototypes for evaluation in clinical studies or commercially available devices also in studies or during trainings for external sales partners. The second group are product managers. Product managers are “the voice of the customer” within any company and define the market or user needs at the start of product development. This is also their task within Ottobock. Their knowledge make them good interview partners in the context of this thesis. Third, there are also a number of experienced development engineers that have frequently contact to amputees and evaluate the current prototypes with them.

The findings made during data analysis will be discussed with at least five colleagues that are part of these group. Respective interview partners will be chosen so that they fit the results obtained. E.g.: Topics that relate to lower extremity will be discussed with product managers or development engineers working in this area. Moreover, CPOs that have experience in the relevant field will be interviewed.

Interview partners will first be asked to rank their top five topics from the list of search-terms in relation to the following aspects: (a) most important for the amputee, (b) most positive associated topic and (c) most negatively associated topic. Afterwards their assessment is discussed against the findings from the online-data. Before being asked to rank the data, interview-partners will be briefed about the background of the data and the investigation that has been performed. At

this stage no results will be provided. Search terms will be provided in alphabetical order (which will be specified to the interview partners in a short explanation) in order to prevent any bias.

“People think focus means saying yes to the thing you’ve got to focus on. But that’s not what it means at all. It means saying no to the hundred other good ideas.”

Steve Jobs (1955 – 2011)

Chapter 3

Results

3.1 Data extraction

As stated in the Materials and Methods (section 2.4.2 on page 33) data had to be collected semi-automatized for each of the data-sources. Table 2.1 already showed that some of the user-fora are well frequented and will thus contain sufficient data for subsequent analysis.

Table 3.1 gives an overview over the number of threads as well as the number of single posts that were extracted from all online sources. Each thread can consist of an initial post and comments, whereas the number of comments was limited by the extraction method. A total of more than 15,000 user posts were extracted in this first step. This pool of data-entries will be made available for further analysis in the next step.

type	name	# of URLs	# of threads	# total entries (post + comments)
RE	Reddit - Amputee	994	904	4,308
RE	Reddit - Prosthetics	429	365	1,244
OF	The Amputee Discussion & Support Forum			
SF	Prosthetics	157	157	879
OF	Heather Mills - Amputee Forum			
SF	General Forum	500	500	2,726
SF	Prosthetics and Related	500	500	3,453
SF	Tips and Tricks	285	279	2,238
FB	Welt der Prothesenträger	n/a	102	164
FB	Prothesenwelt	n/a	24	69

Table 3.1: Number of entries extracted from each online source. The following abbreviations are used in the table: RE .. Reddit-forum, FB .. Facebook group, OF .. online forum, SF .. relevant sub-forum, n/a .. not applicable, Data valid 20th June 2020.

3.1.1 Facebook groups

On Facebook a total of six groups relevant for this thesis were initially identified and subscribed to successfully. Further observation of these groups showed that the content of two groups is of real interest. Two more groups are strongly centrally organized and are more information channels than discussion channels. The *Bundesverband für Menschen mit Beinamputation* and the *Informationsplattform für Prothesenträger* are these two groups. One has limited activity and the activity posted is more focussed on providing information than enticing discussions. The final groups showed often posts that already also appeared in other groups. Here it was observed that users posted the same content in numerous groups in an attempt to widen their reach. These groups were not analysed further. The groups of interest are the “Welt der Prothesenträger” and the “Prothesenwelt”. In a manual process a total of 102 threads were identified for “Welt der Prothesenträger” and 24 threads for “Prothesenwelt”.

3.1.2 Online fora

As stated in the Material and Methods several different landing pages were identified. These are either based on proprietary platforms or on the Reddit platform.

3.1.2.1 Reddit fora

Reddit is a platform, housing - by their own statement - “every day, millions of people around the world...” with a monthly activity of

on average 430M+ users and 130k+ active communities.¹. On Reddit two user groups or communities relevant for this work were identified. These are called “Amputee” and “Prosthetics” and both have more than 3,000 users each. Both also show regular activity and an active discussion within the communities was observed. The total number of posts is not available.

Extraction of data followed the two-stage process described earlier. For the two communities the following results were obtained. For “Amputee” a total of 994 URLs covering approximately one year were identified and fed into the Octoparse task. Octoparse extracted 904 threads successfully. The initial data extraction does not differentiate between original posts that contain just an image or such that consist of text. As a result in some threads the initial post remains empty, but may contain comments. These threads have not been manually removed or modified in any way. For “Prosthetics” 429 URLs spanning a time-frame of more than one year have been identified. This resulted in 365 threads that were extracted via Octoparse.

3.1.2.2 Heather Mills Forum

From the Heather Mills Forum landing page three sub fora were considered for further analysis. These are the fora named “General Forum”, “Tips and Tricks” and “Prosthetics and Related”. As stated in the Materials and Methods extraction of ULRs was limited to a maximum of 500 threads per forum, due to its manual definition. In total 500 URLs were extracted for “General Forum” and “Prosthetics and Related”, while 285 URLs were extracted for “Tips and Tricks”. The

¹<https://www.redditinc.com>

time span covered by these threads are twelve years for the “General Forum”, fourteen years for “Prosthetics and Related” and seventeen years for “Tips and Tricks”. For the first two all 500 threads could be extracted via Octoparse. For the “Tips and Tricks” 279 threads could be extracted.

3.1.2.3 Amputee Discussion & Support Forum

As in the previous section several sub-fora were identified on the “Amputee Discussion Forum”, out of which the forum “Prosthetics” was extracted. A total of 157 threads, spanning a time-frame of eleven years were extracted from this forum.

3.2 Analysis of data

As described in the Materials and Methods (section 2.6 on page 38) of this thesis all posts available were imported into the webLyzard platform. Following this step a total of 15,787 entries were available for further analysis. Of these 15,787 posts 295 were in German and 15,492 posts were in English. Analysis was performed along search terms as described earlier. For common topics not only one, but multiple search terms and expressions were used. E.g.: for the activity of walking the terms *walk* and *walking* were used. Similarly for the generation of noise the terms *noise*, *noisy* and *loud* were used.

In the following sections results along the dimensions stated earlier will be presented:

- Pain
- Socket & Comfort
- Activities of daily living
- Usability
- Performance
- General topics

If multiple search terms were used these will be presented as single results, whereas a combined result will also be given. The combined result is the average of the single terms used. In such a case the combined term is also set in **bold characters** for easier identification. Ranking according to number of posts was performed on the averaged results.

3.2.1 Pain

Pain is a major limiting factor for amputees in their daily life, often limiting their ability to perform specific activities. In severe cases pain may even prohibit the use of prosthetic devices at all, or at least on certain days when pain is more pronounced. Pain can occur even without a prosthetic device and is then often referred to as *stump-pain*. Also the term *phantom-pain* is often read. This refers to the impression of an amputee that the amputated limb is still present and causing pain. In this case the so called *phantom-limb* is causing pain. As can be seen in table 3.2 the term *pain* itself is most often used in posts, followed by the combination of *phantom-pain* and *limb-pain*. Also *socket-pain*

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
pain	1,215	306	131	778	25	11	64
phantom AND pain	339	80	35	224	24	10	66
stump AND pain	268	57	21	190	21	8	71
painful	251	61	21	169	24	8	67
socket AND pain	213	66	20	127	31	9	60
hurting	58	14	8	36	24	14	62

Table 3.2: Results for aspects of pain related to prosthetic devices.

scores highly. Not surprisingly these terms are predominantly negatively connoted in the posts. Of these *stump-pain* has the most negative sentiment at 71%.

3.2.2 Socket and Comfort

Since socket and pain have been identified as important factors earlier, the area of socket and comfort are also of interest. Sockets have in practice not changed much in the last decades. Despite the fact that modern materials have changed the manufacturing and the processes involved and have made sockets lighter in weight and mechanically more robust they are still produced by hand. Their quality is thus largely influenced by the craftsmanship of the certified prosthetist involved. The socket though is the interface between prosthesis and amputee. As such it crucially impacts the comfort that can be achieved. A poorly fitting socket may negatively impact the impression of the whole prosthetic system, regardless of the quality of single components used in this fitting.

Common topics that are associated with sockets are *the fit of a socket*, *comfort*, *skin* and *sweat* to name but a few. The results for frequent related terms are given in table 3.3 on page 51.

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
socket	1,698	893	517	288	53	30	17
fit	732	419	92	221	57	13	30
skin	675	275	93	307	41	14	45
comfortable	448	313	40	95	70	9	21
fitting	355	183	46	126	52	13	35
adjust	160	85	29	46	53	18	29
sweat	155	56	27	72	36	17	46
comfort	153	111	7	35	73	5	23
uncomfortable	145	53	22	70	37	15	48
sweating	118	40	29	49	34	25	42
discomfort	95	18	8	69	19	8	73
adjustable	90	72	8	10	80	9	11
foot AND adjustable	47	38	3	6	81	6	13
socket AND adjustable	31	23	2	6	74	6	19

Table 3.3: Results for aspects related to the socket and comfort of prosthetic devices.

It can be seen that *socket* is a commonly occurring term in online discussions, followed by *fit* and *skin*. Somewhat surprisingly, especially given the fact that the socket may have a significant impact on the comfort of the amputee the sentiment for *comfort* is quite positive at 53% of the posts. It comes at no surprise that *discomfort* and *uncomfortable* have a higher percentage of posts with negative sentiment at 73% and 48% respectively. This is related to the fact that the two terms are in itself negative. More telling in this respect are therefore the results for *sweat* and *skin* with 46% and 45% of negatively stated posts. Despite the fact that these topics are well known they are also reflected in the online fora. As such our current knowledge about issues related to socket and comfort are confirmed. The high relevance of *sweat* and *skin* should be further considered in future product development projects. Figure 3.1 shows the deviation to the average percentage for positive

and negative sentiment for topics with the biggest difference. It may be concluded from the data that *skin* and *sweat* are unresolved issues.

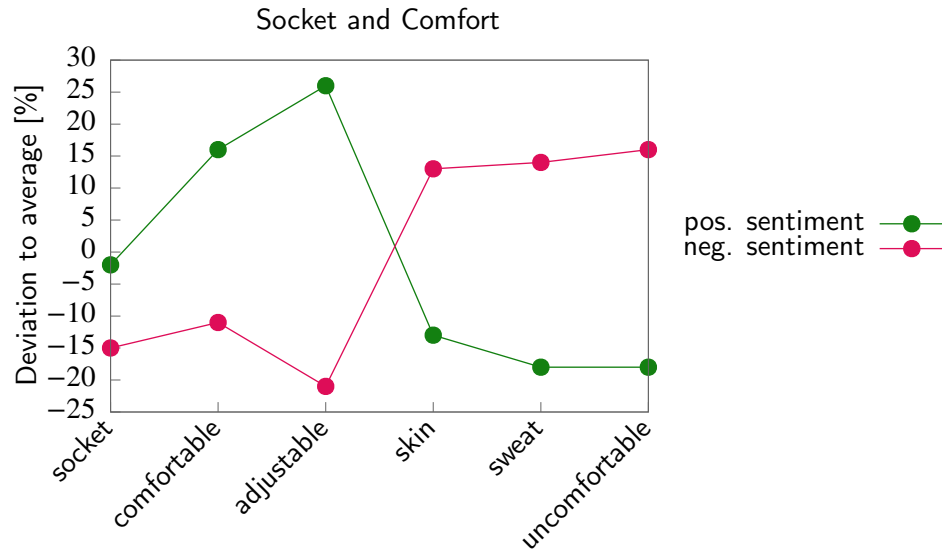


Figure 3.1: Figure showing the difference in percentage value for selected topics related to comfort.

3.2.3 Activities of Daily Living

It may come as no surprise that there is a relation between comfort of a device during use and the activities of daily living (ADL) that are performed with it. In table 3.4 (page 55) results are specified for different ADLs that are commonly performed. As mentioned earlier results given in the table show averaged as well as specific results for separate terms. It is noteworthy that the results probably need to be viewed in light of the limited functionality of prosthetic devices. For example running is only possible with a limited number of prosthetic knee prostheses at all. It is therefore interesting to note that *running* scores highly. This may be related to the fact that also below knee am-

putees post about running and this may skew the result. As discussed later common terms with a number of meanings need to be treated with caution.

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
walk	946	471.5	136.5	338	50	14	36
walk	955	475	134	346	50	14	36
walking	937	468	139	330	50	15	35
run	345	206	46	93	60	13	27
run	370	217	50	103	59	14	28
running	320	195	42	83	61	13	26
balance	245	147	24	74	60	10	30
drive	242.5	149.5	31.25	61.75	65	12	23
drive	252	157	37	58	62	15	23
driving	219	139	29	51	63	13	23
driving AND car	75	57	7	11	76	9	15
driving car	424	245	52	127	58	12	30
sit	230	117	22	91	51	10	40
sit	234	123	23	88	53	10	38
sitting	226	111	21	94	49	9	42
activity	194	127	32	35	65	16	18
standing	186	107	24	55	58	13	30
fall	171.5	64.5	17	90	38	9	53
fall	235	88	27	120	37	11	51
falling	108	41	7	60	38	6	56
stairs	147	94	20	33	64	14	22

Continued on next page

Table 3.4 – *Continued from previous page*

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
sports	140	93	18	29	66	13	21
bike	125.5	72.5	15	38	60	8	32
bike	204	115	29	60	56	14	29
biking	47	30	1	16	64	2	34
riding	114	69	15	30	61	13	26
shower	112.5	64.5	19	29	54	15	31
shower	189	111	34	44	59	18	23
showering	36	18	4	14	50	11	39
skiing	84	53	11	20	63	13	24
hike	48	30	5.5	12.5	64	11	25
hike	31	21	3	7	68	10	23
hiking	65	39	8	18	60	12	28
ramps	44	26	7	11	59	16	25
stance	39	26	6	7	67	15	18
dance	35	22	6.5	6.5	63	19	19
dance	33	21	6	6	64	18	18
dancing	37	23	7	7	62	19	19
skating	29	19	7	3	66	24	10
outdoor	25	21	2	2	84	8	8
jogging	20	12	3	5	60	15	25

Continued on next page

Table 3.4 – *Continued from previous page*

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
<hr/>							

Table 3.4: Results for activities of daily living. Averaged results are specified in **bold** characters. Numbers for these are averaged from the terms and results given below in the table and limited by the next horizontal line.

Walking scores highest with respect to *number of posts [count]*, followed by *run*, *balance* and *drive*. This may reflect the amputees' need and desire to move around independently. It is interesting to note that *sitting* is the next most frequently discussed topic. This may indicate that sitting is a common topic and may even be an unresolved topic. It also indicates - yet again - that amputees do think about their prosthesis as a system that needs to perform overall. They are not differentiating the performance of their knee (which may work great during walking) from the performance of their socket (which may do great during walking but may be very uncomfortable during sitting). As the manufacturer of prosthetic devices, but not necessarily of complete systems, this is an important aspect, that perhaps should be given more consideration.

Figure 3.2 (on page 57) shows a graphical representation of the *number of posts [posts]*, *positive sentiment* and *negative sentiment*, ranked by importance. Importance is defined as a ranking from the most quoted term to the least quoted term and as descending ordered list of the percentage values for sentiment (positive and negative). For reasons of clarity only the top thirteen topics are shown.

It is also very interesting to note that the most often discussed topics do not necessarily also have the most positive sentiment. In the contrary *walk* has 50% positive and 36% negative posts. *Sitting* has 51% positive and even 40% negative posts. The percentage of positive posts for these two is much lower than for the majority of topics that are in the range of 60% and more. At the same time their percentage of negative posts is relatively high too, again on average higher than that of other topics. It may thus be concluded that these two topics are obviously important (number of posts is high) but are not satisfactorily addressed by the prosthetic devices on offer. *Fall* is even more negative, but this is of course related to the topic itself and does therefore not stand out from other results.

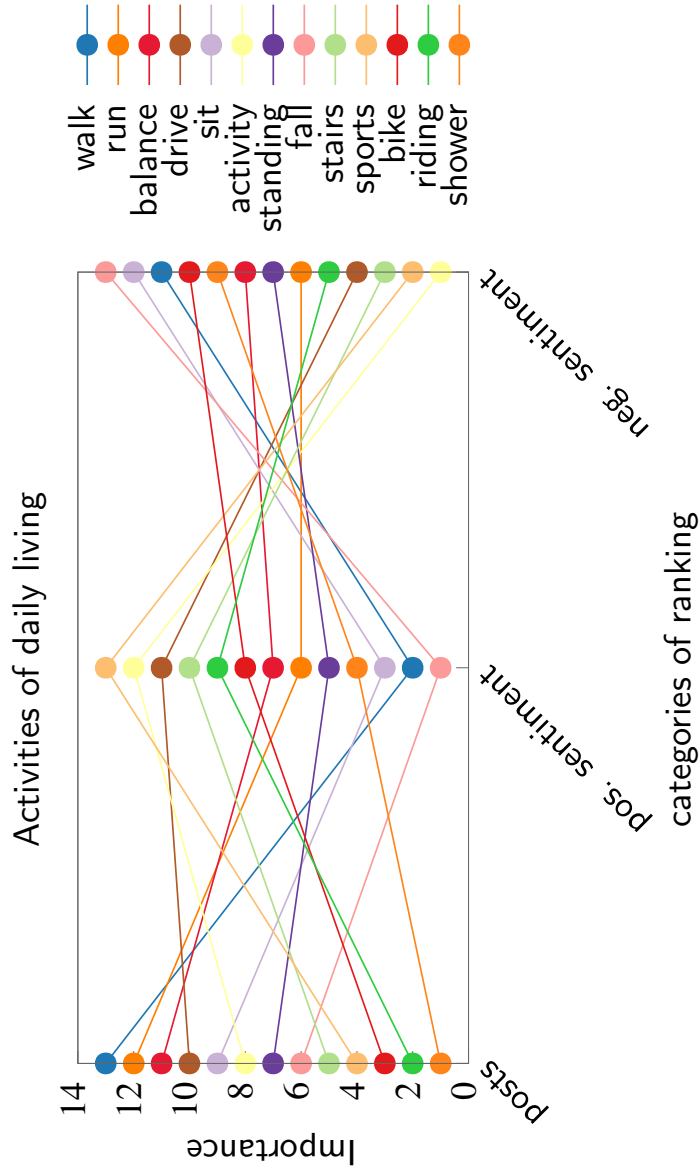


Figure 3.2: Figure showing the results related to activities of daily living for *number of posts [posts]*, *positive sentiment* and *negative sentiment* ranked by importance. The most often mentioned term has the highest importance. For positive and negative sentiment the items with the highest percentage are ranked highest.

In contrast to this *run* is mentioned frequently (averaged result of 345 posts) and receives a high percentage of positive posts at 60%. Given the fact that running is not commonly supported by high-end prosthetic devices this is somewhat surprising. A more detailed analysis has shown that *run* has a lot of different meanings that are leading to this result. Phrases such as *run over by* or *clinic run by* influenced the result. This is less pronounced for the term *running*. But it is also important to note that amputees with different amputation levels and even amputation of different extremities are posting. So posts relating to tying a shoe (in order to go for a run) following amputation of an arm (or even just a finger) would as well be counted as the post of an above-knee amputee asking to run again. The high percentage of positive posts may also be related to the fact that people seem to be more likely to post positive experiences rather than a poor experience.

There are also other results that are noteworthy. *Skiing* is mentioned surprisingly often and also has a high percentage of positive posts. This is somewhat surprising as skiing is not supported by default by any common prosthetic knee device on the market (without special programming). A more detailed analysis suggests that this is based upon a limited number of threads that consist of multiple posts. It must be noted that the fact that threads and posts are not distinguished in the current analysis may impact the results.

When compared to the average positive and negative sentiment it can clearly be seen that some of the most frequently mentioned topics have a below average of positive posts and an above average number of negative posts. Figure 3.3 shows this for the top ten results. More than half of the the top ten topics score below average, indicating that

these topics are of importance to the amputees, yet are not solved to their satisfaction.

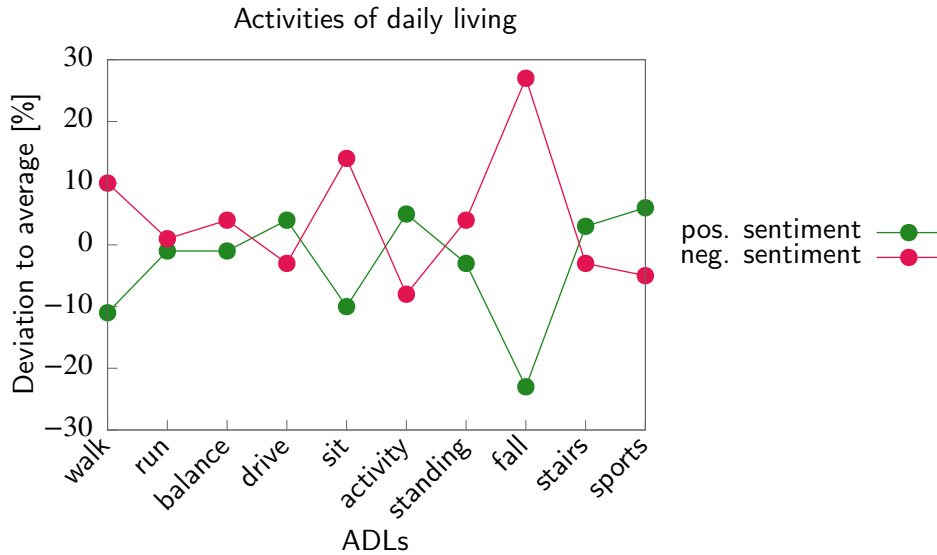


Figure 3.3: Figure showing the difference in percentage value for the top 10 activities of daily living (ADL), ranked by number of posts.

3.2.4 Usability

An important aspect of prosthetic devices is their usability. Usability is of such importance that aspects of usability are even referred to in a specific regulatory standard (IEC 62366-1:2015). Usability in the context of the current analysis is related to aspects of daily interaction with the prosthesis. Since most prostheses have limited interactive features in normal operation this is mainly related to the process of *donning and doffing*, which is the industry-specific term for putting the prosthesis on (in the morning) and taking the prosthesis off (in the evening). As the analysis shows, the two industry specific terms are not frequently used by the amputees themselves. They use the more

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
put on (all words)	899	434	124	341	48	14	38
take off (all words)	489	233	62	194	48	13	40
putting on (all words)	244	116	33	95	48	14	39
simple	173	103	20	50	60	12	29
taking off (all words)	124	64	17	43	52	14	35
donning	48	31	6	11	65	13	23
complicated	28	18	1	9	64	4	32
doffing	5	2	1	2	40	20	40

Table 3.5: Results for aspects of usability of prosthetic devices.

layman terms *take off* and *put on*. Results are displayed in table 3.5.

Not surprisingly these aspects are relatively common topics. They also do record limited positive posts and a higher percentage of negative posts - when compared to most ADLs (see above). Considering the fact that putting on a prosthetic leg prosthesis often involves several steps and may take several minutes this is not surprising. In the worst case the whole procedure even has to be repeated several times if the position of the prosthesis is not perfect. The results highlight the fact that the process of putting a device on and taking it off after use is still not optimally solved. Given the fact that comfort of a socket and its fit (see earlier results) are also often discussed this may indicate another area that perhaps should receive more attention during product development.

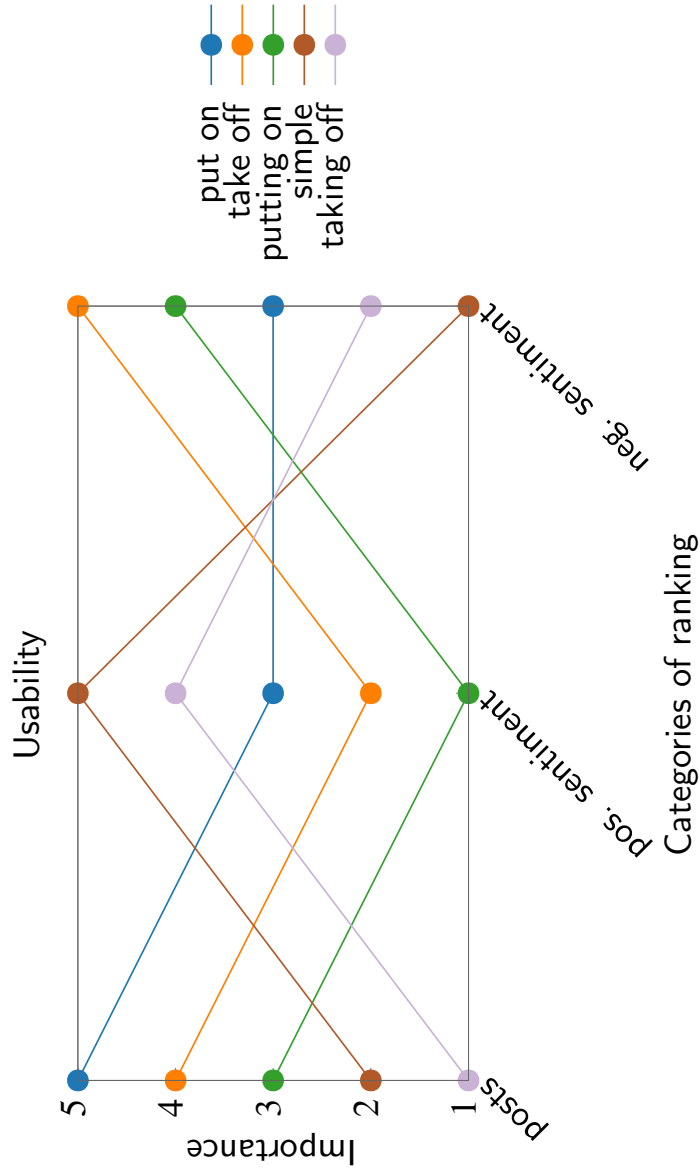


Figure 3.4: Figure showing the results related to usability for *number of posts [posts]*, *positive sentiment* and *negative sentiment* ranked by importance. The most often mentioned term has the highest importance. For positive and negative sentiment the items with the highest percentage are ranked highest.

Figure 3.4 shows again the ranking or importance of *posts*, *positive sentiment* and *negative sentiment* for the five most quoted topics. It can clearly be seen that taking off seems to be easier than putting on. It also shows that the term *simple* has a comparable high percentage of positive posts. This warranted closer inspection of the posts and it could be found that *simple* is commonly used in a lot of expressions that are not related to prosthetic systems at all. As such the results for *simple* need to be treated with caution.

3.2.5 Performance and Fitting

Finally *performance* investigates common aspects of prosthetic devices, such as battery-life or size and weight of a device. But it also covers aspects of the fitting process such as insurance and cost. It is obvious that the results will hardly be device specific. But it should be possible to determine general topics of interest in the community. Though, when interpreting and investigating the results in more detail the diverse nature of the data comes to light. The posts cover a wide variety of topics and the general nature of the search terms adds to this. While *weight* is the most often mentioned term it does generally not relate to the weight of the prosthesis, but often is mentioned in relation to the therapy process and the process of walking in the context of *putting weight on the stump*. Similarly *size* is often mentioned in the context of socket, liners or even just shoes. *Design* - at closer investigation - can often be related to students asking to *how to get involved into the design of prosthetic devices*, so again this does not seem to be a general discussion about design of prosthetic devices itself. *Service* in a lot of cases is related to the *health service* or having been a *servicemen*, only

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
weight	615	322	80	213	52	13	35
insurance	472	274	80	118	58	17	25
cost	309	200	49	60	65	16	19
size	247	129	33	85	52	13	34
design	213	143	32	38	67	15	18
missing	208	106	30	72	51	14	35
height	152	107	12	33	70	8	22
function	113	71	11	31	63	10	27
service	112	77	11	24	69	10	21
waterproof	61	33	19	9	54	31	15
noise	52	13	5	34	25	10	65
battery	38	15	10	13	39	26	34
loud	30	18	3	9	60	10	30
functionality	29	19	6	4	66	21	14
durability	25	20	1	4	80	4	16

Table 3.6: Results for different performance criteria of prosthetic devices.

in some posts the *Service of a prosthetic device* is discussed. This part of the results clearly demonstrates the limits of the data available and great care needs to be taken to not draw false conclusions from the data.

One interesting aspects seems to be *height* as quite a number of the posts relate to heel and foot. This is interesting since an adjustable heel height is required in order to wear different shoes with a prosthetic device. Ideally this adjustment can be done by the amputee directly, without the need to visit a prosthetist. Another result that stands out is the high ranking of *insurance* and *cost*, which indicates that amputees rely on their insurance to get a prosthesis.

Topic	count	sentiment [abs]			sentiment [%]		
		pos	neutral	neg	pos	neutral	neg
leg	4,369	2,221	730	1,418	51	17	32
knee	1,924	1,034	280	610	54	15	32
foot	1,796	1,036	269	491	58	15	27
hand	573	330	86	157	58	15	27
ak	459	242	108	109	53	24	24
bk	430	246	65	119	57	15	28
arm	429	245	62	122	57	14	28
bka	382	167	150	65	44	39	17
ankle	333	186	37	110	56	11	33
aka	248	114	46	88	46	19	35
hip	231	127	32	72	55	14	31
finger	201	78	49	74	39	24	37
shoulder	99	50	16	33	51	16	33

Table 3.7: Results for different amputation levels. Abbreviations are defined in table A.1, page 80.

3.2.6 General Topics - statistical data

Following the more technology and end-user related investigation of the data available it is of course of crucial interest to understand if the data is a valid representation of the population of amputees. In order to do so the data-set was investigated with search-terms that aim at identifying the distribution of posts along the different amputation levels. As described earlier there exist different amputation levels for each of the affected limbs (a short description is provided in section 2.1, page 23).

The results in table 3.7 show approximately a 7:1 relation between *leg* and *hand*. This is not dissimilar to the sales numbers of devices sold by Ottobock. It would thus appear legitimate to assume that the data-set represents the population of amputees. It would also appear that approximately the same percentage of amputees contribute online,

regardless of the extremity affected.

It is also of interest that there appears to be no difference in the perception of the amputees. The percentage of post with positive and negative sentiment is very similar for amputation of the lower or upper extremity. This is unexpected as it is well known that prosthetic devices for the upper extremity have a limited functionality in comparison to the healthy limb and are much more difficult to control than devices for the lower extremity. Moreover, re-fitting rates are much lower for prostheses of the upper limb than for the lower limb, thus suggesting that amputees are less satisfied with the performance of the device. Interestingly there is no evidence of such impressions in the data analysed.

Other aspects of the general investigation of the data-set show that only the two dominating brands, namely Ottobock and Ossur are frequently mentioned with 243 and 251 posts respectively. Other brands are mentioned a lot less often, with Freedom Innovations being mentioned only 36 times. It can also be seen that the relation to the personal prosthetist is important as this search-term results in 1,021 posts, of which actually 56% have a positive sentiment, suggesting that more than half of amputees is satisfied with the support they receive. The fact that the term *liner* results in 1,097 posts of which only 46% percent are positive shows that there is possibly room for improvement in this product category. In comparison, the C-leg (a product by Ottobock) has 61% of positive posts. Due to the diverse nature of the data and the differing number of posts available for different devices no overall analysis on a device level will be presented here.

3.3 Data validation/verification

As described earlier, it appears meaningful to reflect on the results obtained. In order to do so the results were discussed with colleagues who are in regular contact with amputees and thus have a good understanding of the needs and issues they face. The data obtained was discussed with colleagues as described earlier. In total, interviews with nine colleagues were conducted. Five of them were certified prosthetists, two were product managers and two were experienced development engineers.

During the discussion it was observed that a strong connection to the products under current development was present. Colleagues automatically assumed inherently a much more focused online discussion than was present in reality. Also important, issues of internal development, such as the reduction of noise of a prosthesis, were assumed to be related to any discussion concerning noise too. In fact, almost all posts mentioning *noise* relate to noise that is caused by movement of the stump in the socket and not to noise emitted by the prosthesis.

Also, internally there was strong focus on devices, while online this differentiation does not appear to happen. Amputees posting online describe their whole prosthetic system, rather than think about a socket, a knee joint and a foot. Finally there seems to be a stronger focus on achievements, rather than a discussion of possible *what-ifs* online.

The averaged ranking for ADLs of the expert group was similar to that of the online discussion, only *driving* was ranked considerably lower².

²Due to the smaller number of participants the same score was calculated for a number of topics. Detailed results are therefore not presented but are rather discussed in the text.

For usability related topics a relatively strong emphasis was given to terms such as *donning & doffing*, which in fact scored low in the online posts. It was thus recognized in the discussion that care should be taken when using industry specific terminology, as the terms may be unknown by the end-user - the amputee. Experts also ranked the topic of *putting on* a prosthesis highly. In the discussion the previously mentioned difference between the device itself and the prosthetic system was again recognized. In the area of Comfort and Socket only *skin* was ranked low from the expert group. In the area of performance the experts' focus was on traditional engineering related performance criteria, while the online discussion focus also ranked *insurance* highly. Due to the rather high prices only prostheses that are reimbursed by the health insurance of the amputee sell well. This fact is evidently also a concern for amputees and thus the company would be well advised to continue to work with the insurance partners in order to achieve reimbursement for as many products as possible. Pain was seen as being of high importance by all experts.

“Discussion and argument are essential parts of science; the greatest talent is the ability to strip a theory until the simple basic idea emerges with clarity.”

Albert Einstein (1879 – 1955)

Chapter 4

Discussion

4.1 Discussion

Given the nature of the data and the analysis, together with the feedback from the experts there are numerous topics and observations that are worthwhile to be discussed. The first question that arises is if the data can ethically be used at all. Users in fora did most likely not think that their data would be analysed systematically. Although no user in this thesis has been interviewed there is some evidence that people think that this indeed is possible. [Bond et al., 2013] interviewed 26 people posting online and they agreed that doing so put their opinion into the public domain and made it thus usable for research or other uses. Since the data is posted on online fora the *User Agreements* of these hosting platforms or services need to be considered too. Reddit and ProBoard have similar licence statements in that respect. Both grant an extensive (details to be found on the respective websites) licence

to the service-provider. ProBoard even mentions that “You (the user) have no expectation of privacy.”¹. Comparable regulations are in place on Facebook.

4.1.1 Data related - Research hypotheses

Some of the observations made need to be discussed in the context of the data itself. Three aspects of the posts have been used throughout this thesis. These were *number of posts*, *positive sentiment* and *negative sentiment*. The results for all search-terms for different aspects are given above in various tables. Results in the tables were ranked by number of posts, which made a comparison for other aspects rather difficult to get. For easier comparison of ranking of percentage of sentiment the most interesting results were also presented as figures.

The results obtained also need to be put into context of the research hypotheses and research questions that were stated earlier in this thesis. Results were obtained for the research questions with the aim to answer the hypothesis. For reasons of easier reading, first the research questions will be addressed with short answers, leading to the acceptance or rejection of the hypotheses stated.

- **Pain:** *Is pain or phantom pain really a dominating issue for amputees, regardless of their amputation level? Is pain related to the used prosthetic device? Does a consensus exist how pain can be alleviated?*

- Based on the data gathered it is obvious that *Pain* is a dominant issue for amputees. It scores highly in absolute number

¹<https://www.proboards.com/tos>

of posts for any topic (see table 3.2 for details). There is limited directed discussion on how pain can be treated and no common method to do so could be identified. There seems to be a relation of pain to the socket, but this is not more frequently mentioned than phantom-pain or stump-pain.

- **Socket & Comfort:** *Are sockets and their fit a common topic amongst amputees? Is comfort a topic that is regularly addressed amongst amputees?*

- *Socket* itself is the single most quoted term in posts. *Fit* and *skin* are also amongst the most often occurring terms. This shows that the socket and the related comfort are very highly sought after (see table 3.3 for details). This confirms the renewed interest into the development of commercially pre-fabricated sockets. Currently sockets are custom fitted by the prosthetist for each amputee. The quality of fit seems to leave room for improvement.

- **Activities of daily living:** *Which activities of daily living are most often mentioned amongst amputees? Is there a common activity of daily living that is not addressed by modern prosthetic devices?*

- As stated earlier there is a ranking of activities that most likely is related to the interest of amputees to move around freely. The relatively high ranking of *balance* and *sitting* is probably a bit surprising (see table 3.4 for details). There were no unexpected or new activities that could be identified from the posts.

- **Usability:** *Is usability of prosthetic devices (regardless of a specific product) mentioned amongst amputees?*
 - Usability investigations concentrated on putting-on and taking-off of the device. Both need improvements in order to satisfy amputees fully (see table 3.5 for details). A broader context of usability could not be observed in the posts.

- **Performance:** *Are there common performance issues that are discussed amongst amputees? Are specific topics such as battery lifetime, size or weight discussed amongst amputees?*
 - Some aspects seem to be regularly discussed, but these also involve topics that are not related to the prosthetic system at all (e.g. *Insurance*). As pointed out above in the specific section of the results, a number of terms are also discussed in a different context than just the prosthetic system, and therefore need to be analysed in detail and carefully. Table 3.6 gives details, yet please consider the accompanying discussion.

- **General topics:** *Is it possible to identify further frequently mentioned topics that are not covered by the above questions?*
 - Associations that were linked to general terms were not uncovered during the analysis. The general data though was useful to confirm that the data-base itself seems to contain data that represents the population of amputees (see table 3.7 which specifies the number of posts in relation to amputation level).

Following the research questions the broader hypothesis also need to be reviewed.

- *It is possible to identify (currently unknown) user demands or user needs for high-end prosthetic devices from online-sources generated by amputees.*
- *It is further possible to identify (currently unknown) usability issues and/or performance issues that amputees may have with existing high-end prostheses.*
 - After carefully reviewing the data available and investigating several aspects in more detail it seems clear that both hypotheses have been confirmed in parts and should be rejected in parts. It was not possible to identify currently unknown user demands or usability issues. But the data confirmed existing knowledge about amputees and prosthetic devices. Moreover the data available may even be useful to re-adjust the ranking that may have been given to user needs and performance criteria in the past. The results though need to be carefully investigated to avoid misinterpretation based on broad terms such as *simple* or *weight*.

While it is of course valuable to find current assumptions that are broadly used during product development confirmed, it is also disappointing that no new topics were identified. While it may be a matter of discussion whether Henry Ford ever really said “*If I had asked people what they wanted, they would have said faster horses.*” it nevertheless

points out one very important aspect. People in general are not necessarily innovators and find it (extremely) difficult to imagine new things. Sometimes people find it difficult to see the potential of new technology even when it becomes readily available. An example for this came from the chief technology officer (CTO) of Motorola at the time the first iPhone was launched. He wrote in a blog “*There is nothing revolutionary or disruptive about any of the technologies.*”². So, when even industry insiders find it difficult to see the potential in existing technology it perhaps cannot be expected from the community of amputees to generate new ideas in online user fora.

At the beginning of the thesis stood the assumption that amputees might discuss things they cannot currently do with their devices! Interestingly though this seems not to be the case. It seems much more likely that posts relate to things or activities they are proud of having achieved and therefore want to share. Knowing that some of the functionality of prosthetic devices is limited it is almost surprising how high the percentage of positive posts is even for these topics. There may be some topics that not every amputee can achieve, but posts seem to be written with a focus rather on what was achieved and not on what could not be achieved. It may be noted that *missing* is a common term in posts but most often is used in the context of the *missing limb* and not a missing function or feature of the prosthesis used.

Although limited evidence was found for the behaviour of users in online fora, our personal experience and social interaction allows to draw a comparison. How do we react to the question: “How do you feel?”

²<http://web.archive.org/web/20070114215511/http://blogs.motorola.com/author/padmasree-warrior/>

Most often we would reply on a positive note, just as we most often will send or show images of sunshine from our vacation, even if perhaps the weather was rather average. It seems to be either in our very nature or in our upbringing to be positive and show and discuss positive things, rather than concentrate on the negative. There is no reason why this should not be the case in online fora too. [Johnsen et al., 2002] found that even negative main posts often received positive replies in other health related online fora. This social support that is apparently available in online fora may also be one of the reasons to participate in these communities [Pendry and Salvatore, 2015, Kummervold et al., 2002].

In terms of directly usable results some general observations could be made. Amputees seem to focus on their independence when it comes to ADLs. This explains the high number of posts for *walk* and *drive*, to name but a few. The relatively high score for *sitting* and *balance* should also be noted. Especially sitting - with its high percentage of negatively associated posts - most likely is related to the socket. The data thus also supports the notion that the socket itself is still problematic. Moreover pain is a common theme among amputees. This confirms existing knowledge. Interesting is the fact that there seems to be limited device related discussion in online fora. There are of course a number of posts that relate to specific devices, but there are only a few devices that come up more frequently. Most of the threads for these devices are often not related to functionality, but rather focus on reimbursement, or describing in general whether a specific device should or could be used or not. These discussions often emerge around the question (or a similar phrased question): “Has anyone experience with *device X*?”

4.1.2 Feedback of experts

During the discussion with experts within the company the idea to use online-fora as a data source and attempt to identify new or support or challenge existing knowledge was very well received. A number of them expressed interest to gain access to the results obtained so far. The potential to get further insight into user discussions was seen by all participants in the expert discussion. The strong “focus” of amputees on systems rather than the single prosthesis (at the centre of the system) was considered as an important reminder that the amputees depend on all components of the system they use.

During the discussion an interesting proposal was made for future data analysis. It was suggested to perform an cross-topic analysis. In this analysis it was suggested to compare the average of the top topics in each category across categories rather than the topics within one category. This could indeed be useful to identify for example if user satisfaction (average of positive sentiment across top results) was higher for ADLs or for usability topics. Looking at this data it may be concluded that the amputees seem to be happier with the performance during ADLs (58% average for positive sentiment across ten most frequently mentioned topics) when compared to usability (average of 53%) and socket and comfort (average of 54%). Care has to be taken though as especially in socket and comfort also negatively connoted terms such as *skin* and *sweat* would be included. Nevertheless the approach seems to be interesting for future work. Using the same idea just for the average of number of posts across the top five topics it may be noted that pain and socket are more often mentioned than ADLs or usability topics. This may be an indication that indeed pain and the performance of the

socket are important topics. These topics may even warrant to receive more focused attention in future products or developments.

4.2 Outlook and final conclusion

At the end of any academic work it is of course useful and meaningful to reflect on things that could have been better. Moreover it is also meaningful to think about future research that could and should be done. The work presented here also has shown potential next steps as well as potential shortcomings of the approach.

The main benefit of the data analysis as used in this thesis is the fact that it was relatively easy to implement and therefore did not require any special tools or programming. This was actually done so specifically in order to test if useful data could be generated with existing tools. As stated above the data generated re-confirmed several existing topics of interest and re-adjusted some insight that were available. As such this data-set is an important piece of the overall jigsaw of user requirements in the prosthetic industry.

The analysis has also demonstrated though that the nature of the online fora and the unspecified raw-data generates issues in the results. For example one does not know what type and level of amputation the author has (if any). This information might be useful though to rate the quality of a specific post. Also it might be worthwhile to consider posts in their original structure as original post and replies (aka threads). As it stands now one thread could generate multiple hits and therefore “increase” the count on a specific topic despite being discussed only

in the context of one thread. Also the time of the posts might be of interest as topics might have lost relevance due to new developments in the industry. This information is currently not available.

So in more general terms, it probably is advised to generate a more detailed source data-set with more information on the posts and the author. One might even try to analyse the type and level of amputation from the posts of the author and store this information in a separate database. This would probably require an extra step of data-extraction and subsequent analysis. Moreover one would have to be careful to still work with fully anonymized data-sets in the end.

Future research might also want to differentiate topics clearer as several terms can be used in a number of different meanings, e.g.: *weight*, *size* or *simple*. This increases the number of posts and reduces focus of these terms. One approach to resolve this could be to put these terms into an specified context by combining them with other search terms. A quick trial of this method showed that results were still quite unspecific or had a serious impacted on the number of posts found (decreasing them at large). This suggests that probably a more thorough analysis on the post-level may be required. This pre-processing step could attempt to better understand the post and provide a more specific meaning (e.g.: level of amputation, discussion about weight in general or weight of the prosthesis, ...). Combining this with the previously suggested database on authors this could provide more specific data-sets to compare. As discussed in the section on the experts' interviews some quite general comparisons among areas of interest may provide meaningful data too. Nevertheless, despite not having uncovered previously unknown activities of daily living or performance issues with existing devices,

this work established the usability of user fora as a data-source. It also highlighted several areas which possibly may be under-represented in the current discussion in the company. Specifically the following conclusions should be mentioned and are important new insights for the organisation (a) users concentrate on systems rather than single components thereof, the system performance should thus (perhaps) receive more attention during development of the single components, (b) based on the number of posts the areas of socket and pain seem more relevant than the activities of daily living, (c) based on (b) development of better sockets is a key area that needs further investigation and consideration for product development. This is supported by (d) frequent occurrence of sweat & skin, also indicating that sockets have not reached their full potential. These insights will be taken up by the author for further internal discussion.

The work also demonstrated that current commercial tools can be used to analyse user fora in a meaningful way. Steps that may improve the quality of results have been identified and have been presented above. Moreover it may be of interest to actively engage with these communities. This must be done openly and under full acknowledgement of one's identity and role. A careful approach is required as the long development times and the limited possibilities to supply early prototypes to amputees need to be considered. Expectations of all involved need to be managed carefully. Nevertheless the current work suggests that there would most likely be a benefit in this interaction. It would allow us as a company to (a) place ideas and receive early feedback that (b) would lead to improved products, which will (c) ultimately result in the better outcomes for amputees.

“If a word in the dictionary were misspelled, how would we know?”

Steven Wright – American Comedian, born 1955

Appendix A

Dictionary of terms

A.1 Definitions

In order to prevent misinterpretation of terms by the NLP engine of the online tool webLyzard a dictionary of abbreviations, company names, product names and common terms was defined.

A.1.1 Abbreviations

The following abbreviations were defined as they may be specific for the context of prosthesis and their use within posts and comments (table A.1).

abbreviation	full term
bk	below knee
btk	below the knee
bka	below knee amputation
lbk	below knee
laka	above knee amputation
ak	above knee
aka	above knee amputation
atk	above the knee
oi	osseo-integration
vgk	very good knee (see device names)
emg	electromyography
tmr	targeted muscle reinnervation
tsr	targeted sensory reinnervation
cpo	certified prosthetist and orthotist
afo	ankle foot orthosis
kafo	knee ankle foot orthosis
O&P	orthotics and prosthetics
bme	biomedical engineering
ms	multiple sclerosis
ul	upper limb
mpc	microprocessor controlled
rpni	Regenerative peripheral nerve interfaces
sci	spinal cord injury
fes	functional electrical stimulation
TF	transfemoral - amputation above the knee
TT	transtibial - amputation below the knee
TR	transradial - amputation below the elbow
TH	transhumeral - amputation above the elbow
knee ex	amputation at the knee (knee disarticulation)
shoulder ex	amputation at the elbow (elbow disarticulation)
hip ex	amputation at the hip (hip disarticulation)

Table A.1: Abbreviations defined for low level analysis in webLyzard.

A.1.2 Company names and product names

The following companies and products are amongst the most widely used within the industry of prosthetic devices. The terms were defined for latter analysis.

name	description
Open Bionics	company name
Touch Bionics	company name
Steeper	company name
Ossur	company name
Ottobock	company name
Freedom Innovations	company name
Hanger	company name
Integrum	company name
Blatchford	company name
C-Leg	prosthetic knee - product name
Cleg	prosthetic knee - product name
C-leg 3	prosthetic knee - product name
C-leg 4	prosthetic knee - product name
Kenevo	prosthetic knee - product name
X3	prosthetic knee - product name
Genium X3	prosthetic knee - product name
Genium	prosthetic knee - product name
Prosedo	prosthetic knee - product name
Linx	prosthetic system
Rheo	prosthetic knee - product name
Rheo knee	prosthetic knee - product name

Continued on next page

Table A.2 – *Continued from previous page*

name	description
Rheo knee xc	prosthetic knee - product name
Power knee	prosthetic knee - product name
Very good knee	prosthetic knee - product name
Plie	prosthetic knee - product name
Plie 3	prosthetic knee - product name
Orion	prosthetic knee - product name
Orion3	prosthetic knee - product name
kx06	prosthetic knee - product name
Michelangelo	prosthetic hand - product name
ilimb	prosthetic hand - product name
i-limb	prosthetic hand - product name
i-limb quantum	prosthetic hand - product name
i-limb ultra	prosthetic hand - product name
Myobock	prosthetic hand - product name
hook	special terminal hand device
smartarm	prosthetic hand - product name
Vincent	prosthetic hand - product name
Bebionic	prosthetic hand - product name
myo plus	prosthetic hand - control system
coapt system	prosthetic hand - control system
Taska hand	prosthetic hand - product name
Harmony	vacuum pump - component
Meridium	Prosthetic ankle - product name
Elan	Prosthetic ankle - product name

Continued on next page

Table A.2 – *Continued from previous page*

name	description
Echelon	Prosthetic ankle - product name
Taleo	Prosthetic ankle - product name
Proprio foot	Prosthetic ankle - product name
Pro-flex	Prosthetic ankle - product name
Triton	Prosthetic ankle - product name
Empower	Prosthetic ankle - product name
Biom	Prosthetic ankle - product name
seal in liner	a specific liner - product name
seal-in liner	a specific liner - product name
skeo sealing liner	a specific liner - product name
Fillauer	company name
Rush foot shell	company name
blade	special foot made for running
opra	osseo integration system
e-opra	a deviation of the above
AOS	advanced orthotic system
C-Brace	advanced orthotic system
Varos	prosthetic socket - product name

Table A.2: Product and company names defined for low level analysis in webLyzard.

term	meaning
liner	a prosthetic component inside the socket
socket	the connecting component between prosthesis and user
stump	the remaining part of the amputated limb
osseo-integration	a new technology where an implant is used to generate a better fit between prosthesis and user
body powered	prostheses that use the user's residual function to move the prosthesis
donning and doffing	the process of putting on and taking off the prosthesis
TED talks	the common tech talk format
phantom pain	still feeling the lost limb or extremity
phantom sensation	still feeling the lost limb/extremity
pin system	a special way to connect liner and socket
plexus injury	nerve injury in the upper extremity
drop foot	a common injury following stroke (unlikely topic)
dropped foot	a common injury following stroke (unlikely topic)
foot drop	a common injury following stroke (unlikely topic)
cover	may refer to cosmetic cover (mainly of lower limb prosthesis)
transradial	specific amputation level
transhumeral	specific amputation level
transtibial	specific amputation level
transfemoral	specific amputation level

Table A.3: Terms defined for low level analysis in webLyzard.

A.1.3 Common terms

Finally common terms and their specific meaning in the prosthetic industry were defined in table A.3.

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