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**THE USE OF SOCIAL MEDIA IN PATIENT RECRUITMENT FOR CLINICAL TRIALS
IN MEDICAL DEVICE START-UP FROM THE PERSPECTIVE OF SOCIAL MEDIA
AGENCIES AND PATIENT RECRUITMENT FIRMS: CASE SYNOSTE**

Master's Thesis

Marketing

10/2017

Unit Department of Marketing			
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Title The use of social media in patient recruitment for clinical trials in medical device start-up from the perspective of social media agencies and patient recruitment firms: Case Synoste			
Subject Marketing	Type of the degree Master's thesis	Time of publication October 2017	Number of pages 82
<p>Abstract</p> <p>The aim of this research is to provide novel approach how to use social media in patient recruitment for clinical trials. This research has been commissioned by a Finland based company Synoste, and is limited to consider the patient recruitment in a medical device start-up with a very limited number of patients. To be able to produce new approach into existing literature, this study has been conducted as a qualitative case study from the perspective of social media agencies and patient recruitment firms.</p> <p>Understanding the factors, such as scarce information about the clinical trials, possible benefits, lack of support by patients and families as well as lack of encouragement to participate by practicing physicians all affect a decision of an individual, whether to participate into a clinical trial or not. Understanding these factors enables to analyze proper social media strategies for patient recruitment. Challenges and benefits of different social media strategies have been discussed in the theoretical part of this study also. Theoretical framework concludes previous literature about the research subject together by focusing on the different aspects of promotion, including channels, content, communication and messages.</p> <p>Theoretical framework created a base for a request for quotation (RFQ), which was used to collect approaches from social media agencies and patient recruitment firms. These companies were selected by searching Finland based marketing companies with a high level of competence about the use of social media. Due to the lack of actual patient recruitment firms in Finland, and to get more comprehensive approach about the overall situation, a few professional patient recruitment firms out of Finland are also included for this study. Empirical analysis follows both abductive and inductive reasoning.</p> <p>The participant companies suggested a wide variation of different strategies for the use of social media in patient recruitment. The right kind of content and advertising, selecting the most suitable channels to reach target group and driving traffic to trial website are important stages when planning the social media strategy for patient recruitment.</p> <p>The main findings of this research indicate that increasing the awareness and targeting, as well as Google advertising can be used as effective methods to recruit patients into clinical trials, when social media is not used as an only strategy for patient recruitment. Due to the fact, that the use of social media misses the establishes practices, there is not a "right way" to use social media in a patient recruitment process.</p>			
Keywords patient recruitment, clinical trials, social media			
Additional information			

CONTENTS

1 INTRODUCTION	5
1.1 Background and purpose of the study	5
1.2 Research question and research method	7
1.3 Structure of the study.....	7
2 THE USE OF SOCIAL MEDIA AGENCIES AND PATIENT RECRUITMENT FIRMS IN PATIENT RECRUITMENT FOR CLINICAL TRIALS	9
2.1. Definition of key terms	9
2.1.1 Medical industry and clinical trials terms	9
2.1.2 Marketing terms	11
2.2 Recruitment for clinical trials	11
2.2.1 Recruitment and participation for clinical trials	11
2.2.2 Marketing and clinical trials.....	12
2.2.3 Outsourcing patient recruitment.....	13
2.3 The use of social media in patient recruitment	14
2.3.1 Social media strategies for patient recruitment.....	15
2.3.2 Challenges of using social media	18
2.3.3 The power of social media.....	19
2.3.4 Social media channels.....	21
2.3.5 Online patient communities	23
2.3.6 Outsourcing and relationship between an advertiser and media office	24
2.4 Regulations and ethical consideration	26
2.4.1 Regulations	26
2.4.2 Ethical consideration	28
2.5 Theoretical framework	28
3 RESEARCH METHODS AND EMPIRICAL RESULTS.....	32
3.1 Qualitative case study research	32
3.2 Case company Synoste	33
3.3 Data collection	34
3.4 Request for quotation (RFQ).....	36
3.5 Data analysis	39
3.6 Participant companies	40
3.7 Declined companies.....	42

3.8 Empirical results	43
3.8.1 Recognizing the challenges.....	44
3.8.2 Strategy.....	46
3.8.3 Content	50
3.8.4 Advertising.....	53
3.8.5 Channels	56
3.8.6 Website.....	58
3.8.7 Social media management	59
3.8.8 Other ideas related to social media.....	59
3.8.9 Regulations	62
3.9. Discussion	63
4 CONCLUSIONS	68
4.1 Research results and answers to the research questions.....	68
4.2 Theoretical contribution	69
4.3 Managerial implications	72
4.4 Research reliability and limitations.....	74
4.5 Future research.....	76
REFERENCES	77
FIGURES	
Figure 1. Theoretical framework	30
Figure 2. Promotion perspective. (Edwards et al., 2002, Patel et al., 2003, Formoso et al., 2007, Hinyard & Kreuter, 2007)	31
Figure 3. The flowchart of extensive data collection	35
Figure 4. Theoretical base for RFQ	36
Figure 5. Themes of empirical data	44
TABLES	
Table 1. Social media and clinical trials: considerations. (Thompson, 2014)	23
Table 2. Companies included in data collection process	41
Table 3. Themes of the quotations	63

1 INTRODUCTION

This research explores the role of social media in a recruitment process for clinical trials in a medical device start-up from the perspective of social media agencies and patient recruitment firms.

Successful patient recruitment for medical research studies and clinical trials appears to be significantly difficult (Topolovec-Vranic & Natarajan, 2016) and according to Allison (2009) approximately 30% of trial sites are unsuccessful to recruit even a single patient. Allison (2009) continues that more than 80% of clinical trials are delayed, and 50% of these because of the failure in patient recruitment. The unsuccessful recruiting can delay the clinical trials or cancel the whole trial, which has significant economic and societal implications (Institute of Medicine, 2012, Galli, Knight, Robertson, Hoile, Oladapo & Francis, 2014). This research aims to provide a new approach for existing literature how to use social media in patient recruitment process in a medical device start-up, which has no experience about the use of social media and very limited number of eligible patients.

1.1 Background and purpose of the study

There are numerous studies about recruiting patients for clinical trials, but using the social media in recruitment process is a less studied approach, even though increased use of social media has created some studies about the subject in recent years (Allison, 2009, Giustini, 2014, Frandsen, Thow & Ferguson, 2016). The increased use of social media in recruitment has recently generated a new term “social media recruiting” into the literature. For instance, Burton-Chase, Parker, Hennig, Sisson and Bruzzone (2017) used social media recruiting to find participants into Lynch Syndrome study. They created a successful Facebook campaign in a co-operation with Lynch Syndrome International (LSI) advocacy organization, even though this study was an online survey without clinical trials. The previous studies about the use of the social media in clinical trial recruitment process have mainly focused on providing a narrow view of the overall situation and presenting some specific cases from different industries. Rosa, Campbell, Miele, Brunner and Winstanley (2015)

indicate in their study, that more research is needed from the specific content, specific disease types, when and how to target specific demographic subgroups, and other participant variables to measure the effectiveness of social media in a recruitment phase of clinical trials.

This study was commissioned by the Finnish company Synoste (henceforth Company), who expressed their interest for a research about the use of social media in patient recruitment for clinical trials. Company has developed an intramedullary implant, which will be going into the final round of clinical trials. The implant will help lengthen the bones of people with Limb Lengthening Discrepancy in a novel way providing several advantages compared to the standard procedure, which has been used over 60 years. Because the phenomena of using social media in the recruitment process for clinical trials is relatively new and it's missing the established practices, new research is needed about the topic. Hence, Company wants to explore opportunities of using social media in the patient recruitment process. Understanding the importance of the innovation of the Company, and the fact that the new technology has the potential to help people lead better lives, inspired the researcher to take part in this research process.

This study aims to provide an overall understanding of using social media in clinical trial recruitment process, the possibilities and challenges, and consider the possible ways of how to use social media in this process. To be able to produce a whole new information for literature, the author of this thesis decided to view the phenomena from a whole new perspective, by gathering empirical data from social media agencies and patient recruitment firms and compare approaches from these companies into a theory, which is a review of existing literature about the topic. These approaches have been collected from social media agencies and patient recruitment firms with a request for quotation (RFQ), which was built based on the theoretical framework of this study. In such a case, that a quotation of a particular participant company was relevant, it was possible for this company to act as a strategic partner in patient recruitment for the Company, but this matter is outside the scope of this study and won't be discussed further.

1.2 Research question and research method

This research focuses on the role of the social media in patient recruitment for clinical trials from the perspective of social media agencies and patient recruitment firms. The research question of the study is:

How to use social media in patient recruitment for clinical trials in a medical device start-up?

The aim of this study is to answer the research question by identifying the factors affecting the decision of an individual, whether to participate into a clinical trial or not, and analyze the challenges and benefits of the use of social media in patient recruitment process for clinical trials and conclude the most suitable methods for a medical device start-up. The research method of this study is qualitative case study and a more specific description about the methodology will be presented further in this study, in chapter 3.

1.3 Structure of the study

This thesis proceeds as follows. The chapter 2, will provide the theoretical framework of this study, which introduces the factors affecting the decision of an individual, whether to participate into a clinical trial or not. This helps us to understand and analyze different methods how to recruit patients for clinical trials through social media. Therefore, this study focuses on the earlier research conducted about the patient recruitment for clinical trials and then discusses the use of social media in the recruitment process. The study represents the use of different social media strategies by demonstrating few cases from the previous researches about the topic and addresses the challenges and possibilities of using social media in the patient recruitment process. Due to the fact, that the empirical data of this study has been gathered from social media agencies and patient recruitment firms, the theoretical framework considers also the outsourcing approach and the relationship between the advertiser and the media office. This makes it possible for the researcher to contact the chosen companies from the suitable perspective. The regulations and ethical consideration concerning the patient recruitment for clinical trials and the use

of social media are examined and this composes the theoretical framework of the study.

Research method and data collection will be represented in chapter 3. The empirical results of this study explore the approaches from the professional social media agencies and patient recruitment firms about the use of social media in patient recruitment for clinical trials and will be presented also in chapter 3. This data is analyzed and compared with the theoretical framework of the research establishing a discussion about the research subject. Chapter 4 concludes this study by presenting the research results and answering the research question. Also theoretical contributions, managerial implications, research reliability and limitations as well as suggestions for future research will be discussed in chapter 4.

2 THE USE OF SOCIAL MEDIA AGENCIES AND PATIENT RECRUITMENT FIRMS IN PATIENT RECRUITMENT FOR CLINICAL TRIALS

To be able to analyze how to recruit patients for clinical trials, it's necessary to understand the factors that affect the decision of an individual whether to participate into a clinical trial or not. This chapter proceeds to introduce these factors from the existing literature. The chapter starts with the definition of key concepts to optimize the understanding of the reader. The chapter continues with analyzing the relationship between marketing and clinical trials and expands the approach to consider the use of social media and online patient communities. Also regulations and ethical considerations of patient recruitment for clinical trials will be discussed. The last part of this chapter discusses outsourcing in terms of patient recruitment and the relationship between the advertiser and the media office; in other words, the relationship between Company and a social media agency or a patient recruitment firm.

2.1. Definition of key terms

To be able to discuss patient recruitment in clinical trials, this chapter defines relevant terms used in the medical industry, as well as the main concepts of marketing in regards to this study.

2.1.1 Medical industry and clinical trials terms

Clinical trials

National Heart, Lung and Blood Institute (NIH) defines clinical trials as researches, which examine the safety and effectiveness of medical strategy, treatment or device for humans (nhlbi.nih.gov, 11.1.2016). Reuter, Ukpolo, Ward, Wilson and Angyan (2016) continue to elaborate, that to develop new approaches for preventing, diagnosing and treating disease clinical research needs to have volunteers. In the context of this case study, Company is a sponsor for the trials and it has to have a certain number of patients acceptably tested in clinical trials to gain the permission

for commercializing their medical device. Clinical trials are a necessary part of a new drug or medical device development process and Thompson (2014) underlines, that the existing medicines are based on laboratory research and participation of patients into the clinical trials. According to Gupta, Calfas, Marshall, Robinson, Rock, Huang, Epstein-Corbin, Servetas, Donohue, Norman, Raab, Merchant, Fowler, Griswold, Fogg and Patrick (2015) clinical trials has four elements – recruitment, enrollment, engagement and retention. Temkar (2015) continues to explain, that there are several significant participants, in addition to surgeons, in clinical trial process like pharma company, Contract Research Organization (CRO), investigators and sites and hospitals. (Temkar, 2015)

Participant

Clinical trials have inclusion and exclusion criteria about individuals who have the potential to participate into a clinical trial. The Company is looking for participants suffering from Limb Length Discrepancy (LLD) in a specific geographical area, and an individual has to be excluded from the trials for instance for cosmetic reasons.

Limb Length Discrepancy (LLD)

Basically, Limb Length Discrepancy (LLD) signifies a difference between lengths of the limbs, which can be caused through traumatic injuries, infections, cancers or congenital abnormalities. The phenomena of lengthening a limb is not new, since external fixators has existed in the markets already from the 1950's, but the innovation of Company introduces a 3rd generation solution as a treatment method.

Physician

Practicing physician is a doctor who is going to conduct the medical operation of a clinical trial. In the case of Company, these doctors will perform a distraction osteogenesis treatment, which means breaking a bone of a patient and gradually separating the bone parts with an expanding implant.

2.1.2 Marketing terms

Social media

Topolovec-Vranic and Natarajan (2016) define the commonality for social media sites to be the profiles, which users create into these websites and connect and interact with others through these profiles.

Social media agency

In this study, social media agency signifies a media office, which provides various social media services for businesses with a high competence.

Patient recruitment firm

A patient recruitment firm stands for a company, which is specialized into a patient recruitment.

2.2 Recruitment for clinical trials

2.2.1 Recruitment and participation for clinical trials

Rosa et al. (2015) and Frandsen et al. (2016) stress the difficulty of patient recruitment seeing it as one of the most challenging part of clinical research and recognize the fact, that this might be an expensive task to fulfil. Reuter et al. (2016) emphasize, that the scarce information about the clinical trials is a major reason, why potential participants don't enroll in clinical studies. Also according to Institute of Medicine (2012), physicians and patients are missing the information about the available clinical trials that could be relevant, and also the possible benefits of enrolling in these trials. The unsuccessful recruitment can delay the clinical trials or cancel the whole trial (Institute of Medicine, 2012). Also Galli et al. (2014) recognize the recruitment as a major challenge for many trials, and add that a failure in the recruitment process has significant economic and societal implications.

According to Institute of Medicine (2012) the potential participants for clinical trials suffer from the lack of support by patients and families, community leaders and academic medical centers. One significant shortage can also be seen the lack of encouragement to participate in clinical trials by the practicing physicians. According to Galli et al. (2014) the engagement to clinical trials might demand extra effort and expenses from participants without having a certainty to gain any direct benefits, and this can create a barrier to participate into a trial. Frandsen et al. (2016) emphasize the importance of a recruitment strategy, not only in the recruitment process, but the participants to commit for the trials during the whole clinical trial process as well.

2.2.2 Marketing and clinical trials

In their study about improving patient recruitment to clinical trials, Galli et al. (2014) define marketing as a discipline that consist of the understanding of the factors that affect the sign-up decisions in order to answer the need of customers. Galli et al. (2014) introduce five stages in marketing a trial; set-up, market planning, signalling, learning and reinforcing phase. The authors emphasize the difference between understanding the inevitable phases in marketing a trial and comprehending the required actions to optimize recruitment.

In their book “Principles of Marketing” (2010: 613) Armstrong and Kotler presents five frameworks for conducting a marketing strategy: 4P marketing mix (product, place, price and promotion); 3C analysis (customer, competitor, and company); segmentation, targeting and positioning; value and context analysis; and the buying decision process (Armstrong & Kotler, 2013: 613). To get a specific comprehension about target market’s opinions towards the trial, Galli et al. (2014) extend Kotler’s 4P’s into 7P’s, where the additional P’s stand for processes, people and physical environment. These 7P’s form the value proposition, the actual benefit the participants can receive from the trial, and the P for promotion defines how to communicate this value proposition (Galli et al., 2014). Since this research is exploring the use of social media in the recruitment process of clinical trials, it will be focusing on the last P - promotion and communication.

The role of promotion is to communicate the credits of other components of the marketing mix (Galli et al., 2014) and to be successful in this, there has to be messages with a proper content. These messages have to be framed, the suitable channels have to be chosen, and a convenient mode of communication to be founded. (Edwards, Roberts, Clarke, DiGuseppi, Pratap, Wentz & Kwan, 2002, Patel, Doku & Tennakoon, 2003, Formoso, Marata & Magrini, 2007, Hinyard & Kreuter, 2007)

Gupta et al. (2015) define the purpose of the marketing to be the value creation for a customer and communicating this value to the customer through various media channels. When choosing which media channels to use, the costs, size, and type of audiences reached by different channels has to be recognized as well as deciding the suitability of the channels for the content of message and target audience. (Kotler, Roberto & Lee, 2002, Galli et al, 2014)

Ross, Grant, Counsell, Gillespie, Russell and Prescott (1999) present that the information, or more specifically, the availability and the quality of it, is a significant component that can affect recruitment. Galli et al. (2014) further explain, that the misunderstandings need to be corrected and the trial process has to be instructed to participants in order to have a powerful communication.

2.2.3 Outsourcing patient recruitment

Chin (1997) presents that health care organisations have increasingly started to outsource management of their information systems. This enables companies to focus on their core competencies, re-allocate resources and gain access for more information technology and skilled labour, while sharing the risk with a partner. Temkar (2015) further discusses the role of technology transformation and outsourcing in clinical trial industry indicating that the use of mobile data, cloud computing, social media, robotic automation and electronic source enable clinical trial industry to optimize the efficiency of the clinical operations.

Jones and Minor (2010) state that the reasons for outsourcing have traditionally been based on the lack of capacity and for the opportunity to receive new research experience. The authors also emphasize that the approaches of pharmaceutical

companies and sponsors regarding outsourcing have changed from tactical to more strategic relationships, expecting those relationships to be founded on a strong partnership and to be more creative and transformational. (Jones & Minor, 2010)

2.3 The use of social media in patient recruitment

Advertising in newspaper and radio, the conventional "face-to-face", word of mouth (WOM) and other "offline" media approaches have been traditionally used for clinical trial recruitment (Gupta et al., 2015 , Rosa et al., 2015 , Frandsen et al., 2016). However, the increased importance of e-technology has created new "online" media, including the use of apps, registries and the social media, which has changed the nature of communication (Gupta et al., 2015 , Rosa, et al., 2015). Gupta et al. (2015) add, that the continuously changing technology has the potential to make clinical research and recruitment more effective, for instance by making it possible to reach and deliver targeted messages to target groups. However, the novel ways of communication haven't replaced the traditional methods and finding a balance between analogic and digital communication channels is essential. The combination of using information technology and marketing also enables to allocate existing resources, for example staff, time and materials in the most efficient way, which can accelerate the recruitment and decrease personnel and operations costs (Gupta et al., 2015). Recruiting patients through Internet is not a new phenomenon (Etter & Perneger, 2001) and Thompson (2014) emphasizes the role of the Internet as a source of an information and knowledge after patients get diagnosis. Temkar (2015) widens Thompson's (2014) approach by taking into account the role of social media in clinical trial industry as an information source for medical products.

Nowadays, patients want to communicate through Internet and integrate social media and smartphones into their lives. The significant number of smartphone users enables the clinical trial information to be available for patients and keep them up to date, for example when patients are looking for a support from online communities like Twitter and Facebook (Temkar, 2015). Clinical trial industry has understood the potential of using social media, and many clinical trials have started to utilize this way of communication and recruit participants through the social media (e.g. Facebook, Twitter) and blogs. (Rosa, et al., 2015) Giustini, Grajales and Hooker

(2011) introduce the patient recruitment for clinical trials as one of the top reasons for using social media in clinical research. Other reasons for the use of social media were encouraging interprofessional communication and collaboration, developing virtual patient interactions and training, setting up health advocacy groups, promoting funding and fundraising opportunities and issuing public health alerts (Giustini et al., 2011). Also Allison (2009) recognizes social media as a way to clinical trial recruitment and Ghinn (2012) continues, that companies and healthcare stakeholders are starting to understand the role of social media as strategic approach, rather than experimental pilot. Storrar, Brown, Balls, Chauhan and Fogg (2015) express a more radical approach regarding the use of social media, indicating that social media has been an underutilized resource and seeing it as a potential way to revolutionise the clinical trial recruitment.

2.3.1 Social media strategies for patient recruitment

Johnson, Mueller, Williams and Gutmann (2014) investigated the effectiveness of different recruitment methods, like Facebook and Google advertising, government and academic websites, patient advocacy groups and healthcare providers, to recruit hard-to-reach participants to online patient registries and found social media to be a successful method in recruitment process. In their study, Topolovec-Vranic and Natarajan (2016) explore the use of social media in recruitment for various medical studies. Every study in the sampling didn't include clinical trials, but the authors discuss of the social media as a potential way to recruit patients, especially younger individuals, hard-to-reach populations and populations with specific conditions or disorders. Study specific characteristic such as age and hard to reach population are critical factors for the effective recruitment. Topolovec-Vranic and Natarajan (2016) emphasize the correlation between recruited participants and the use of resources for the social media recruitment, in those studies, where each recruitment method was recognizable. The use of resources consists of the number of social media websites used, how extensive the social media strategy was compared to the strategy of traditional methods, the frequency with which recruitment was conducted and the time spent on the social media recruitment.

When designing social media recruitment strategy, Topolovec-Vranic and Natarajan (2016) state that such factors as sex, how the social media is being used among target population, the likelihood of comparable sample and the probability to reach the target population through traditional recruitment methods should be considered. Topolovec-Vranic and Natarajan (2016) present, that studies used in various types of social media recruiting strategies, which included the creation of a separate page for study advertising, targeted advertisements on social media websites by focusing on specific age groups and locations based on the profile information and private messages. The authors discuss, that the use of different strategies affect the number or demographics of participants recruited, which might distort the comparison between social media and other methods.

Topolovec-Vranic and Natarajan (2016) indicate several concerns for these strategies. For instance, advertising the study through social media or a separate page might not reach every participant. Also, the verification of the information individuals provide through online surveys and the possibility for multiple responses are a major challenge. Johnson et al. (2014) add the fact, that participants might report their source of recruitment falsely. Topolovec-Vranic and Natarajan (2016) underline, that measuring the quality of recruitment strategy misses the settled practice, and more research is needed of the effectiveness of social media in a recruitment process in specific groups.

Thompson (2014) addresses the role of social media in the recruitment process from the perspective of oncology. The standards of using social media are in transition, so the principles concerning it have to be transformed also. Social media can be a powerful instrument to instruct and engage patients, not least because in addition to patients, also families and other physicians are using it. For instance, compared to mass mailing, the advantage of using social media is the chance to share the knowledge without “spamming” the people, who are not excited about clinical trials. (Thompson, 2014)

A good example of the social media transition presented by Thompson (2014), is a web-based tool called “Trial Promoter”, which automates the generation and distribution of social media messages in clinical trials (Reuter et al., 2016). Basically,

the tool imports information from a certain database, creates messages using disease hashtags (#-symbol) based on preapproved message templates, schedules and distributes these messages via the social media (Twitter and Facebook) for a target group (patients, disease advocates and physicians), and finally, measures the success of these messages. These messages also include a link, which directs potential patients into the clinical trial landing page for more information and the possibility to fill a contact form and reach the study team.

As indicated earlier in chapter 2.2.1, Reuter et al. (2016) have recognized the unawareness of clinical trials as a major issue in the recruitment process. This impacts the attitudes toward clinical trials, enrolment and the benefits of participation. Therefore, the “Trial Promoter”, which is designed to boost and ease the promotion and advertisement phase, as well as the engagement phase, provides a new approach as a source of information.

Giustini (2014) emphasizes, that social media platforms, such as Facebook, LinkedIn and Twitter can be seen as equally important with such websites as Clinicaltrials.gov and the International Clinical Trials Registry Platform especially, when communicating about the research and trying to encourage patients to take a part in clinical trials. Giustini (2014) also introduces Health 2.0, a patient-centered Web, which involves the stakeholders to co-create patient stories. The social media has an important role enabling two-way interactivity between patients and providers, while unidirectional practices seem to belong to the past. (Giustini, 2014)

Storrar et al. (2015) present in their study “the LASER Trial”, that explores an allergen intervention for allergic asthma patients, how they used several social media approaches in the recruitment process of the study. The study was conducted in collaboration with Asthma UK (27,000 Twitter followers and 35,000 likes on Facebook) and Allergy UK, who advertised the trial via their social media channels Facebook and Twitter. This promotion has positively affected to study profile and created remarkable amount of traffic to trial website for patient registration. (Storrar et al., 2015)

In addition to co-operation with Asthma UK and Allergy UK, the study created a social media advertising campaign targeting asthma patients within 50km from the recruiting centres. The campaign reached nearly 50,000 people/month through paid advertisement in Facebook and Twitter, encouraging individuals to explore the trial and direct them to the trial website for registration. (Storrar et al., 2015)

2.3.2 Challenges of using social media

There are numerous aspects that has to be considered before using social media tools. There are issues concerning the patient privacy and confidentiality in Canada and the United States, because they are lacking ethical and regulatory frameworks for social media (Glickman, Galhenage & McNair, 2012). Posts about drugs and medical devices made by third-party is also a tricky issue; do pharmaceutical companies also have the responsibility of patients' comments about off-label uses? (Giustini, 2014)

Before, health providers practiced a one-way communication to patients (Wicks, Massagli, Frost, Brownstein, Okun, Vaughan, Bradley & Heywood, 2011), but nowadays Health 2.0 patients want to interact and share information with other patients (Giustini, 2014). Although the social tools and information sources have changed patients' attitude towards communication, one-way communication can still be found in hospitals and doctor's offices. There, where one-way communication still exists, Health 2.0 provides opportunities for patients to learn how to communicate with physicians about their problems and find solutions to these problems in collaboration with others.

Daley (2011) stresses the online information overload as a problem, which affects also to consumers' health literacy. Giustini (2014) also discusses how patients and their families understand the information they receive and explains that it's possible to recognize family members in online conversations with incorrect basis. Reynolds (2011) mentions, that some clinical trial recruitment firms have started to communicate directly with patients and inquire their participation in clinical trials. Giustini (2014) considers the patient anger also as a significant preoccupation. Patients want to communicate in social media without any kind of filter, which they would have in face-to-face communication. Freedom to express one's personal

opinions is the reason, why patients use social media in the first place. However, this has led to a situation, where some doctors don't want to take part in the conversations regarding social media. (Giustini, 2014).

Quach, Pereira, Russel, Wormsbecker, Ramsay, Crowe, Quan and Kwong (2013) present, that monetary incentives can increase recruitment through social media and Bower, Brueton, Gamble, Treweek, Smith, Young and Williamson (2014) agree with this approach in medical health studies. In their study Quach et al. (2013) researched the recruitment of Ontario parents to participate in specific focus groups, and found the use of multiple online advertising methods for recruiting to be effective. Nevertheless, Quach et al. (2013) indicate issues for multiple submissions and potentially fraudulent information, because of the monetary incentives. Rosa et al. (2015) continue by indicating a criticism, that the participants recruited from social media consist of a non-representative sample for most studies, which can lead to distortion.

Frandsen et al. (2016) recognize the potential of using social media in the recruitment process, but they underline the fact, that to have truly committed participants this kind of strategy might be doubtful. The authors suggest to use a combination of conventional and social media strategies in marketing. In their social media toolkit, Toronto Change Foundation (2011) believes that missing the best practices in the use of social media creates a barrier to social media adoption. These practices could provide an opportunity for organizations to be less risk-averse. Rosa et al. (2015) continue that the scarce empirical evidence of the benefits of using e-technologies in clinical trials and missing the regulatory guidance and policies, when FDA-approval is required, are the main reasons for slow adoption of e-technologies in clinical trials.

2.3.3 The power of social media

Due to the fact, that the most delays in clinical trials result from the recruitment, plenty of pharmaceutical companies use social media to speed up their recruitment strategies (Allison, 2009). Also Giustini (2014) agrees that social media has a significant power to reach new global audiences and the easiness of using social

media almost everywhere has made it very tempting to both scholars and drug companies. For instance, Johnson & Johnson and Pfizer have reached patients through YouTube and Facebook. The unquestionable power of social media is based on the requirement to share the best practices. For example, when launching its YouTube channel, The Association of Clinical Research Organizations declared their one mission to be educating the public, media and policy makers about clinical trials and clinical research. (Giustini, 2014)

O'Connor, Jackson, Goldsmith and Skirton (2014) researched the use of Twitter in their study of antenatal experience of mothers of advanced maternal age. The authors found out that social media is a potential tool for patient recruitment in addition to the conventional recruitment methods. The use of social media has several benefits, because it is a cost-effective way to operate, collecting data is fast and it creates a possibility for research to stay anonymous and transparent.

In their study, Frandsen et al. (2016) compared the traditional recruitment methods and the use of social media in recruitment process. The opportunity to collect plenty of available personal data from user profiles and to reach the kind of people that might be difficult to reach in other terms, were founded valuable social media features. In social media, it's possible to choose the location (i.e. banner, newsfeed) and the visibility of the ad for selected population. This helps to define the amount of money to use on advertising, for instance in the valuation of each click on the ad. Also deciding when to show the ad and when to hide it, provides an option to control the reached population and the potential participants in real time. The other benefits of using social media were based on the cost effectiveness and usability of it. The authors also present an interesting point of view about the individuals, who click the ad. According to their study Frandsen et al. (2016) present, that clicking the ad will lead the potential participant to an extensively informative study website, which offers the information for instance about the inclusion and exclusion criteria of the study. This might lead to situations, where the participants recruited through social media have better overall understanding of the trials than the ones recruited via conventional methods. The authors also suggest that offering specific information about the clinical trials might influence the study completion and cost per participant. (Frandsen et al., 2016)

According to Lindemann, Freeman, Kilchenmann, Harrison, Chan, Wygonik, Haines and Gossens (2016) the desire to speed up patient recruitment and clinical trial enrolment is generating a new kind of cooperation between patients, health care professionals and the sponsors of clinical trials by focusing on patients' opinions and preferences. Also Thompson (2014) agrees, that nowadays the patients are collaborators and there is a need to focus on their independence.

2.3.4 Social media channels

In their article about recruitment for medical studies via social media Topolovec-Vranic and Natarajan (2016) define the commonality for social media sites to be the profiles, which users create into these websites and connect and interact with others through these profiles. This chapter represents social media channels Twitter and Facebook through an earlier research about the topic, for instance implemented by O'Connor et al. (2014) and Thompson (2014).

Twitter

Twitter is a micro-blogging service, where users can send "tweets" up to 140-characters. In 2016, Twitter had over 300 million users (The Statistics Portal, 8.1.2017), who can share "tweets" ("retweeting"), links, images, blogs and videos by using various of digital devices. Java, Song, Finin and Tseng (2007) divided Twitter users into three category based on their use of a service; information source, friends and information seeker.

According to O'Connor et al. (2014) the connection between social media and healthcare has been explored before, but the authors deepened the approach in their study of antenatal experience of mothers of advanced maternal age in the use of Twitter in the recruitment process for clinical trials. The old recruitment strategy "snowball sampling" was used as a base of the study. O'Connor et al. (2014) reflected this theory into the use of Twitter, through which participant of the study had a possibility to reach significant number of other potential study participants. They created a Twitter account and sent "tweets" to potential organisations, communities, businesses, charities, individuals and even some celebrities (followers

more than 60 000) who might have been curious about their study, and requested these account users to “retweet” the posts to their own followers. Altogether, 162 “tweets” got 359 “retweets”, and all the activities were analysed through specialist analytical software application ”Twitonomy”.The authors came into the conclusion that exceptional amount of the potential participants can be reached through Twitter. (O’Connor, 2014)

Facebook

According to Frandsen et al. (2016) Facebook as an advertising platform produces a significant amount of data and is user-friendly in addition to its’ massive reachability. In December 2016, Facebook had on average 1,23 billion daily active users (Facebook.com, 29.4.2017).

Thompson (2014) presents a framework for the principles of using the social media in clinical trial recruitment. The framework focuses on Facebook, Twitter and blogging, but the principles adjust also to other social media channels.

Table 1. Social media and clinical trials: considerations. (Thompson, 2014)

Platform	Question	Response
Facebook		
Before creation of the page	Who owns the page (you, sponsor, or institution)?	The creator of the trial page is responsible for content.
	Is your Institution aware the page will exist?	Engage your institution's media department so you are aware of guidelines.
	Is the trial sponsor aware you plan to do this?	Ensure the page is allowed under the clinical trial agreement.
	Is IRB review required?	Consult local research administration to determine whether the page meets institutional or state definitions of advertising.
Placing content on the site	Are you placing content on that is consistent with the trial?	Refrain from providing significant details of any trial. Only basic study information should be available.
	Where is the content coming from?	Beware of using proprietary information.
	Is there a potential for liability or claims of false advertising?	Avoid making claims of treatment efficacy or side effects. Use disclaimers to reduce risk.
Controlling access	Who is your audience?	Will it be publicly available for the general public to "like" and follow?
Security monitoring	Who will monitor posts?	A mechanism to protect against HIPAA violations and inappropriate posting must be in place.
Communication	Do you plan to interact with individuals who post?	What type of information will be shared? Avoid using social media to screen for eligibility; always refer to your institution.
		Be aware that you cannot be assured that people are using their true identity when posting.
Twitter		
Communication	What is the purpose of using Twitter?	If raising awareness of trial, make sure to link to a site where more information can be found (eg, clinicaltrials.gov).
		If protocol specific communication method, make sure it is allowed per protocol.
		Avoid disclosure of preliminary results or nonpublic information.
Blogs		
Communication	Are you involved in the study?	Bloggers involved in the conduct of a study should not write about that trial or drug because such commentary (depending on the writer's role) may be reasonably viewed as advertising.
	What will you write about?	Avoid discussing specifics related to the trial or patients treated on the trial, particularly if there is a reasonable chance this information could lead to identification of the patient.

Table 1 is illustrated without any modifications to the original table presented by Thompson 2014. Table 1 processes themes focusing on the content and professionalism, which seem obvious social media principles, but in practice might generate some challenges when using various channels and platforms. (Thompson, 2014)

2.3.5 Online patient communities

When discussing the patient recruitment, it's relevant to take into account also online patient communities, in addition to social media channels. Thompson (2014) presents that peer-to-peer communication is a not a new phenomenon since patients have communicated with each other for a long before Internet and social media.

Nowadays, many of these communities such as Facebook, PatientsLikeMe and Smart Patients exist online and have a role to provide support and education for patients and caregivers as well as indicate links to resources and present even research ideas. In addition to online patient communities, professional online communities, such as Doximity, HealthTap, LinkedIn, ResearchGate and Sermo provide an opportunity for physicians to share medicine and clinical trial information. (Thompson, 2014)

PatientsLikeMe

PatientsLikeMe (PLM) is a site promoting the patient recruitment for clinical trials and providing a platform for invites to active clinical trials for over 400 000 members. Openness and transparency are the key factors of PatientsLikeMe and the company sells collected data to pharmaceutical companies, which it has gathered from the use of its site. On the site patients have access to medical data as well as an opportunity to share their experiences with other patients about treatments and therapies. Other similar websites to patientslikme.com are healthunlocked.com and patientsknowbest.com. (Al-Ubaydli, 2012 , Giustini, 2015 , PatientsLikeMe.com, 29.12.2016)

2.3.6 Outsourcing and relationship between an advertiser and media office

In their study of allergic asthma patients, Storrar et al. (2015) used an online recruitment company Trialbee for advertising their trial on social media, in addition to paid advertisement social media campaign and the co-operation with Asthma UK and Allergy UK. Trialbee pre-screened the eligibility of patients online and referred the eligible patients to the nearest recruiting centre for the actual screening. According to Storrar et al. (2015) the combination of different social media recruitment strategies and traditional methods enhanced the patient recruitment for the study.

In her article, Harless (2016) presents 7 tips for hospitals how to outsource social media effectively; explain value, set expectations, convey priorities, plan for flexibility, develop protocols, determine paid media budget and provide assets. Harless (2016) states that social media can reduce the health care costs by sharing

health information for public, trust with the patients can be deepened through social media and being active on social media provides plenty of measurable data. Effective operation needs planning the content and posts due to timelines and Harless (2016) suggests once a month for a content and once a week for posts. The author indicates that each health system has their own priorities on branding, promotion, recruitment and relationship goals, and establishing new outsourced relationships requires to develop the content of a social media strategy in terms of these goals. Harless (2016) emphasizes the importance of having a flexible social media team, which enables to communicate the right message at the right time. Even though, there should be a clear posting schedule in the social media strategy for upcoming events including prewrite posts for several social media channels, this schedule should be open for modifications, for instance updating the information or adding photos to the posts.

In his guide about the cooperation with media offices, Pimenoff (2009: 6) states that the effectiveness of advertising depends on the function between the media strategy and the content, so the result of marketing communication depends on the cooperation between the advertiser, the media office and the advertisement office. As a first reason to use a media office the advertiser has to trust that the media office has strong competence about media development and functionality between different target groups. The second reason is that the media office has to understand the target group of an advertiser. For instance, if a customer gives a “bad brief”, it leads to a worthless outcome as if the media office creates a “business as usual” proposal. (Pimenoff, 2009: 8-9)

Pimenoff (2009: 9) discusses that the scale of media office offerings varies from buying a single advertising campaign all the way to strategic research and consultancy work. The cooperation between advertiser and media office can be divided into three levels. Strategic cooperation is common for big advertisers. In such a case, the media office and advertiser cooperate closely and the media office develops and actively proposes new ways to operate, and it has a strong understanding about the business and goals of an advertiser. Operative/tactical cooperation means focusing to optimize an operation in short-term and for the success of single campaigns. Not using a media office is a path that usually small companies choose and operate directly with media. (Pimenoff, 2009: 9)

One crucial factor to include and integrate for the media planning Pimenoff (2009: 14) appoints is a content of advertising. Even the best media planning is ineffective, if the content of a message is not simultaneously taken into account. Media choices set demands for the content, which means that advertising office, or other producer of ads, has to be part of the planning process at some level. (Pimenoff, 2009: 14)

Pimenoff (2009: 30) presents four concepts to consider when approaching media offices. The first one is a description about the own current situation, which can consist from introduction of a company, including background, structure and stockholders, annual report, recognisability of a company and position in the market, the goal of a business and business idea in the short-term and in the long-term, product range, the structure of an organisation and decision making. The second concept includes brands and products with a description of the most important functions, brands, products and services of a company, current and potential customers and target groups, competitive situation, the structure and the position of product selection, pricing and distribution channels. Marketing communication is a third concept, which aims to clarify existing advertising offices and other partners, the main goal of communication, the role of an advertising office in a planning process, fresh examples of creative executions, product specific investments for media and other marketing communication compared to competitors, current media services, currently used meters and the size of a media budget. The fourth concept proposes to indicate the background of bidding, meaning the preliminary results of analysis about the current situation, challenges and goals, reasons for changing current arrangements, the possible compensation, what kind of structure of an agreement is targeted, clearly defined goals and responsibilities for a media office, criteria for selection and the measurement methods for evaluating services of a future partner. (Pimenoff, 2009: 30)

2.4 Regulations and ethical consideration

2.4.1 Regulations

The clinical trials have an exclusion and inclusion criteria for an individual to participate, but there are also certain other limitations concerning the clinical trials,

such as regulations. Conducting clinical trials by these regulations, for instance, Food and Drug Administration (FDA) guidance in the United States, is not inexpensive and technological advances can reduce operational costs, raise productivity and decrease timelines. (Temkar, 2015)

Thompson (2014) indicates that for example a fear of regulatory punishments, bad public relations or the unknown have been the reasons, why many pharmaceutical companies haven't adapted into the social media. Companies operating in medical sector in the United States, need to adopt their use of social media in compliance with current Food and Drug Administration (FDA) guidance. Temkar (2015) further discusses by defining the use of social media as follows: "...the objective should be to convey correct, accurate, and nonmisleading information to patients and healthcare providers". FDA has created few documents in 2014 and 2015 as a recommendation concerning the use of social media. These documents, for instance FDA Draft Guidance for Industry (2014), advise to provide sufficient information about risks and benefits, when sharing product information. The document also includes the aspects of the responsibility of the company about the promotional communication on the sites, such as company website, Facebook page or Twitter feed, which are owned, controlled, created, influenced or operated on the behalf of the company, including content created by its employee or agent (i.e. paid speaker or a blogger), who is promoting on behalf of the firm, as well as replying to medical surveys with character space limitations in the social media or other online channels. Promotion on third-party sites, for instance promotional content given to a third party, is under company's responsibility. FDA also presents proposals how to process the misinformation expressed by independent third parties, which was discussed earlier in this text by Galli et al. (2014) and Giustini (2015) as one of the challenges concerning the use of social media. (FDA, 2014)

According to Thompson (2014) the links used in social media have to obey institutional standards, but publicly free "static" websites like ClinicalTrials.Gov can be linked. Sharing any extra information, for instance private information, may need to be approved by Institutional Review Board (IRB). Also Snipes (2015) discusses in her article about the regulatory considerations of the use of social media in patient recruitment for clinical trials. Both types of products, investigational as well as

marketed ones are under the FDA regulations when speaking to the product advertising and messaging. Institutional Review Board (IRB) controls also social media communication and this may make some social media platforms unsuitable for advertising products with complex indications or serious risk.

2.4.2 Ethical consideration

Thompson (2014) presents one of the ethical questions concerning the persons, who receive research funding or consultant fee not related to social media, but still actively talks about a certain company or a product on social media. Thompson (2014) underlines the difficulty to define whether these persons are “agents” of a company or not.

Even if social media is nowadays present almost everywhere, there is only a little regulatory guidance how to use social media in clinical research and the existing guidance depend on a country, federal, state and local regulations. Rosa et al. (2015) stress an issue that the privacy of individuals is exposed for the violence, when more technology is being used. But the technology itself doesn't make the harm and the authors emphasize also the responsibility of individuals, who share their personal information on social networks, apps and wearable devices, where the data automatically moves to another online source. Freedom to express one's opinion is the main reason, why people use social media (Giustini, 2014), but public posting to Facebook disposes the expectation of having privacy for that information (Moreno, Goniu, Moreno & Diekema, 2013). Rosa et al. (2015) states that this provides an opportunity for researchers to use this information without the review of IRB, but the authors stresses also a concern about the “trolls” and the difficulty to verify one's identity through online.

2.5 Theoretical framework

Figure 1 aggregates the different aspects and approaches from the theoretical framework of this study to consider when planning a social media strategy for a medical device start-up to recruit patients for clinical trials. The building process for social media strategy begins by emphasizing different aspects that affect into a

decision of an individual, whether to participate into a clinical trial or not. After being familiar with these factors it's possible to create a recruitment strategy. This study considers approaches for the creation of a recruitment strategy from the perspective of promotion, regulations, outsourcing and ethical consideration. When discussing about the outsourcing, media planning with the media agency has to be taken under the consideration. Nevertheless, the main focus of this study is in the promotion, and both, benefits and challenges of using social media have been evaluated. Figure 2 instead widens the theoretical framework (Figure 1), by focusing to demonstrate the approach from the perspective of promotion.

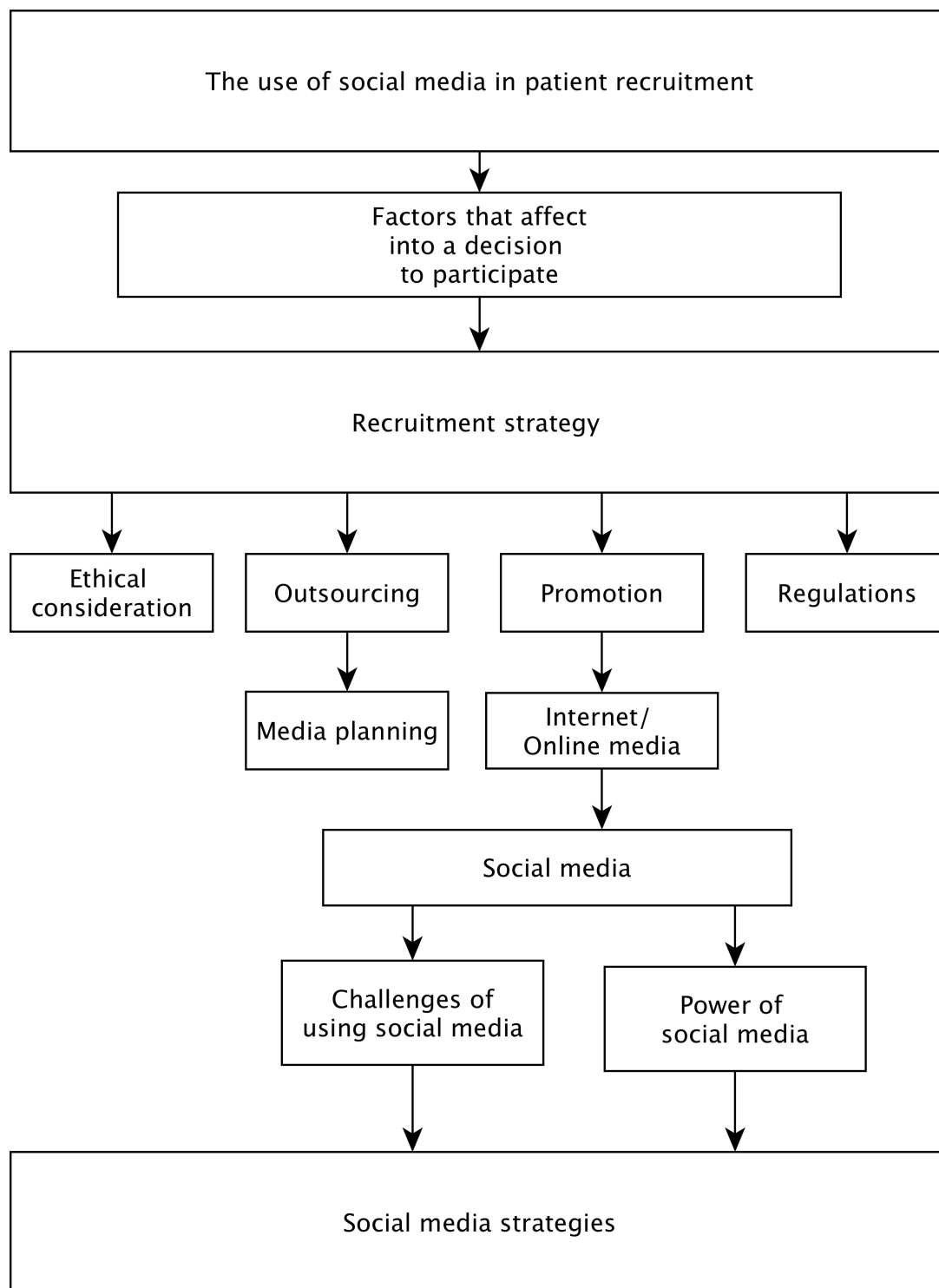


Figure 1. Theoretical framework.

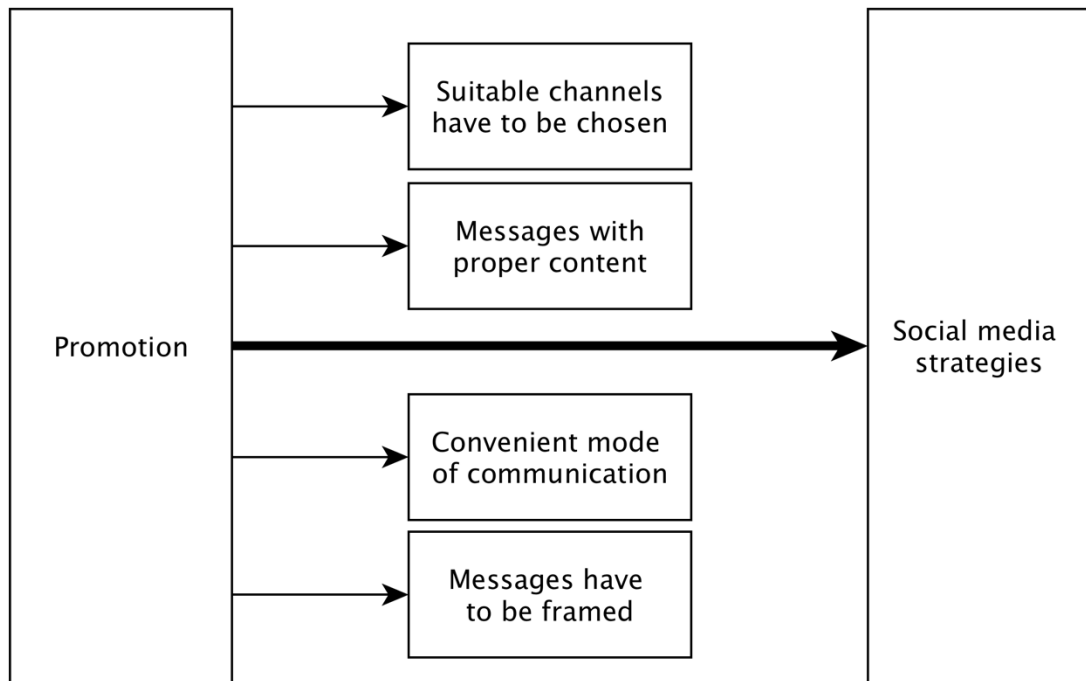


Figure 2. Promotion perspective. (Edwards et al., 2002, Patel et al., 2003, Formoso et al., 2007, Hinyard & Kreuter, 2007).

3 RESEARCH METHODS AND EMPIRICAL RESULTS

According to Ghauri and Grønhaug (2010: 37) to be able to choose and combine research methods, the actual research problem needs to be understood. This chapter represents the research method, as well as the data collection and analysis method of this study, and explains why these particular methods were chosen. This chapter also represents the participant companies of the study and discusses the empirical results of the research.

3.1 Qualitative case study research

To be able to produce novel approach, or actually whole new information on the use of social media in patient recruitment process for clinical trials for scientific literature, the author of this research decided to implement a qualitative case study.

According to Sarajärvi and Tuomi (2009: 17-18) when considering qualitative research, the main question is the relationship between qualitative research and theory; does qualitative research need theory and does qualitative research represent theoretical or empirical analysis? The authors define “theory” to consider the theoretical framework of a study and identify theory as a crucial factor necessarily needed in qualitative research. The definition of “theory” to consider only the theoretical framework might however be too restricted to perceive an overall approach of a study, because a study needs also theory about methods, reliability and ethics of the study (Sarajärvi & Tuomi (2009: 17-18).

According to Sarajärvi and Tuomi (2009: 20) qualitative research relies on the theoretical content of the observations in the justification of the study. Theoretical content of the observations means that the way an individual perceives the study, as well as the significance given to the phenomena and the assertions used in the study, all affect the study results. In other words, the results of the research cannot be entirely separated from the study methods or the researcher. Therefore, there is no purely objective information in this study – instead all knowledge is subjective in the sense that the researcher has decided on the research setting based on his own understanding. In this sense, the arguments of qualitative research emphasize

theoretical content of the observations as a basis for all the research. The theory used in the study may, of course, be “good” or “bad”, but this is related to the quality of the research. (Sarajärvi & Tuomi (2009: 20)

Ghauri and Grønhaug (2010: 109) define case research as qualitative research, which has a field-based structure and which includes analysis of case studies, but authors indicate that case study is not suitable method for all studies. Guest, Namey and Mitchell (2013: 14) instead indicate that the primary purpose for implementing a case study is to understand the specific features of the case or the cases. The authors continue that the knowledge generated from the case study can be used in other cases and contexts (Guest, Namey & Mitchell (2013: 14).

According to Ghauri and Grønhaug (2010: 109) separating phenomena from the social context usually makes it hard to understand. When considering the current study, implementing a research on the use of social media in patient recruitment for clinical trials without having a case study or a case company, would probably have led to a different kind of outcome. For instance, a company conducting clinical trials with significantly broader inclusion criteria for participation, is probably able to use wider scope of social media actions than the Company.

3.2 Case company Synoste

In 2007 three engineering students wanted to develop a solution for people suffering from bone deformities and five years later in 2012, Synoste was established. The founders wanted to create an application for Limb Length Discrepancy (LLD) that could decrease the high complication rates, which were common for the technology that had been used for over sixty years in the treatment of LDD. Company’s strategy to recruit patients for the clinical trials of the novel product is currently based on the referring surgeons in their existing network. Time is of the essence with the commercialization of a novel product and thus the Company wants their recruitment to success. To ensure having sufficient number of patients in their clinical trials and due to the fact that patients suffering from Limb Length Discrepancy do not really have a community where a company with a new treatment method, limited budget and without a proper knowledge of social media behaviour could execute the

promotion, Company wants to pioneer in implementing a pilot project to evaluate the possibility of using social media as a tool to reach potential patients.

3.3 Data collection

This study aims to understand how social media can be used in patient recruitment for clinical trials in specific circumstances, and this is the reason why a qualitative research method was chosen. Because the research is executed as a case study for a medical device company, the data collection was executed in the form of a request for quotation (RFQ) for social media agencies and patient recruitment firms.

Sarajärvi and Tuomi (2009: 21) emphasize the importance of data collection and analysis methods in empirical analysis. According to the authors, it is impossible to think of empirical research that would not explain the method of collecting and analysing the material. Such description gives the reader an opportunity to evaluate the research and is an essential part of the credibility of the study results (Sarajärvi & Tuomi (2009: 21).

The process of collecting data on approaches for patient recruitment from the social media companies was divided into ten (10) phases, which have been named as Step 1, Step 2 etc., and can be found in Figure 3. In the first phase of the process, the researcher prepared a “Request For Quotation (RFQ)” for patient recruitment in social media in the name of the Company. The second phase was to contact the selected service provider companies by phone. After reaching the right person in the target organization by phone, RFQ was sent to a named contact person and the RFQ was went through carefully together with the contact person to help him/her to understand the RFQ thoroughly and to get more insight in the overall situation. After the discussion, the companies were given a deadline for submitting their quotations to the Company. After companies had created their quotations, the author of this study had a video meeting or a phone call, where these quotations were examined together. Feedback on the quotations was given to all the companies through a phone call or an email.

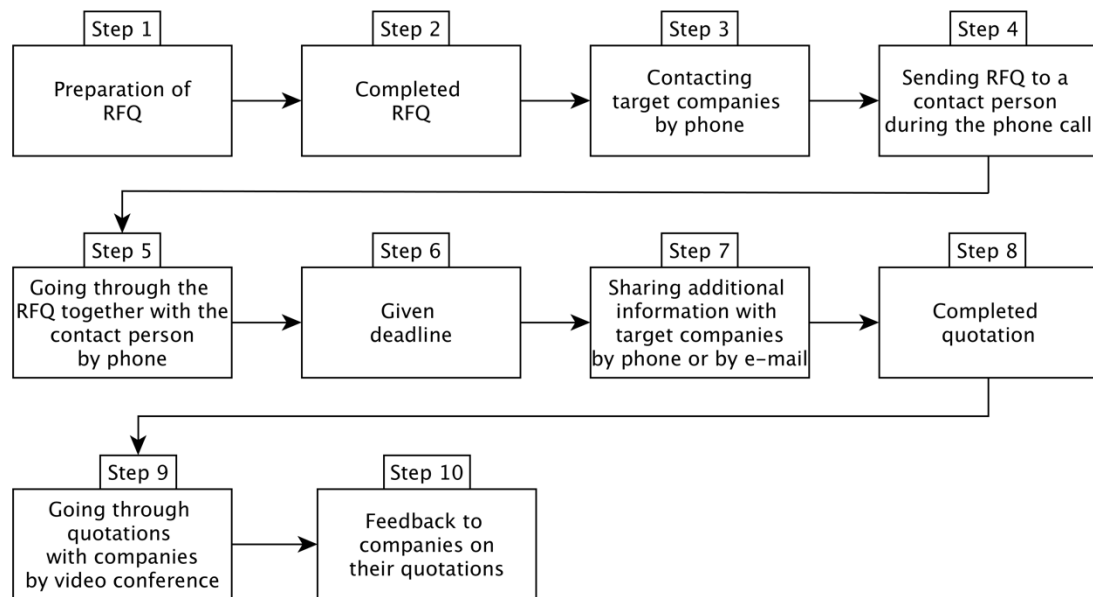


Figure 3. The flowchart of extensive data collection.

There are few exceptions to the data collection process presented in Figure 3, for instance due to the restricted access into a contact information of a company. If the right contact person was not found, the RFQ was sent into a general email address of a target company, excluding the Steps 3 and 5 from Figure 3. This method was used with all the patient recruitment firms, including Firm 1 and Firm 2, which both created a quotation. The importance of Step 7 was emphasized with Firms 1 and 2, when both firms contacted the author of this thesis for further information. Also Step 9 was missing with Agencies 3 and 4 and Firms 1 and 2, and these quotations were received by an e-mail.

This study includes remarkable amount of relevant empirical data on the use of social media in patient recruitment process for clinical trials from different social media agencies and patient recruitment firms. The aim of using RFQ was to assist the Company to find a suitable partner for patient recruitment by implementing a social media campaign with the chosen media agency or a patient recruitment firm. From the personal perspective of the researcher, the amount of data gathered would probably be much smaller, if the data collection would have been implemented without the request for quotation. For instance, conducting a survey and/or an interview for Master's Thesis would have provided some data about the topic, but the rate of response in terms of companies answering would probably have been much

lower and the information received would not have been as detailed, which naturally would have decreased the relevance of the study findings.

3.4 Request for quotation (RFQ)

As a basis for creating the request for quotation (RFQ), the author used Pimenoff's (2009) guide about the cooperation with media offices. The most relevant parts from Pimenoff's (2009: 30) concepts in terms of this study were incorporated into the request for quotation and these concepts were combined with the aspects from the theoretical framework of this study, presented in Figure 4.

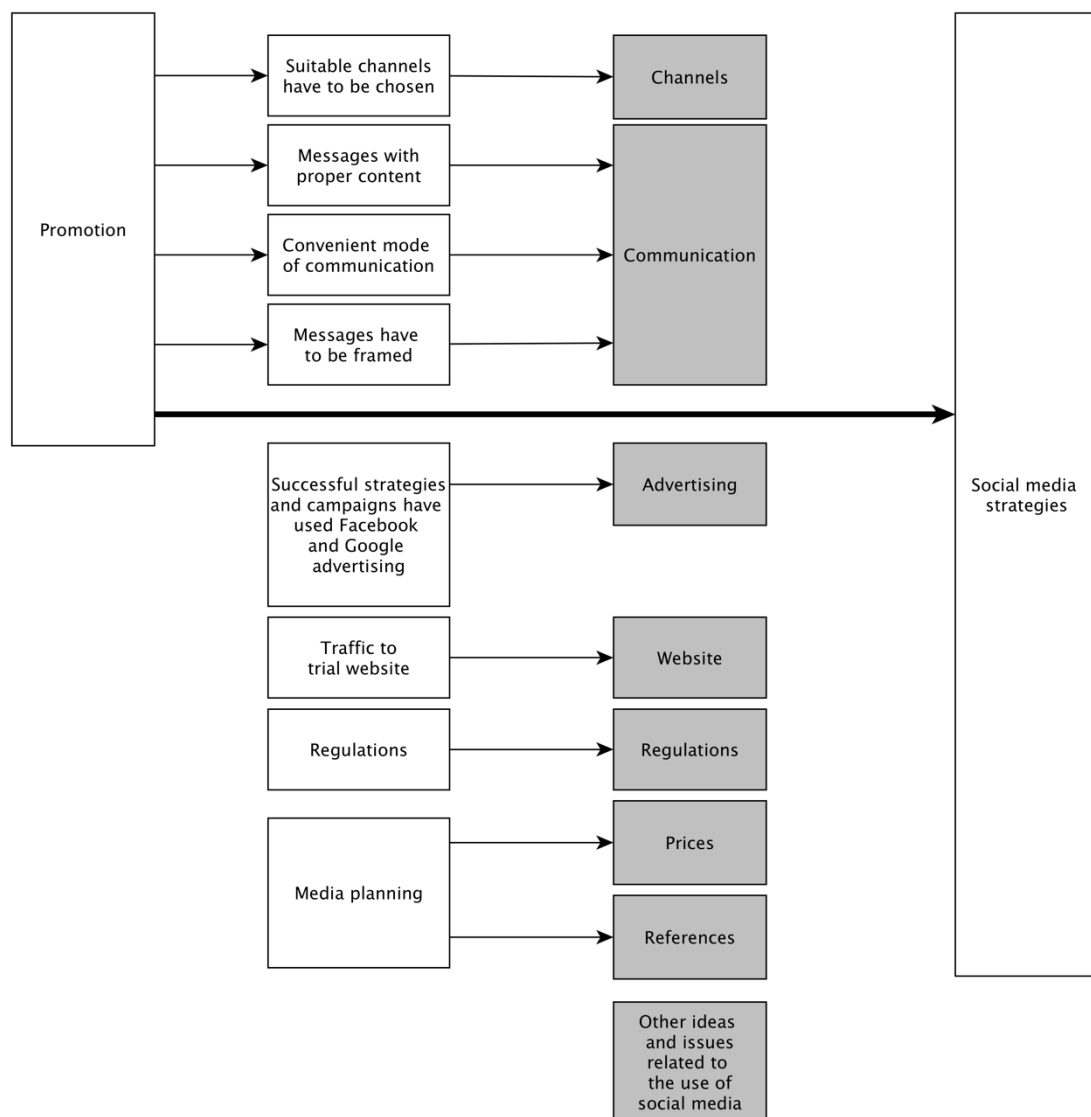


Figure 4. Theoretical base for RFQ.

The request for quotation (RFQ) included an introduction about the Company, presenting it as a Finland based start-up company developing medical devices in the hope of providing a solution for the millions of people around the world who live their lives in pain, both physical and psychological, due to some type of bone deformity. Company's product was described to be an intramedullary implant, that will help lengthen the bones of people with Limb Lengthening Discrepancy in a novel way providing several advantages compared to the standard treatment procedure, which has been used over 60 years. Limb Lengthening Discrepancy (LLD) itself was explained in an understandable manner to significate one leg to be shorter than the other.

The present situation of the Company was described so that the product (implant) will be going into the final round of clinical trials in May at three sites. The companies were told about Company's lack of presence in social media, but also the willingness of the Company to pilot the role of social media in clinical trial patient recruitment was indicated in the RFQ, because the existing data about the effectiveness of the role of social media in this process is limited as indicated earlier in this study (Rosa et al., 2015). Target countries for patient recruitment were explained to be Turkey, Finland and Germany.

The goal of the Company was told to be achieving the target recruitment of 20 patients, which means finding at least 30 patients that fit the criteria of the study. Also the referring surgeons as well as the recruited patients need to be fully briefed about the actions after the surgery ("post-op"). Also the exclusion criteria of the study were presented, as the number of eligible patients is very limited; approximately 8 out of 1,000,000 will be treated for LLD and from this group maybe 10% is suitable for this clinical trial. Company was described to target only patients, who have true Limb Lengthening Discrepancy, not patients seeking cosmetic limb lengthening (meaning lengthening of both legs in order to gain more height). Given the high number of patients seeking cosmetic lengthening, the challenge is to ensure not setting false expectations to this potential customer group in the future.

The RFQ indicated also that each target country (TUR, FIN, GER) has their own specific regulations considering advertising clinical trials. In order to give an example, a link to regulations in the United States was shared.

Based on the theoretical framework of this study, the RFQ presented a preliminary strategy for Company's patient recruitment, including three actions considered. The first action is the creation of a study website, where patients can find more specific information about clinical trials. The second one is the creation of an introductory video for patients about the whole trial process, which will present the trial surgeons explaining the procedure, simple animation of the whole process for patient and their relatives. It will introduce the Company and the principle of the Company's product. It will also outline the rehabilitation process for the patients. The third action is to create a closed Facebook group for the enrolled patients, so the communication with the patients would be easier.

The most important part of the RFQ was the request describing what the chosen companies should include in their quotation. The following six points were asked to be included in the quotation: channels, communication, advertising, other ideas and issues related to the use of social media, references and prices. Target companies were asked to make a suggestion, which social media channels Company should use in patient recruitment, which kind of content to use when communicating in social media, how patients can reach Company and how it was supposed to answer them, as well as the approach of how active to be in social media. Target companies were asked to provide also approaches how to advertise in social media, how to direct potential patient to study website and other social media channels, references and previous experiences from patient recruitment or the medical sector and prices to understand the pricing model. Also the total budget for these possible actions was given by the Company. The quotations were told to be evaluated in terms of content, price and quality, but the most important single factor was to estimate how likely it is to recruit patients through methods provided on the quotation. Additional information was told to be found from the Company website and in case of any questions, the contact person was encouraged to contact the author of this thesis.

3.5 Data analysis

The important question, in terms of data analysis, according to Tuomi and Sarajärvi (2012: 93) is to decide, whether to research similarity or diversity in the material collected. According to Tuomi and Sarajärvi (2012: 95) qualitative analysis includes inductive and deductive analysis. The difference between these methods is based on the logic of reasoning; inductive analysis means an approach starting from individual and going into general, whereas deductive means an approach starting from general and going into individual. The authors remind to take into account also third theoretical approach for reasoning looking for most likely explanation, abductive approach (Tuomi & Sarajärvi, 2012: 95).

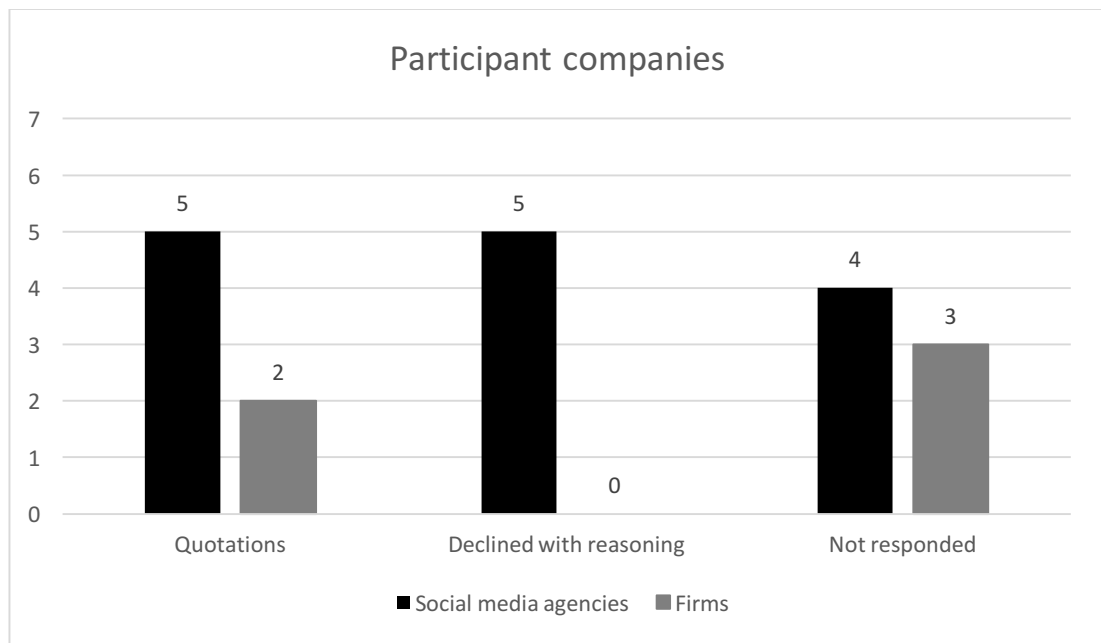
This study is based on theory-bound analysis approach presented by Tuomi and Sarajärvi (2012: 96-97). Theory-bound analysis has connections to theory and it can assist in analysis progress, but it's not directly based on theory. The influence of the earlier knowledge has been identified, but the purpose is not to test the established theoretical framework, but instead to create new approaches. Theory-bound approach enables collecting the data in the most suitable way for the study. First, the analysis will focus on the empirical data, and after that the theoretical framework of this study will be taken as a directive approach for analysis progress. (Tuomi & Sarajärvi, 2012: 96-97)

The logic of reasoning in theory-bound analysis is mainly based on abductive reasoning. The thinking process of the researcher varies from data-driven into existing models, which the researcher derives to combine to each other, and even creating something totally new (Tuomi & Sarajärvi, 2012: 96-97). In addition to abductive reasoning, this study applies also another approach of reasoning in the theory-bound analysis – inductive reasoning, where theory has been brought in to guide the end result (Tuomi & Sarajärvi, 2012: 99-100). The theoretical framework has been taken into account in the later phase of this study in the conclusions (Chapter 4) and this is why the other approach of reasoning is inductive.

3.6 Participant companies

To undertake a comprehensive approach regarding the role of the social media in the recruitment process, 19 companies with high competence in social media use were chosen to participate in the study. These companies were selected by searching Finland based marketing companies with a high level of competence in the use of social media. Due to the lack of actual patient recruitment firms in Finland, and to get a more comprehensive approach on the overall situation, some professional patient recruitment firms outside Finland were also included in this study.

A request for quotation was sent in total to 19 companies including 14 marketing agencies and 5 patient recruitment firms. Companies that were chosen into this study and their quotations will be presented next, but for the privacy of the contact persons and the companies, marketing agencies will be named as Agency 1, Agency 2, etc. and patient recruitment firms as Firm 1, Firm 2 etc. in this study. In total 5 marketing agencies, Agencies 1-5, and 2 patient recruitment firms, Firms 1 and 2 responded with a quotation for Company. For this study, 5 marketing agencies, Agencies 6-10, declined to make a quotation with a reasonable excuse, and 4 marketing agencies, Agencies 11-14, and 3 patient recruitment firms, Firms 3-5 didn't react in any manner for the RFQ. The division of received quotations, declined companies and the ones with no response is demonstrated in Table 2.

Table 2. Companies included in data collection process.

Agency 1 is a Finland based marketing and communications agency with a focus on strategy. They have worked in brand building, public relations, social media, advertising and governmental affairs in the medical industry. Their clients include a med tech giant and top pharmaceutical companies. They have also participated on courses on ethical marketing. Agency 2 is a Finland based marketing agency with core competences in sales promotion and digital marketing. Their services include promotions, merchandising, events, strategies and analytics, inbound marketing and social media as well as campaigns, concepts and materials.

Agency 3 is located in Sweden and this Nordic PR-firm is highly specialized in digital solutions within the PR market. Agency 3 has experience in working with some of the biggest brands in the Nordics. Agency 4 is a Finland based social media agency with core competencies in content, digital and social media strategies, whereas Agency 5 is a Turkey based company providing conventional and digital communication services to the healthcare sector.

Firm 1 is a professional provider of patient recruitment services for clinical trials in Europe. Firm 1 assists companies to develop, manage and monitor recruitment

campaigns in collaboration with study sites. Firm 1 has also developed their own platform to support comprehensive multichannel engagement plans.

Firm 2 is a patient recruitment firm, more specifically a Contract Research Organization (CRO) operating across 20 countries in Europe as well as in the United States providing strategic clinical development solutions for the pharmaceutical, biotechnology and medical device industries.

The contact person of Firm 2 stated in the interview that they do not have previous experience in the use of social media in the patient recruitment process, but regardless were willing to make a quotation. This quotation included two proposals; the first focused on offering study coordinators, which is the core business of Firm 2. The second proposal was co-created by Firm 2 and a partnering creative agency of Firm 2. This partnering agency will be referred to as Firm 2.1. The second proposal was a suggestion for the Company to co-operate with Firm 2.1, which is collaborating on a daily basis with Firm 2 in relation to brand design, visual identity and marketing activities. This research will only consider the second proposal of Firm 2, because the first proposal is not under the subject of this study. Due to this, henceforth, “the proposal of Firm 2” means the second proposal.

3.7 Declined companies

Agency 6 is a Finland based marketing agency providing a wide range of marketing expert services. Agency 6 responded to the request for the quotation that their content and social media units are lacking resources at the moment to focus on this project in such a comprehensive way it would require.

Agency 7 is also a marketing agency in Finland and they declined to submit a quotation, because they do not consider themselves to be the right partner to achieve the goals. Finland based Agency 8 is expertized to Search Engine Optimization (SEO), Pay-Per-Click advertising (PPC) and Conversion Rate Optimization (CRO) and they responded that they will not create a proposal for the Company.

Agency 9 is a Finland based expert in digital customer engagement. They did not make an actual quotation, but they gave a comprehensive response for the RFQ, which is considered in the empirical results of this study. Agency 9 expressed that they do not have a cost-effective method to provide for the Company to achieve the goals nor a professional person expertized on social media.

Agency 10 is an international marketing agency in Finland providing large scale of marketing services. After having discussion about the RFQ with their offices in Germany and Turkey, Agency 10 decided not to submit a quotation, because they could not provide enough value for patient recruitment within the given budget and schedule. The main reason for the refusal is based on the Company's need to increase the social media communities. Because the starting point is zero, Agency 10 does not recognize itself to be the right partner for the Company. Due to the comprehensive response, even when Agency 10 declined to submit a quotation, their relevant ideas and issues have been taken into account in the empirical results of this study. The other 4 marketing agencies, Agencies 11-14 and 3 patient recruitment firms, Firms 3-5, who didn't react in any manner to the sent RFQ, will be not presented more closely in this study.

3.8 Empirical results

The chosen data gathering method enabled the author to collect a remarkable amount of empirical data for this study. To be able to handle, and later on to discuss this amount of data, the research considers a thematising approach presented by Tuomi and Sarajärvi (2012: 93). The thematising approach divides qualitative research into themes which enables the comparison of each theme in the material. The empirical data of this study has been divided into nine (9) themes including recognizing the challenges, strategy, content, advertising, channels, website, social media management, other ideas related to social media and regulations. The RFQ prepared for this study gave guidelines for the division into themes and this has been demonstrated in Figure 5.

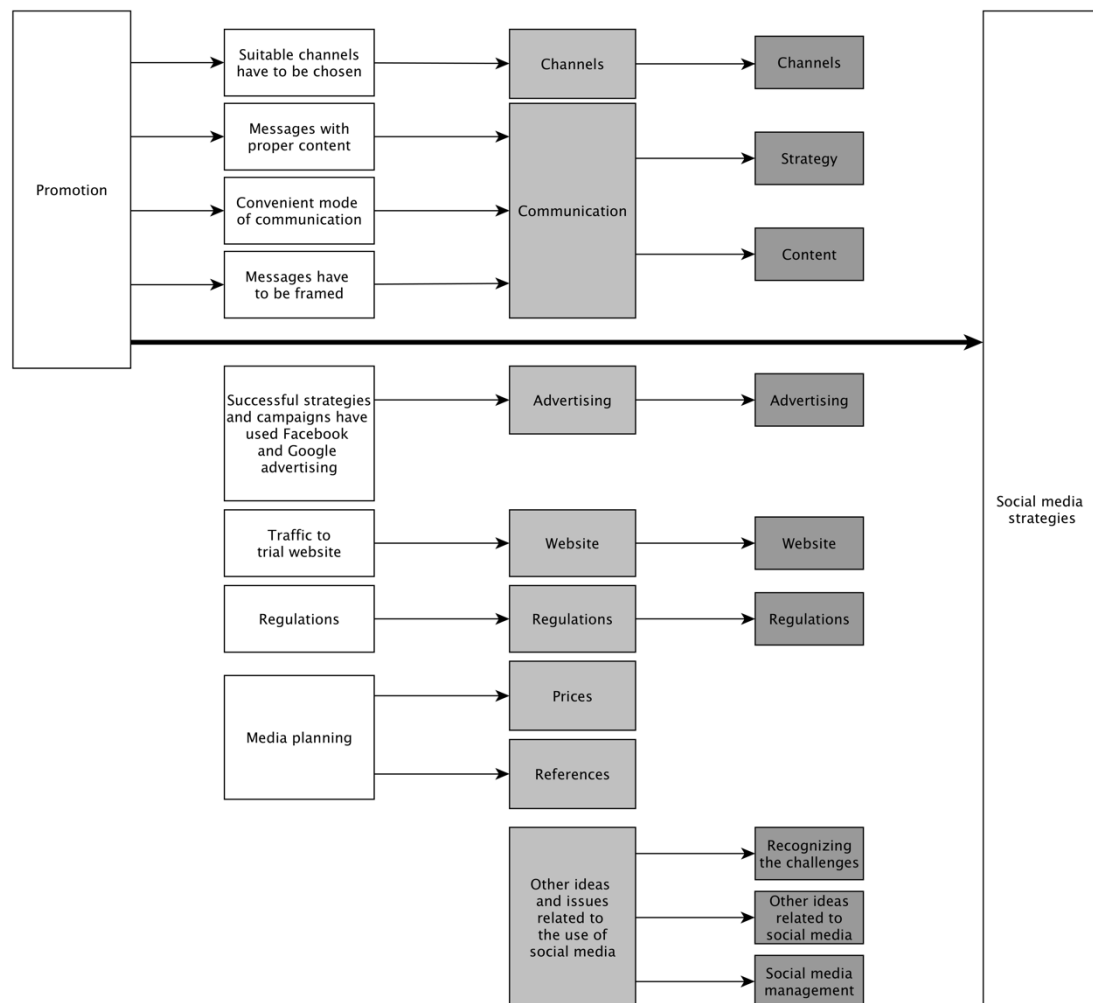


Figure 5. Themes of empirical data.

3.8.1 Recognizing the challenges

Three out of five of marketing agencies, both patient recruitment firms and declined Agencies 9 and 10 recognized the opportunity of using social media to be challenging. All of these companies considered the specific target group and small number of eligible patients to be a challenge. Other challenges indicated by these companies will be presented in the following.

When presenting their view on how to make use of social media when recruiting and engaging patients for a demanding, tough-to-recruit trial, Agency 1 indicates four

challenges in the recruitment process. The first challenge is the small number of eligible patients. Agency 1 emphasizes that despite the possibilities of clearly defined target groups offered by social media, no social media affords targeting options this specific. The second challenge underlines that there is only a little organic content on Limb Lengthening Discrepancy. LLD exists in social media, but the information and communities available there are very limited. For example, a group dedicated into anatomic LLD only has about a 100 members worldwide. This means that normal targeting options, such as targeting members of interest groups at certain regions websites, are not going to be enough.

Challenge number three identified by Agency 1 is that the wrong type of applicants, those who wish to lengthen their limbs for cosmetic reasons or who's LLD is of functional, not anatomic variety, could be interested. Thus, the recruitment communication not only needs to encourage eligible subjects, it also needs to discourage people looking for cosmetic lengthening from contacting the Company to avoid extra work. The fourth challenge considers how to ensure commitment. To succeed, there is a need to recruit patients who are committed and will complete the study. As the procedure involves a recovery phase during which the patient needs to follow instructions, the patients need to be extremely motivated for the study to succeed. So finding eligible patients is not enough, there is a need to get them committed to the cause.

Agency 3 agrees with Agency 1 about narrow target group with a, perhaps, stigmatized need. In addition to the approach of Agency 1, Agency 3 recognizes several issues in the starting position. The first issue concerns the high involvement decision to participate for the study, which will require a lot of information and retargeting. Agency 3 indicates also as challenges the facts that the technology of the Company is unknown and that the test pilot project is to have a high uncertainty of effect. Nevertheless, Agency 3 stresses that it has had many good experiences from other social media campaigns finding different target groups by experimenting with both content and channels and indicates that a test pilot will give many important experiences for Company's future work.

Agency 5 agrees with Agencies 1 and 3 about the issues in recruiting patients for clinical studies when it comes to rare diseases or conditions, with the very low number of eligible patients. Agency 5 adds that specific groups and forums devoted to the subject are non-existent, so targeting members of interest groups will not be sufficient according to Agency 5.

Also Firms 1 and 2 recognize rare disease character and specific and demanding target group as issues in patient recruitment. In addition to that, Firm 2 specifies that a low number of general terms search related to indication, meaning the number of searches related to the disorder is below the minimum required to be registered by Google Trends, is the kind of key information that impacted on their approach.

Declined social media Agencies 9 and 10 agree with each other that the schedule for the campaign is too tight in terms of the goals and the size of the target group. Agency 9 adds that the budget and media are not realizable, and Agency 10 continues that the use of social media for this specific target group is really challenging, especially when starting point for the social media communities is zero.

3.8.2 Strategy

All the social media agencies and patient recruitment firms that answered into the RFQ with a quotation, included some kind of strategy in their quotation as how to recruit patients through social media. Firm 1 presents two strategies how to use social media in patient recruitment. The strategy number one is targeted to the patients and relatives. The goal of this strategy is to increase awareness amongst patients and through this attract motivated and informed patients. Because the target population is “rare”, Firm 1 indicates the targeting to be essential to keep the budget under control. Firm 1 emphasizes that a general Facebook campaign targeting an age group and using cost per click (CPC) might become expensive. According to Firm 1, target patients are actively browsing the internet for information about the condition and for this the use of Google AdWords campaigns can be the solution. Firm 1 also suggests to consider digital advertisement using banners on content related pages, but underlines also that this might be too expensive considering the given budget.

The strategy number two is targeted for “other practitioners” including for instance general practitioners and orthopedists. The goal of this strategy is to increase awareness amongst practitioners and through this improve patient referrals to the novel treatment. Firm 1 suggests to reach professional target population through Google AdWords and professional networks such as LinkedIn and consider digital advertisement using banners on content related pages for healthcare providers. The idea is to set-up an optimized workflow for patient referral by “other practitioners” such as general practitioners and orthopedists by designing a media campaign for “practitioners”. All the “written material” Company has can be used in the campaign, in addition to designing the advertisements, selecting media channels and optimizing the media budget. With the media campaign the aim is to improve awareness of the 3rd generation Limb Lengthening system, improve awareness of the trial for “practitioners” and drive traffic to the study webpage.

Agency 1 agrees with Firm 1 about raising overall awareness of limb lengthening discrepancy to empower patients. In addition to raising the awareness, Agency 1 defines as objectives of the campaign to find, reach and direct the eligible patients to the trial website, to recruit those patients that fit the trial criteria, and to engage and thus enhance commitment of the recruited patients. In order to find LLD sufferers interested in participating in the trial, Agency 1 proposes to use advanced targeting methods combining search words and demographic targeting tools, and as Firm 1, Agency 1 suggests to use Google targeted advertisements for widest reach. Then, this group has to be narrowed down to those patients who actually are eligible to the trial, which can be done with the right kind of content.

Agency 1 also suggests to create a Facebook page to function as a platform for informative posts about the trial. However, the majority of the content on this page would be about LLD, not about the trial. To enhance the visibility of the Facebook page Agency 1 recommends to create a video which aims at being shared. The logic behind all this communication is to build for the future. According to Agency 1, it is a chance to start building a trust within the professional and patient communities as well as a chance to start building anticipation for the treatment and lay a foundation for Company’s brand. For the trial to be carried out successfully, Agency 1

emphasizes the importance to ensure that all the patient communication enforces patient commitment from the start.

A mutual aspect for the strategies of Agency 2 and Agency 1 is the emphasis on content. Agency 2 also agrees with Firm 1 and Agency 1 about the AdWords-advertising. Agency 2 defines the goal of the strategy to be the creation of strong social media presence and to maximize the brand launch reach. The concept to reach this goal is based on the approaches; slogan “Changing people’s lives”, separating Company from the medical environment, and modern storytelling and strong emotional context. The idea of the slogan “Changing people’s lives” is that anyone can feel it, regardless of the country, age, gender or background and that the same concept can be used in Finland, Germany, Turkey, or in any other country. According to Agency 2, when separating Company from the medical environment, the use of emotional content to attract people and spreading information after the attention has been gained are important.

Agency 2 also indicates empathy and helping to be trendy and suggests for a modern storytelling and strong emotional context to collect stories on a video about things that have changed people’s lives. Stories would be the core, but the Company is the brand behind it. For the actual patient recruitment Agency 2 suggests pre-marketing and collecting leads. There is also a possibility to use the concept of Agency 2 as a post-marketing after the medical trial has ended by telling the real patient stories on video like “How the Company changed my life”. As an execution of the campaign, Agency 2 suggests landing page as a pool for all the campaign content, proposes Facebook and Instagram advertising as well as YouTube for the main channels, and considers also social media management approach.

As well as Agencies 1 and 2, also Agency 3 emphasizes the importance of content. When proposing the solution, Agency 3 explains their philosophy to be that they do not know what kind of content works best for each target group, but to get to know, they try out multiple content with different tonality to find out what works best. Through their methods they believe to break the code and find the exact solution to recruit the patients. Agency 3 proposes that due to the short attention span people have in social media, the purpose of communication will be to create interest about

the trials and drive traffic to the website, where more information will be provided. Agency 3 suggests the strategy to include research, creating content, strategic advertising and communication strategy. Agency 3 proposes to focus on the communication strategy, creating content and making sure to find the exactly right patients using strategic digital tools narrowing down the target groups with advertising. Agency 3 agrees with Agencies 1 and 5 as well as Firms 1 and 2, about the use of Google AdWords, but in addition to this Agency 3 recommends also to spend a certain amount of money in advertising expenses for primarily Facebook and Instagram.

Agency 4 proposes to use Facebook as main channel for patient recruitment and Twitter and LinkedIn in a supporting role. People will be directed from social media to fill out a form on Company website or study website and for the communication Agency 4 proposes to create 45 seconds video with Company experts. Agency 4 suggests to target advertisements directly to the most potential candidates and test multiple versions of advertisements simultaneously to see which perform the best in Facebook, Twitter and LinkedIn.

Agency 5 suggests to use 360° (degrees) communication to recruit the patients for clinical trials. Agency 5 emphasizes that although social media's ability to reach and influence individuals seemingly surpasses any other type of traditional method of communication, one cannot risk not to cover all the bases including the conventional methods. According to Agency 5, the Internet is a heavily used resource for medical information and is at least now on par with the traditional model of seeking medical advice through a face-to-face interaction with a healthcare provider. The strategy of Agency 5 is based on the creation of a hub, and making sure the main channel is being fed by every instrument possible is crucial for a successful campaign. Agency 5 shares the idea with Agencies 1 and 3 and Firm 1 about creating a simple, easy to navigate website and generating traffic into it. Agency 5 proposes to create traffic by using social media, advertisement, printed material and Word-Of-Mouth Marketing (WOMM). Agency 5 indicates social media advertisements, sponsored content and boosted posts to be the best ways to reach the target audience amongst the onslaught of content swirling about in the WWW and also suggests to create and grow own interest groups.

As Agency 5 and Firm 1, also Firm 2 indicates study website creation and maintenance as part of the strategy. Firm 2 agrees with all the other companies, apart from Agencies 4 and 5, about the use of Google related services (AdWord). In addition to this, Firm 2 focuses on study branding and media campaign services, including study landing page, module with live advice for patients, Facebook and other social media related services, such as Search Engine Optimization (SEO). Firm 2 suggests also activities on Facebook groups and forums for patients.

Firm 2 divides their proposed concept into 5 stages including research, user profile, preferred message, estimation and country customized approach. The research means conducting a research of spaces in social media that gather possible trial participants as well as identification of groups and forums dedicated to these topics. This leads into a defining and creation of user profile, based on completed research. Preferred message indicates revealing the channels and types of communication preferred by users, as well as the type of statement which is the most efficient. Estimation signifies defining actions that should be taken, and estimate their cost, for example each post on Facebook's fan page is an additional cost of 3 USD, which enhances the range, but scientifically rises the price of actions. Finally, country customized approach contains defining possible different forms and ways of accessing users via Internet, which may be more cost-efficient than social media activities.

Agency 10 declined to create a quotation for Company, but still proposed an idea for the patient recruitment. Agency 10 indicates one of the critical issues to be the increase of the social media communities, where the starting point is zero and encourages to use qualified enquiries to increase these communities.

3.8.3 Content

The solution of Agency 1 is based on three factors; on the same core messages, tone of voice and visual "look and feel" which forms the basis for targeted advertising and community building through the engagement creation. The first step according to Agency 1 is to establish the core messages. With the right kind of content, it is possible to convey a powerful message to the people with the right motivation - anatomic LLD. At the same time, it is possible to discourage the wrong types of

applicants. As the next step, Agency 1 suggests to recognize the suitable tone of voice of all texts and the look and feel of all visuals, which are wanted to be used in the campaign.

Agency 1 presents also more radical approach how to tap into the power of social media. Agency 1 defines that the “social” in social media essentially derives from sharing of thoughts and calls-to-action within one’s own circle of friends, family, co-workers, associates and random people met in passing. This social aspect is what really makes social media special for companies as well. It is the engine which fuels campaigns that really make a difference. A good example of a successful social media campaign is the ice-bucket challenge, which sought to raise awareness of Amyotrophic Lateral Sclerosis (ALS) disease and money to ALS related research. Agency 1 suggests in their quotation to create a sharable video to promote the Facebook page. Because of the goal of recruiting 30 people in few months time, Agency 1 recommends to consider investing in a campaign element, which aims at being shared. This could be a touching video related to living with LLD accompanied with a plea to share the video and a link to the Company’s Facebook site for LLD sufferers – where the actual trial site is then promoted.

Agency 2 suggests as the main content to create a video collecting people’s stories about what has changed their lives by having interviews in Finland in Finnish and providing subtitles in other languages if needed. As an activation, Agency 2 presents an idea: “Say thanks to a person who has helped you to change your life/make change/think twice and win a hot air balloon ride with that person”. Also Agency 4 suggest to create a brief video (45 seconds) to open the recruitment need by using Company’s own experts on video.

Agency 2 suggests to use two types of social media content; emotional and every day content to attract followers, and informational and medical content to build trust. To attract people, Agency 2 suggests emotional campaign page and a video, as well as “Changing people’s life”-theme quotes and photos. To inform people, Agency 2 suggests to present the Company and the patient recruitment, to share informative and medical articles and blog posts and the existing content Company has, and interviewing professionals introducing the method of the treatment.

Agency 3 recommends for the communication to test several contents towards different target groups in order to break the recruitment code. Agency 3 has a pragmatic view upon content; since they do not know what will work, they will find it out by using smart methods and tools. This includes text, pictures, videos, GIFs and other content. By using Facebook's advanced advertisement tool, it is possible to get instant number in what percentage target groups react on the content. The basic idea of the communication is that the patients will reach Company through social media and instant one-button-communication in the feeds and also through the website. Firm 1 emphasizes communication to be a crucial factor in the recruitment campaign and suggests to use all the "written material" Company already has. Firm 2 focuses mainly to provide ideas for the content of website, but mentions also finding out through the definition of user profile, which type of communication and statement is the most efficient in this group.

Agency 5 underlines the importance of having great content to share and to succeed at social media outreach. Agency 5 emphasizes the importance of creating unique content for each platform and encourages to be present in the channels where the audience is. Agency 5 presents that more and more users are consuming media in the same place they are doing their networking, which makes sense to deliver content to them directly and not to take them away from their favourite online communities. This is known as a distributed content strategy. Instead of driving visitors back to a blog or landing page, content should be produced in a way, which allows the audience to remain on the platform they're using. It should be ensured, that each of the chosen social media channels features unique content that differs from one another. This strategy also works in tandem with platforms like Facebook and YouTube which work to keep users contained in the app. As an example, Agency 5 proposes that the trial's LinkedIn channel could showcase behind-the-scenes content and this would differ a lot from the Facebook page, which will be tailored for promoting the website.

Agency 5 suggests to build the social media marketing plan as comprised of strategies for content creation and content curation, which includes types of content to post and promote on social media, frequency, target audience for each type of content, how to promote the content and an editorial calendar. The idea of editorial

calendar is to list the dates and times of blogs, Instagram and Facebook posts, Tweets, and other content by scheduling the messaging in advance, rather than updating constantly throughout the day. According to Agency 5, the editorial calendar gives an opportunity to focus on language and format of these messages rather than writing them on the fly. Agency 5 takes also into consideration that because the campaign will be tri-lingual and tri-cultural, serious modifications will be necessary when designing the messaging.

3.8.4 Advertising

Firm 1 suggests to create the media campaign based on website banners, social media advertisements including Google AdWords, newsletters, classical media, online surveys and patient interest groups to create click-through into the study website. It also indicates to consider the possibility of referral strategy and follow up and emphasizes the importance of communication and well defined processes. Agency 2 instead suggests Facebook and Instagram advertising, as well as retargeting for the people who have visited the landing page.

Agency 1 proceeds in chronological order and proposes that after establishing the core message and tone of voice it is possible to move forward to choosing the correct social media channels and methods. Agency 1 emphasizes that today social media platforms offer highly advanced advertising frameworks that can be tapped into, but Agency 1 still wants to attain organic reach. For the widest reach, Agency 1 suggests to use Google Ads. They demonstrate this approach indicating that when people have a condition which makes their life hard, they Google it. To maximize the reach of the recruitment campaign Agency 1 suggests to harness the power of advertising based on words used on search. This means that people who Google LLD and other related works are then tailed with advertisements of the trial. Targeting advertisements to these people needs to be done by using Google ads, which utilize demographic data along with search words as a means of targeting.

Agency 1 suggests, instead of a one master advertisement for the recruitment campaign, to have several advertisements, and optimize the use of these advertisements based on their performance. Agency 4 agrees with Agency 1 and

suggests also the use of A/B testing with advertisements to test multiple versions of advertisements simultaneously and target the advertisements directly to the most potential candidates, to see which perform best to be able to make a successful campaign. This means that the advertisements which actually lead to a person applying for the trial are more heavily promoted. These advertisements all have a direct call-to-action, which is always an invitation to visit the trial's site. Agency 1 strongly advises to use Google advertising as the backbone of the recruiting campaign and execute the Google banner advertising campaign in all three countries (Finland, Germany and Turkey). However, Google ads alone are not perfect. As LLD is a chronic condition, according to Agency 1 it is unlikely that people who suffer from it, actively Google it within the short time frame of the campaign. This is why the advertisement campaign needs to pick up speed by the other social media means.

Agency 3 agrees with Agency 1 by proposing to build the whole campaign around advertising. According to Agency 3, the point of making regular updates from a Facebook page is zero, due to the limited target group. Agency 3 suggests to create specific advertising account in Facebook Business Manager to create customized target group. By optimizing the advertising to generate traffic to the website it is possible to ensure that as many as possible of the people with the affliction and people in their surrounding are reached.

Agency 5 presents an advertising strategy based on e-recruitment and directing traffic to Company's channels. Agency 5 defines Search Engine Marketing (SEM) as a practice of marketing a business by using paid advertisement, which appear on search engine results pages (or SERPs). Advertisers bid on keywords, which users of services such as Google and Bing might enter when looking for a certain products or services, which gives the advertiser the opportunity for their advertisements to appear alongside results for those search queries. These advertisements, often known by the term pay-per-click advertisements, come in variety of formats. Some are small text-based advertisements whereas others, such as product listing advertisements (PLAs, also known as "Shopping ads") are more visual product-based advertisements, which allow consumers to see important information at-a-glance, such as price and reviews. According to Agency 5, SEM is one of the most effective ways to be found on World Wide Web from millions of other businesses. The

strength of SEM is, according to Agency 5, that it offers advertisers the opportunity to put their advertisements in front of motivated customers who are ready to make a purchase at the precise moment. Agency 5 underlines that no other advertising medium can do this, which is why SEM is so effective and such an amazingly powerful way to grow business.

Agency 5 presents that due to the fact that there are more than 25 million Internet users in Turkey and 92 percent of them are on Facebook, Agency 5 suggests to use Facebook as the main social media channel and to use advertising tools Facebook provides. In addition to Facebook, Agency 5 suggests to advertise on Google, Bing and Yandex to create traffic to website.

Agency 5 indicates to get higher conversions with targeting options by having a control over where the advertisement is displayed, when it goes out and to whom it gets delivered to. Agency 5 proposes to create advertisements easily and quickly by using advertisement formats. Facebook has a variety of advertisement types to choose from, including slideshow advertisements, video advertisements, dynamic advertisements, and more. To review the results, Agency 5 suggests to create custom reports based on the most important metrics. This enables to see top-performing advertisements, where the leads are coming from and how audiences are engaging with the content. Agency 5 emphasizes the need to make all the actions mobile-friendly, as they indicate 80 percent of social network users to access social media via mobile.

Firm 2 suggests targeted digital advertisements, Google Ads and Facebooks Ads for the advertising. These tools are concentrated on value provided by the whiners and live advices, and are targeted at specific group of users. Firm 2 emphasizes the activity on local forums, in blogosphere and Facebook groups, and encourages to share knowledge and promote content among people at least interested in Company's product.

Agency 9 indicates that remarketing is not allowed in paid advertising and estimates that because the target group is so narrow it is almost impossible to reach the right people through advertising. For instance, if Company wants to recruit 30 patients

through social media and less than 1 out of 1,000,000 is suitable for the trials and if 10% of the advertising displays leads to an action, it would require 300,000,000 visitors. This estimation on visitors is based on the assumption that the ad is presented for a random group of people. Nevertheless, Agency 9 indicates that the given budget wouldn't then be in a reasonable use. In Facebook average per click is 0,30€ and if Company would use the whole budget into Facebook, it would get 6,700 clicks, mostly irrelevant clicks.

3.8.5 Channels

Firm 2 considers the study to be country and region characteristic and specific. For instance, even though Facebook is a popular social network, there are other communication channels in each one of these countries which are no less important, and possibly more cost-efficient, i.e. WhatsApp in Turkey, YouTube in Finland and KWICK! and Yappy in Germany.

Firm 1 sums up in their quotation to use Google/Google partners, LinkedIn and Facebook as main channels for patient recruitment. Firm 1 agrees with Firm 2 about the study to be country specific and recommends to limit the campaign to 2 or 1 country to optimize the limited budget (e.g. Finland and Germany) or optimize the campaign only for one country, which would release more budget for advertisement.

For the community building and engagement creation, Agency 1 suggests Facebook as the main channel due to the sheer number of users which can be reached through the channel. Within the Facebook community, there is a chance to promote the trial site and the trial. Furthermore, its private character is best suited for creating true engagement. On top of this, all the other channels have flaws in patient recruitment according to Agency 1. LinkedIn is a professional channel and Instagram does not allow posting links and Twitter's handicap is the poor reach. This is why Agency 1 outlines the solution around Facebook even though using Facebook requires creating an audience, a group interested in LLD, first.

For the main channels Agency 2 names Facebook and Instagram advertising and YouTube. When creating the social media presence, bringing Company close to

people is essential. Facebook will be the easiest channel for people to contact Company. For the advertising, Agency 2 suggests retargeting for the people who have visited the landing page through such channels as Google, YouTube, Facebook and Instagram. For social selling, by training Company employees to spread the campaign, Agency 2 proposes Twitter and LinkedIn for the channels.

Agency 3 suggests Facebook and Instagram to be the primary social media channels that will be used due to the best conditions of micro targeting. The limitations of both Instagram and Facebook are however, that it might be hard to target just the people who meet the criteria. Agency 3 proposes to use Google AdWords to ensure that the right people will be reached – those who may search for information about Limb Lengthening Discrepancy and related search terms. Agency 4 proposes to advertise on Facebook, Twitter and LinkedIn and optimize the advertisements to direct traffic to Company website or the study website. The advertisements are targeted directly to the most potential candidates and with specific targeting.

According to Agency 5, social media, and Facebook in particular, is playing an ever increasing role in medicine as many users depend on their connections and the aggregating nature of social media to identify trustworthy information. Agency 5 continues that due to this utility and prevalence the research community has begun to publish sophisticated Facebook pages dedicated to clinical trials, conditions of interest, and sites of research. According to Agency 5, Facebook is the most popular social media platform with over 71 percent of adults, who are online using Facebook on a regular basis. Agency 5 indicates that Facebook users are also the most active with 70 percent visiting Facebook daily and the most exclusive in that many use Facebook as their only social media outlet. Agency 5 suggests that while there will be considerable earned reach through the physician's pages, significant amount of paid reach can be created through Facebook's very detailed advertising tools with a very good ROI. Agency 5 suggests that YouTube and Uzman TV could be used to share instant articles and video and LinkedIn channel to showcase behind-the-scenes content.

Attempt to reach individuals from the target group through social media and advertising, from the perspective of Agency 9 are not the methods to use. Agency 9

suggests to focus on other channels, such as the network of operating surgeons, publications and magazines from the industry, through which it might be possible to reach the target group.

3.8.6 Website

One of the solutions Firm 2 recommends, is to create product oriented website, which should be treated as a gateway to all channels and services presented. Firm 2 proposes the website to be a dedicated site with live advice for patients, positioning Company as a reliable source of knowledge. Informative materials such as animations explaining the usage of Company's products, the trial and its predictable outcome, as well as sharable infographics describing the product and its use, are the ways Firm 2 suggests to use to distribute knowledge about LLD and Company's product. Through the website it is possible to create immediate value for patients, who are asking questions and receiving answers. This also builds knowledge base with questions and answers. As an example of benchmark Firm 2 mentions askthedoctor.com and stack exchange community. Firm 2 takes also the language approach into consideration and indicates that three language versions are probably needed for the campaign.

Agency 5 indicates the website to be the main information centre for the campaign. Although most of the interaction will take place on social media channels, Company should provide information through the website and the enrolment process should be managed through this channel. Agency 5 suggests that the website should be designed and coded as to be responsive to all kind of mobile tools and also in modular structure which enables to build extra modules easily into it. Agency 5 proposes the website to include the scope of the trial, information about the team, type and group of patients to be recruited, contact information, registration form, the enrolment procedure, compensations and Company info.

Instead of having a website, Agency 2 suggests to create a landing page. About the structure of the landing page Agency 2 agrees with Agency 5 and Firm 2 to include the information about Company and patient recruitment. Agency 2 also proposes to place a contest and brand video named "What has changed your life", a guidance

video about Company and contact form to collect leads on landing page. Also Agency 4 agrees about the idea to reach patients by directing people from social media to fill out a form on Company website or study website and Agency 10 continues by recommending to create an own campaign page with existing tools, for example by Squarespace.

The idea of the strategy for “other practitioners” is to set-up an optimized workflow for patient referral and in addition to improving the awareness, the aim of the actions is to drive traffic to study website. Firm 1 provides also two optional approaches including a launch of a study website by using the platform of Firm 1. Firm 1 emphasizes that this is not necessary as Company will make own study webpage, but they also question how interested candidates will be captured.

Also Agencies 1 and 3 both mention in their strategy driving traffic to the website, for instance through advertising. However, neither of these Agencies widen this approach more.

3.8.7 Social media management

When considering the social media management Agency 2 suggests for a post frequency to be 2-3 times a week and underlines the importance of being present in social media by taking part of the conversation and building a customer service channel. Agency 3 instead indicates that activity in social media is required once a day with minor community management, whereas Agency 4 suggests that during an active campaign phase there should be posts at least two times a week and run at least five different advertisement sets for paid social media.

3.8.8 Other ideas related to social media

Firm 2 implicated a preliminary research about the used search terms, indicating that simpler terms (e.g. “one leg shorter”) bring results in Turkish and English, but are not popular in Germany and Finland. According to preliminary research of Firm 2, the most popular term in all of the target countries is LLD (Leg Length Discrepancy).

Based on that information, Firm 2 states that patients are looking in the web for knowledge, in majority cases, only after they have consulted a specialist.

Firm 2 proposes Search Engine Optimization (SEO) for two month period in all three countries, and for the other ideas, activities on forums connected to the topics, starting a partnership with local bloggers or influencing parents, and testing and evaluating results on other social media channels such as KWICK!, WhatsApp, YouTube and Yappy. The idea of Firm 2 about SEO is completely against the approach of Agency 9, who presents also an idea to use SEO which can place Company in the top of the organic search results, but indicates that this is a long-term building process, which cannot be done in few month time period.

Firm 1 presents a patient recruitment accelerator, which consist of six factors; advertisement builder, monitoring system, webpage builder, registration form builder, secured database and encrypted data sharing. Advertisement builder creates creative advertisements to get noticed, whereas monitoring system is for optimization and reporting. Webpage builder aims to creation of a study website for online presence and the registration form builder to online registration and qualification. Secured database optimizes the registration management and encrypted data sharing the referral management.

The second optional approach that Firm 1 presents focuses to facilitate the contact between “practitioners” and investigators. This can be done by using an online webform for submission by “practitioners” and organizing the follow up by phone with these practitioners with pre-qualification of patient referrals. This would facilitate communication between pre-qualified contacts and study sites for easy referrals.

Agency 2 questions how to use social selling in Twitter and LinkedIn and proposes to focus on the training of Company employees and owners to spread the campaign and to create conversation through their own professional networks. Also securing the PR for the campaign by covering the main PR-channels in Finland, as well as writing, sharing and sending out a press release are the ideas Agency 2 proposes.

Agency 5 indicates that to find out the adjustments needed to be made to social media marketing strategy, constant testing has to be done. For this, Agency 5 proposes to track the number of clicks the links get on particular platform and, to use social media analytics to track the success and reach of social campaigns, to track page visits driven by social media with Google Analytics, and to record and analyse successes and failures, and then adjust the social media marketing plan in response. Agency 3 agrees with Agency 5 about tracking the visitors by proposing to set up a pixel.-code to webpage to track every visitor to make it possible to retarget them.

Agency 5 also emphasizes being aware of the existing algorithms and presents that as soon as logging into a social media site, news feed and online behaviour is being scanned and noted. Agency 5 indicates that most social media platforms use algorithms which are designed to deliver the most relevant content to each individual user – giving preference to posts from family and friend, for instance. Agency 5 suggests to study these formulas closely and understand how they work. Agency 5 presents that on Facebook the posts in News Feed will rank with friends and family first, information second, and entertainment third. According to Agency 5 there are as many as 100,000 factors which influence the Facebook algorithm alone, and most of these factors are based on how users behave and how they interact with the content they like. Due to the consideration, how user behaviour is always changing, Agency 5 recommends to keep up-to-date with how each platform ranks content.

Agency 1 indicates that direct advertising with instant calls-to-action are meant to drive traffic to the trial site, but are very limited in their ability to foster a good relationship with potential candidates from the beginning. This is why Agency 1 wants to take a longer perspective and think one step ahead from the immediate problem at hand. The trial gives a chance to take on thought leadership in treating LLD and build a strong brand within the patient and professional communities. This is why Agency 1 suggests to create an open Facebook page. The site should feature varied content on the issue ranging from alleviation of pain and reasons behind LLD to psychological support. The content should be planned ahead for 2-month time period and the page can be promoted within Facebook with geographic parameters related to the research sites and with parameters, which target those who have followed private medical clinics, preferably orthopedic ones.

In addition to Agency 9 estimation about the reach of advertising, Agency 2 was the only company from all the participant companies, which estimated the campaign reach. This estimation is based on their previous campaigns, and Agency 2 indicates the costs to be 0,45 cents per user reached in Facebook and 0,06€ per view in YouTube. Based on these estimates, for instance within a media budget of 4000€ for Facebook it's possible to reach 888 900 users and media budget of 4000€ to YouTube could give 16 700 views.

3.8.9 Regulations

Agency 1 appoints that all the communication in the heavily regulated medical field requires special expertise, but Agency 1 doesn't indicate regulation as a source of frustration or as an obstacle to creative ideas. Agency 1 emphasizes heavy regulation as an essential building block in establishing trust in the medical industry.

Agency 1 underlines that the promotion should follow along the lines of the instructions of the EU Commission's Ethical committee opinion and feature the following:

1. The research nature of the project
2. The scope of the trial
3. Which type/group of subjects might be included
4. The investigators clinically/scientifically responsible for the trial, if possible or if required by local regulations
5. The person, name, address, organisation, to contact for information
6. That the subject responding will be registered
7. The procedure to contact the interested subjects
8. Any compensations for expenses
9. That a response on the part of a potential subject only significates interest to obtain further information. (EU Commission's Ethical Committee, 2006).

Firm 1 agrees with Agency 1 about the regulations, and instead of presenting specifically different instructions, Firm 1 emphasizes to have a competence to prepare regulatory documents for ethics committee. Also Firm 2 has competence for

regulatory services and indicates substantial amendment submission to introduce listed tools and services.

Agency 5 is familiar with the Turkish healthcare communication regulations and indicates them to be vague and outdated, because regulations were set even before the Internet existed. This is why grey areas are vast and Agency 5 proposes to check every action carefully.

3.9. Discussion

Empirical analysis aims at understanding how to use social media in patient recruitment for clinical trials in a medical device start-up company with very limited number of eligible patients. Empirical findings support theoretical findings, presented in Table 3, in terms of the chosen themes being repeated in various quotations.

Table 3. Themes of the quotations.

	Agency 1	Agency 2	Agency 3	Agency 4	Agency 5	Firm 1	Firm 2	Agency 9 (declined)	Agency 10 (declined)
RECOGNIZING THE CHALLENGES	●		●		○	○	●	○	○
STRATEGY	●	●	●	○	○	●	●		●
CONTENT	●	●	○	○	●	○	○		
ADVERTISING	●	○	●	●	●	●	●	●	
CHANNELS	●	○	●	○	●	○	○	●	
WEBSITE	○	●	○	○	●	●	●		
SOCIAL MEDIA MANAGEMENT		○	○	○					
OTHER IDEAS RELATED TO SOCIAL MEDIA	●	●	○		●	●	●	●	○
REGULATIONS	●				○	●	●		

● = emphasized in a quotation ● = considered in a quotation ○ = mentioned in a quotation Empty = not mentioned in a quotation

The RFQ prepared for the study indicated channels, communication, advertising, website, regulations, prices, references and other ideas and issues related to the use of social media as themes, and aimed to discover how to manage these concepts in

patient recruitment process. Empirical data transformed these themes into recognizing the challenges, strategy, content, advertising, channels, website, social media management, other ideas related to social media and regulations. Budget and references are out of the scope of this study which aims to understand how to use social media in patient recruitment, and due to this, these aspects will not be discussed further in the results of this study.

Table 3 demonstrates how each of the above listed themes were valued by the Agencies and Firms in their quotations. The measurement scale of Table 3 is illustrated with different coloured taps; empty box is the lowest level, meaning that the theme has not been mentioned in a quotation at all, white tap signifies that the theme has been mentioned in a quotation, grey tap means that the theme has been considered in a quotation, and black tap is for the highest level symbolizing that the theme has been emphasized in a quotation. These levels are arbitrary and are based on the evaluation of the researcher which is based on the quotations, how Agencies and Firms ranked each theme and also which themes were seen as most important parts. This estimation was implemented by evaluating how significantly the quotation emphasizes each theme and also how much the theme was emphasized in the RFQ.

Due to the limited number of eligible patients for the clinical trials and the fact that the existing amount of organic content on LLD is very limited and number of general terms search related to indication is low, targeting this specific group without existing communities might be problematic through social media. From the perspective of a potential participant, there is a high involvement decision to participate for the study that uses still unknown technology. However, new treatment method might tempt wrong type of applicants trying to participate for the study. A failure in patient recruitment may lead to a weak commitment for the study, which in the worst scenario can lead into a drop-out from the study.

When creating a strategy how to use social media in patient recruitment for clinical trials, targeting is essential, no matter if the target group itself consists from the patients and relatives or “other practitioners”, such as general practitioners and orthopedists. The use of social media aims to increase awareness, study branding as

well as creating and increasing the social media communities and interest groups where the starting point is zero, in order to find eligible patients for the clinical trials.

Target group is possible to reach through various methods. The right kind of content, whether it is modern storytelling, sharable video (even radical one), or emotional context – enables to deliver a powerful message to the target group, and also discourage the wrong type of applicants. If the right kind of content is not clear after the definition of the target group, it may be found by testing several contents. Editorial calendar enables to plan the content in advance and focus on language and format of messages. The strategy of using content aims to establish interest with emotional and every day content to attract followers, or with informational and medical content to build trust and attempts to drive traffic to a landing page or trial website. Distributed content strategy works on the contrary, by allowing users to stay in the same platform they're using. To monitor and evaluate the content, Facebook's advanced advertisement tool enables to get instant number in what percentage target groups react on the content.

Remarketing is not allowed in paid advertising and because the target group is so narrow, it might be impossible to reach the right people through advertising. A general Facebook campaign targeting an age group and using cost per click (CPC) might become expensive and due to the limited target group the point of making regular updates from a Facebook page is zero. However, through digital advertising, such as Google AdWords, it is possible to utilize the advanced targeting methods combining search words and demographic targeting tools. There can be multiple versions of advertisements simultaneously, because when people have a condition, which makes their life hard they Google it.

Even if SEM is one of the most effective ways to be found on World Wide Web from millions of other businesses, LLD is a chronic condition and it's unlikely that people who suffer from it actively Google it within the short time frame of the campaign. SEO is also a long-term building process, which cannot be done in few month time period. This is why other options, such as banners on content related pages, social media advertising, social media channels Facebook, Instagram and YouTube, as well as advertising on Bing and Yandex, the use of ad formats and specific advertising

account in Facebook Business Manager to create customized target group and sponsored content and boosted posts also need to be considered. The creation of custom reports based on the most important metrics enables to see top-performing advertisements and adapting all the actions mobile-friendly may increase the opportunity to reach right people. In addition to digital advertising, the conventional methods, such as newsletter, classical media, online surveys and patient interest groups, printed material, qualified enquiries and Word-Of-Mouth Marketing (WOMM) are possible ways to reach the right target group.

Even if using Facebook requires to create an audience first, a group of people interested in LLD, it is the most popular social media platform and the easiest channel for people to contact the Company. Facebook is also a suitable channel for community building, engagement creation and promoting the trial. Limiting the campaign to one or two countries requires also country specific channels, such as WhatsApp in Turkey, YouTube in Finland and KWICK! and Yappy in Germany. Twitter and LinkedIn are the most suitable channels for social selling and YouTube and Uzman TV suit for sharing articles and videos. Outside the social media, network of operating surgeons, publications and magazines from the industry as well as activity on local forums and in blogosphere are possible channels to reach the target group.

Dedicated website should be the main information centre for the campaign and it serves as a gateway to all channels positioning Company as a reliable source of knowledge. The website should include informative materials, such as animations explaining the usage of Company's products, the trial and predictable outcome, sharable infographics describing the product and its use, scope of the trial, information about the team, type and group of patients to be recruited, contact information, registration form, the enrolment procedure, compensations and Company info. Providing live advice for patients creates immediate value for patients who are asking questions and receiving answers and this also builds knowledge base with questions and answers. Also the enrolment process can be managed through the website by filling out a form on the site. The website is either created or it is established by using the existing platforms, but it should be designed and coded as to be responsive to all kind of mobile tools and also in modular

structure, and consider different language versions for the campaign. In addition to website, a landing page can be created, including a contest and brand video, a guidance video about Company as well as a contact form to collect leads.

The use of social media literally requires to be social; i.e. being present, taking part of the conversation and building a customer service channel are crucial aspects in social media management. Suggested post frequency and activities in social media vary from two times a week to a once a day.

Patients are looking in the web for knowledge, in majority cases, only after they have consulted a specialist, which is why activities on forums connected to the topics and starting a partnership with local bloggers or influencing parent can be effective ways to reach target group. By focusing to train Company employees and owners, social selling enables to spread the campaign and create conversation through the professional networks of employees and owners. Facilitating the contact between “practitioners” and investigators through an online webform for submission, and organizing the follow up by phone enables easy communication between pre-qualified contacts and study sites for easy referrals.

Through constant testing, for instance by tracking the number of clicks the links get on particular platform, the use of social media analytics, tracking page visits driven by social media with Google Analytics or setting up a pixel.-code to webpage to track every visitor it is possible to conduct retargeting. Also estimating the campaign reach, securing the PR, press release, patient recruitment accelerator, being aware of existing algorithms and keeping up to date with how each platform ranks content might boost the patient recruitment. The use of social media, for instance the creation of an open Facebook page, enables also the creation of a strong social media presence and maximization of brand launch reach.

All the communication in the heavily regulated medical field requires special expertise, and should follow the instructions of the EU Commission’s Ethical committee. This is an essential building block in establishing trust in medical industry.

4 CONCLUSIONS

The aim of this study is to understand how social media can be used in patient recruitment for clinical trials. The topic has been approached from the perspective of social media agencies and patient recruitment firms. This chapter represents the conclusions of the research, including the answer to the research question, theoretical contribution and managerial implications. Also research reliability and limitations, as well as suggestions for future research are presented.

4.1 Research results and answers to the research questions

This study aims to provide proper view on how social media can be used in a patient recruitment process based on the existing literature about the topic and the approaches from the social media agencies and patient recruitment firms.

To be able to discuss about the alternatives how to use social media, it is crucial to understand the factors that affect a decision of an individual whether to participate into a clinical trial or not. Scarce information about the trials and possible benefits, lack of support by patients and families, community leaders and medical centres as well as lack of encouragement to participate by practicing physicians are the kind of factors, which affect the participation of an individual. Comparing these factors with the empirical results of this study generates several findings about the social media use in patient recruitment process. Empirical results answer directly to the issue of scarce information about the trials, by indicating the aim of using the social media to increase awareness and create and increase social media communities and interest groups. Discovery from the empirical results about the idea of targeting patients and relatives, as well as other practitioners, answers directly into the theoretical finding on the lack of encouragement by families and relatives and practicing physicians.

This study looks for an answer to the research question *how to use social media in patient recruitment for clinical trials in a medical device start-up*.

According to this research, *increasing the awareness* and *targeting* are crucial factors, when creating a social media strategy to find patients for clinical trials.

Increasing the awareness and targeting can be implemented through the social media campaign, by using *Facebook and Google advertising* as main channels, and *creating a separate webpage*. These discoveries also support the approach *to use the social media in patient recruitment for clinical trials* in general.

Trying to define just one “correct” target group is not meaningful, and it might be even impossible, but defining a specific target group when planning the social media strategy for patient recruitment is strictly necessary. Whether the target group consist from patients and relatives or physicians, target group definition enables to choose proper methods, such as channels and content, to reach this specific group. This research indicates Google AdWords to be the most suitable channel for advertising due to its advanced targeting methods, even if all the participant companies do not agree about the effectiveness of advertising. To reach and communicate with the right target group, as well as for the community building, Facebook is the best channel. The selection of other channels depends on the target group, which also defines the proper content to use. The website has an important role as an information center and is crucial step for enrolling patients. All these steps aim to increase the awareness about the clinical trials, Company, LLD and the new treatment method.

Nevertheless, participant companies shared very wide range of various approaches how to use social media in patient recruitment. This finding indicates, that due to the lack of established practices and existing processes in the use of social media in patient recruitment for clinical trials, there is not a “right way” to implement the use of social media. With limited number of examples about the successful use of social media in patient recruitment, it is not even confirmed that social media is the right place to conduct the patient recruitment. However, this speculation needs to be carried out before selecting to use social media in the recruitment process.

4.2 Theoretical contribution

This study aims to provide a new approach for existing literature about the use of social media in patient recruitment for clinical trials by introducing views of social media agencies and patient recruitment firms about this process.

Participant companies agree about the difficulty of recruiting patients for clinical trials (Rosa et al., 2015 , Frandsen et al., 2016) by recognizing many challenges in the recruitment process. The recognized challenges are mainly focused on the overall situation and difficulty to find patients by using social media in the patient recruitment, whereas the challenges from theoretical findings are more focused on the challenges that might appear when actually using the social media in the recruitment process.

The main findings of this research are focusing to increase awareness and targeting, which are suggested also by the participant companies. These are directly related to the factors, such as scarce information about the trials and possible benefits, lack of support by patients and families, community leaders and medical centers as well as lack of encouragement to participate by practicing physicians (Reuter et al., 2016, Institute of Medicine, 2012, Ross et al., 1999) affecting a decision of an individual to participate into a clinical trial.

The approach of this study is based on Kotler's 4P's, presented earlier in this study in chapter 2, or actually more precisely to promotion and communication in 7P's model (Galli et al., 2014). Successful promotion and communication requires messages with a proper content, framing these messages, choosing suitable channels, and a convenient mode of communication (Edwards et al., 2002, Patel et al., 2003, Formoso et al., 2007, Hinyard & Kreuter, 2007, Gupta et al. 2015), which is in line with the approaches of social media agencies and patient recruitment firms included in this study, indicating these aspects important in the patient recruitment process.

According to this study, patients are looking for information from the Internet after getting diagnosis (Thompson, 2014) and empirical findings indicate LLD to be the most popular search term, suggesting patients are searching knowledge after having consulted a specialist. Finding a balance between using analogic and digital communication channels (Gupta et al., 2015) and combining conventional and social media strategies in patient recruitment (Frandsen et al., 2016), is in line with empirical findings indicating not to forget the traditional and conventional methods in the recruitment process.

The importance of defining target group and reaching it through different channels meets with the approaches of Kotler et al. (2002) and Galli et al. (2014), who indicate to recognize costs, size, and type of audiences reached by different channels and to decide the suitability of the channels for the content of message and target audience, when choosing which media channels to use. The use of social media also enables to choose the location, such as banner or newsfeed, and the visibility of the advertisement for selected population, which helps to define the amount of money to use on advertising, for instance the valuation of each click on the advertisement (Frandsen et al., 2016). In addition to agreeing about various targeting options, empirical findings support also to estimate the reach of the social media campaign and costs.

When considering the selection of channels, theoretical findings differ from the empirical findings. Especially the role of Twitter as supportive online community (Temkar, 2015), advertising channel (Storrar et al., 2015) and an information source (O'Connor et al., 2014) was not seen an effective channel, and only two Agencies suggested to use Twitter as a channel for advertising. Other differences consider the use of websites and patient communities like Clinicaltrials.gov (Giustini, 2014) and PatientsLikeMe and Doximity (Thompson, 2014), which were not suggested by Agencies and Firms, who instead of proposed to use other social media channels and take into account also country specific factors. Due to the country specific factors, Twitter may not be an efficient channel in these specific countries (FIN, TUR, GER) and the fact that the platforms are in English, makes it difficult to use them in these countries. About the use of Facebook (Frandsen, 2016, Temkar, 2015, Storrar, 2015, Johnson, 2014) and Google advertising (Johnson, 2014) theoretical framework of this study agrees with the empirical findings. The fact that patients also want to communicate through Internet and integrate social media and smartphones into their lives (Temkar, 2015) is directly related into empirical findings approach about making all the actions mobile-friendly.

Galli et al. (2014) also present, that in order to have a powerful communication, misunderstandings need to be corrected and the trial process has to be instructed to participants. The creation of an informative website (Frandsen et al., 2016), might lead to situation, where the participants recruited through the social media have

better overall understanding of the trials than the ones recruited via conventional methods. The creation of website was suggested by various Agencies and Firms, as well as the idea of avoiding drop-outs by having well informed patients raises from the empirical findings.

4.3 Managerial implications

This research provides a novel approach how to use social media in patient recruitment for clinical trials in a medical device start-up, which has very limited group of eligible patients and no previous experience about using social media. Even if Toronto Change Foundation indicated already in year 2011, that missing the best practices in the use of social media creates a barrier to social media adoption, and the results of this research agree that due to the lack of established practices and existing processes in the use of social media in patient recruitment for clinical trials, there is not a “right way” to implement the use of social media, various valuable managerial findings can still be made.

Theoretical framework presented in Figure 1 of this study represents the factors affecting into a decision of an individual to participate into a clinical trial. Understanding these factors is necessary in order to be able to make managerial conclusions. It also enables to analyze different social media strategies, and estimate the probability to recruit patients through these various methods.

The interesting aspect is the wide variation of different strategies the social media agencies and patient recruitment firms suggest to use for the social media. For instance, Firm 2 proposes two totally different concepts, from which the other concept is totally separated from the social media. This can be seen as a sign that at least companies experienced in recruiting patients who already have existing processes for patient recruitment, are uncertain about the effectiveness of using social media in patient recruitment. However, Firm 2 admitted not to have previous experience on social media campaigns, which might have affected their approach. Also suggestions to try multiple contents and channels, as well as constant testing which approach works best, indicates the uncertainty of the best social media actions.

Nevertheless, according to this research and based on the best understanding of the researcher, properly used social media can accelerate patient recruitment into clinical trials, even if it is missing the best practices. This conclusion is based on the assumption that social media is not used as the only strategy for patient recruitment and the role of the social media has been defined clearly in the overall patient recruitment process. Increasing awareness and targeting are crucial for a medical device start-up with a limited number of eligible patients to be successful in recruitment process. Implementing a social media campaign based on Facebook and Google advertising as main channels, and creating a separate webpage seem to be the most effective ways to reach potential participants for clinical trials.

Defining the target group is the most essential action to be made, because it defines basically all the other actions, such as selecting channels, content and advertising. Different kind of target groups need differentiated content, and can be reached through different channels. The country specific approach has to be considered also, because certain channels are more effective in some countries than in others.

Based on the theoretical framework of this study, RFQ presented a preliminary strategy for Company's patient recruitment including the creation of study website, where patients can find more specific information about clinical trials, the creation of an introductory video for patients about the whole trial process, which will present the trial surgeons explaining the procedure, simple animation of the whole process for patient and their relatives, and the creation of a closed Facebook group for the enrolled patients, so the communication with the patients would be easier. These aspects seem to be relevant actions also according to empirical results, even though participant companies suggested to create an open Facebook page instead of a closed group for the recruited patients. Due to the fact that LLD is a chronic condition, it is unlikely that people who suffer from it actively Google it. This is why implementing a social media campaign to generate attraction by using Google advertising is the most effective method according to this research. Facebook instead seem to be the most suitable channel for community building, engagement creation and promoting the trial. Measuring all the actions made in social media is important to analyze the best ways to reach the target group.

When discussing about the regulations, the difference between the participant companies stems from the different level of competences concerning the regulations of these companies. Due to the strong competence about regulations, patient recruitment firms, Firms 1 and 2, do not emphasize the regulations seeing it as obvious part of the patient recruitment process, whereas major part of the Agencies not even mention the regulations, because of the lack of competence in this area. Different levels of competences in regulations requires a careful consideration on which approaches are actually possible to implement in social media. For instance, the slogan “Changing people’s lives” might be questionable to use in the promotion of clinical trials, as it is forbidden to promise to improve the quality of patients’ lives. However, Company should use CRO to review the social media strategy before submitting the strategy for ethics committee. Company has to ensure that all the employees are familiar with the regulation regarding to communication in case it considers to use social selling.

Patients recruited through social media might be better informed than patients recruited in other methods. This probably has positive influence to engagement level of a patient decreasing the possibility for drop-out. According to this research, the use of social media might have an impact also on other aspects in addition to patient recruitment. In addition to potential to recruit patients through social media, the use of social media has an influence on a brand image for a Company, which has no existing presence in social media. This is why all the actions in social media should be planned carefully. Due to the fact that the starting point for Company’s social media communities is zero, Company has a potential to be a pioneer in the use of social media by establishing, or at least assist to establish the community for LLD. It is noted that the proper use of social media enables to strengthen also the brand image.

4.4 Research reliability and limitations

Mäkelä (1990: 53) indicates that to estimate the reliability of a qualitative research it is required to have a clear description of implemented categorization and interpretation, which enables to repeat the study according to these methods and end up into the same results. Also Aaltola and Valli (2007: 82) agree that describing the

research process is not just a part of a research methodology, but also the crucial aspect in terms of research reliability. This is based on an assumption that describing the research process helps the reader to understand the approach of study, as well as the emphasis on theoretical and data analysis. It is important to describe how the data has been collected and which kind of assumptions has been made during the different phases of research process. (Aaltola & Valli, 2007: 82)

The openness in research process helps to analyze the reliability of a research (Aaltola & Valli, 2007: 81) and this study aims to provide as specific description on the research methods as possible in chapter 3. Repeating the study by using the same RFQ should establish at least similar kind of empirical data in terms of empirical themes. The competence of the researcher, for instance the personal approach for a topic and analyzing skills, has naturally developed during the research process. The variety in data collection process, for instance when collecting approaches from the participant companies required some adaptations, which according to Aaltola and Valli (2007: 81) is a natural part of the development process of research. It is important to recognize, which kind of variation happens during the research process in researcher, data collection methods and research subject. This kind of description makes it possible to estimate also the research validity (Aaltola & Valli, 2007: 81).

According to Mäkelä (1990: 53) to be able to estimate the research validity, research requires to describe the deductive reasoning of a researcher in a logical way and provide tools to agree or disagree with the researcher. This research is an interpretation of the researcher of the current study and another researcher might have interpreted the research subject differently, for instance by emphasizing some other aspect more (Aaltola & Valli, 2007: 82). Theoretical framework of this study has been collected from current publications related to the topic, providing a relevant base for further study. The researcher of this study has created as logical description as possible about the research methods, data collection and interpretations, and the reasons behind these choices, aiming to increase the validity of the study.

When estimating the validity of this study, it is favorable to discuss also the approach of data collection method. Participant companies of this study have a natural tendency to provide their services, but this has been considered in the empirical

analysis by estimating the quotations critically by the researcher. Indicating categorization and interpretations made in the research as facts might be impossible to address, but researcher has aimed to provide suitable tools for a reader to estimate the validity of research (Aaltola & Valli, 2007: 83).

Because of the continuous increase in the use of social media and the research concerning to it, this study might lack some of the relevant studies published recently and is limited to studies published before 1st of April in 2017. The theoretical part of this study focuses on social media channels, which the author of this thesis has found most relevant, based on the existing literature about the topic. Therefore, some of the sites, such as Craigslist and Kijiji, which for example Shere, Zhao and Koren (2014) define as social media sites, are being excluded from this study. Due to the researcher's limited resources, the major part of the participant companies are Finland based, but to gain a broader perspective for the subject, and because of the lack of actual patient recruitment firms in Finland, few foreign companies specialized into a patient recruitment have also been included for the study.

4.5 Future research

This research focuses to provide an approach how to use social media in the patient recruitment for clinical trials in a medical device start-up with very limited number of eligible patients. Theoretical framework of this study provides relevant discussion about the role of the social media in patient recruitment in general and empirical data has been gathered from the social media agencies and patient recruitment firms.

At the moment of writing this thesis, these approaches from participant companies haven't been implemented into actual patient recruitment process of a Company, so the effectiveness of these actions is difficult to estimate in practice. According to this study, implementing a social media campaign focusing on targeting and increasing awareness, as well as creating attraction by using Google AdWords, are the most effective methods to use. The future research could benefit this study as basis and research, for instance through quantitative research, how effective these methods indicated in this study actually are when implementing them into a patient recruitment process.

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