



**EXPLORING THE IMPORTANCE OF BRAND IDENTITY FOR
NON-PROFIT ORGANISATIONS**

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*Submitted in partial fulfilment of BA Honours in Strategic Brand Communication
(Part Time) at Vega School, a brand of the Independent Institute of Education (IIE) on 06
November 2017.*

Table of Contents

ABSTRACT.....	4
CHAPTER 1.....	5
1. INTRODUCTION.....	6
1.1 Contextualisation.....	7
1.2 Rationale	8
1.3 Problem statement	8
1.4 Research questions.....	9
1.5 Research objectives	9
CHAPTER 2.....	9
2. LITERATURE REVIEW	10
2.1 Conceptualisation and Theoretical Framework	10
2.2 Non-profit organisations	13
2.2 Research Paradigm.....	14
CHAPTER 3.....	16
3. RESEARCH DESIGN	17
3.1 Research Population	18
3.2 Sampling	19
3.3 Data collection method.....	20
3.4 Data analysis methods.....	23
CHAPTER 4.....	24
4. RESEARCH FINDINGS	25
4.1 Understanding Brand Identity	25
4.2 Strategic Brand Identity System	26
4.3 The importance of Brand Identity	28

CHAPTER 5	28
5. INTERPRETATION OF FINDINGS	30
5.1 Understanding Brand Identity	30
5.2 Strategic Brand Identity System	30
5.3 The importance of Brand Identity	33
6. TRUSTWORTHINESS OF THE STUDY	34
7. ETHICAL CONSIDERATION	35
7.1 Ethical issues: participants	35
7.2 Ethical research: the researcher	36
8. RESEARCH LIMITATIONS	36
9. CONCLUSION	37
REFERENCES	39
Annexure 1: Consent Form	42
Annexure 2: Permission email	43
Annexure 3: Interview Guide	44
Annexure 4: Participant 4 Interview	46
Annexure 5: Ethical Clearance Letter	50
Annexure 6: Participant 2 Interview	51
Annexure 7: Participant 1 Interview	54
Annexure 8: Participant 5 Interview	60
Annexure 9: Participant 3 Interview	65

Figures

Figure 1: Aaker and Joachimsthaler's Strategic Brand Analysis (2000)	11
Figure 2: Aaker & Joachimsthaler's Strategic Identity System (2000).....	12
Figure 3: Aaker & Joachimsthaler's Brand Identity Implementation System (2000).....	12
Figure 4: Aaker's Brand Identity System: Value Proposition, Credibility and Relationship (2000)	13
Figure 5: Wallace Foundation (2017): Steps involved in conducting in-depth interviews...	21

ABSTRACT

Rare Disease South Africa is a Non-Profit Organisation established in support of and, advocating for patients and families affected by rare diseases, in order to improve their quality of life (Rare Disease South Africa, 2017). There are approximately 7,000 different types of rare diseases and disorders, with more being discovered each day (Rare Disease South Africa, 2017). Rare and genetic diseases, and symptoms, tend to be uncommon to most doctors and rare diseases as a whole represent a large medical challenge globally (Rare Disease South Africa, 2017). This together with the lack of financial or market incentives to treat or cure rare diseases poses a serious public health problem that requires the necessary attention (Rare Disease South Africa, 2017). This study aims to make a contribution to the brand identity of Rare Disease South Africa by exploring the importance of brand identity for Non-Profit-Organisations. Brand identity is defined by Aaker (1996) as a set of unique traits that a brand has, which can be used as an identifier and to which a brand aims to create, reflect and maintain. This study explores the current brand identity of RDSA within the framework of Aaker and Joachimisthaler's brand identity model (2000). This study has been conducted by using *Case Study* qualitative research design, approached from an *interpretivist* paradigm point of view, which allowed the researcher to have a subjective dialogue with participants around the topic of the study, in order to uncover inside perspectives, views and meaning through the participants' eyes. The data collection method used for this study was in-depth interviews and qualitative content analysis was employed in analysing collected data. The findings were aligned and analysed within the framework of Aaker and Joachimisthaler's brand identity model, and indicated that Rare Disease South Africa does not have a strong brand identity but understands and acknowledges the importance of having a strong brand identity in order to be unique and to stand out from other Non-Profit Organisations.

CHAPTER 1

1. INTRODUCTION

A Non-Profit Organisation (NPO) is defined by the South African Department of Social Development (2011) in terms of section 1 of the NPO Act, as “a trust, company or other association of persons established for a public purpose and of which its income and property are not distributable to its members or office bearers except as reasonable compensation for services rendered”. Non-Governmental Organisations (NGOs) and community based organisations are collectively known as non-profit organisations (NPOs). In some instance, NPOs are also referred to as Civil Society Organisations (Department of Social Development, 2011). NPOs are organisations that are cause-oriented and are formed and followed by people with a particular common interest. NPOs can also play a role in a variety of humanitarian functions and services, in order to bring the concerns of the society to government and to influence policies, and also to encourage political participation through provision of information (NGO Global Network, 2015). NPOs also depend on sponsorship funding and service volunteers in order to achieve their mission and objectives (NGO Global Network, 2015). In 2015, South Africa had over a hundred thousand registered NPOs (Department of Social Development, 2016). This means that there is a lot of competition within the NPO industry, since all NPOs depend on sponsorship for funding. Therefore, it becomes important for an NPO to be unique and to stand out from other NPOs, in order to attract the attention of sponsors. This means that there must be a distinct positioning of a particular NPO in the mind of sponsors, which can be achieved by addressing the branding issue of that NPO.

Branding has become an important issue for NPOs because “it has been demonstrated that branding can communicate the beliefs and values of an NPO to potential sponsors, and suggests compelling reasons why is might be worthy of support” (Ritchie, et.al., 1998). An NPO can show its uniqueness in branding by having a strong brand identity. Brand Identity being a concept of branding, is defined by Aaker (1996) as “a unique set of brand associations that a brand aspires to create or maintain”. A key to building a strong brand is to develop and implement brand identity to which brand associations can represent what the brand stands for, and also implies a promise to customers (Aaker, 1996). The purpose of this paper is to explore the following topic: ‘The importance of brand identity for Non-Profit Organisation.’ This study focuses on advancing knowledge of brand identity in regard to Rare Disease South Africa’s current brand identity and their understanding of the concept of brand identity and its importance for their organisation.

1.1 Contextualisation

The key concepts utilised for this study are; *Brand, Branding, Brand Identity, Non-Profit Organisations and Rare Disease South Africa*. These were viewed to determine how they link with each other, and how they can be used in conjunction to establish a brand identity that is understood by both employees and stakeholders of an organisation.

A brand is far more than a name and logo - it is 'an organisation's promise to a customer to deliver what the brand stands for' (Aaker, 1996). A brand is also more than just delivering a promise, it is a journey, an evolving relationship based on the experiences and perceptions that a customer creates at every contact point with a brand (Aaker, 1996).

Branding is defined as the process involved in creating a unique name and image for a product in the consumers' mind, mainly through advertising campaigns with a consistent theme and aims to establish a significant and differentiated presence in the market that attracts and retains loyal customers (Branding Dictionary, 2017).

Brand identity is defined by Aaker (1996) as a 'set of associations that an organisation and its brand strategy team aim to create and maintain for a particular brand'. A brand's identity reflects its particular vision and aim, and what it wishes to achieve and be associated with. The framework of this paper is based on Aaker and Joachimisthaler's Brand Identity Model (2000). The model is broken into three systematic categories namely: *Strategic Brand Analysis, Strategic Identity System and Brand Identity Implementation System*. For this study, only the second section of the model (*Strategic Identity System*) which covers elements of brand identity was considered.

An NPO is defined by the South African Department of Social Development in terms of section 1 of the NPO Act, as a trust, company or other association of persons established for a public purpose and of which its income and property are not distributable to its members or office bearers except as reasonable compensation for services rendered. Nongovernmental organisations (NGOs) and community based organisations (CBOs) are collectively known as non-profit organisations (NPOs). In some instance, NPOs are also referred to as Civil Society Organisations (Department of Social Development, 2011).

Rare Disease South Africa is a Non-Profit Organisation in the health category established in support of and, advocating for patients and families affected by are diseases in South Africa.

1.2 Rationale

There are approximately 7,000 different types of rare diseases and disorders, with more being discovered each day (Rare Disease South Africa, 2017). Rare and genetic diseases, and symptoms, tend to be uncommon to most doctors and rare diseases as a whole represent a large medical challenge globally (Rare Disease South Africa, 2017). This together with the lack of financial or market incentives to treat or cure rare diseases poses a serious public health problem that requires the necessary attention (Rare Disease South Africa, 2017).

The subject of this study, RDSA was chosen by the researcher after conducting brand homework about the NPO during the 2017 Vega Brand Challenge. The researcher, at that point, identified that the organisation does not have a strong brand identity which could help communicate messages to stakeholders and assist in their efforts to attract sponsors, especially for a cause that seems to not be receiving the attention it deserves. The researcher found the issue to be of importance, and believed that RDSA needed to focus on building a strong brand identity if it required to gain awareness and to generate sponsorship. Although, NPOs are slowly acknowledging the importance of having a strong brand identity, the NPO Habitat for Humanity in the United State of America which is said to be having a strong brand identity and is currently worth one billion dollars, proves that brand identity should not only be taken seriously by commercial brands but by NPOs as well (Sargeant, et al., 2008).

This study is therefore, about gaining knowledge on the current RDSA brand identity and to explore their understanding of the concept of brand identity in relation to its importance for an NPO. This study also provides an indication of how RDSA can develop a solid brand identity model which may strengthen their brand identity. 'Existing work demonstrates that branding can convey the values and beliefs of an NPO to potential donors and suggest very compelling reasons why it may be worthy of support (Sargeant, et.al., 2008).

1.3 Problem statement

According to RDSA (2017), if all the people diagnosed with rare diseases would live in one country, it would be the World's 3rd most populous country. About 30% of children diagnosed with rare diseases will not live to see their 5th birthday (Rare Disease South Africa, 2017).

This is an alarming fact, and yet the issue surrounding rare diseases seems not to be receiving some priority and attention, or support especially for families affected by rare diseases - this is the fundamental reason to which RDSA was established (Rare Disease South Africa, 2017).

The researcher believes that in between RDSA's efforts to generate funding, signing up volunteers and registering patients, brand identity should also be prioritised and properly addressed, because a strong brand identity may assist in gaining exposure and awareness for the brand which may result in increased funding, volunteers and activists (Sargeant, et al., 2008).

Therefore, the purpose of this study is to explore the importance of brand identity for RDSA. Whether the strength or lack thereof, of RDSA brand identity could influence brand exposure and awareness, stakeholders and increase sponsorship.

1.4 Research questions

This study will focus on answering the following questions:

1. Does RDSA have a relevant brand identity?
2. What are the elements of RDSA brand identity?
3. How important is having a relevant brand identity for RDSA?

1.5 Research objectives

The following are the objectives of this study:

1. To explore the current brand identity of RDSA.
2. To unpack the elements of RDSA brand identity within the framework of Aaker and Joachimisthaler's brand identity model (2000).
3. To explore the importance of having a relevant brand identity for RDSA.

CHAPTER 2

2. LITERATURE REVIEW

2.1 Conceptualisation and Theoretical Framework

Branding has become a strategic and important subject in all sectors of organisations, business and individuals, including NPOs. Branding allows for the ‘recognition of the source or developer of a product and simultaneously affords consumers (either individuals or organisations) to allocate responsibility to a specific distributor or manufacturer’ (Klopper & North, 2015). Kotler and Keller (2016) states that it is important to understand how the brand is perceived by consumers, and also what impact a brand identity strategy has on the formation of these perceptions. These formed perceptions can be described as brand image, which refers to the attributes that consumers afford the brand in order to differentiate it from other brands (Kotler & Keller, 2006). These perceptions are independently formed by consumer in their minds and may not reflect the intended brand image by a particular brand, and can also differ widely from a brand’s true physical characteristics (Kotler & Keller, 2006). Brands are also able to change the consumer perceptions in ways that are not related to the actual characteristics of the product, or service in the case of RDSA (Cant, et.al., 2014).

Products are consumed because of taste or texture, but the product is also perceived in a particular way because of the packaging, logo and product name (Cant, et al., 2014). In the case of NPOs whose brand offering is service, one can therefore say that a donation or sponsorship is provided because of a specific cause, but an NPO is perceived in a particular way because of ‘packaging’ of the service, the logo as well as the NPO name. This means that it is not only the cause that draws donors towards an NPO, but also the way the NPO represents itself, and therefore, how it is perceived by consumers and sponsors, especially in terms of credibility as well as trustworthiness.

Brand Identity being a concept of branding, is defined by Aaker (1996) as “a unique set of brand associations that a brand aspires to create or maintain”. A key to building a strong brand is to develop and implement brand identity to which brand associations can represent what the brand stands for and also implies a promise to customers. The two brand identity gurus whom have explored the concept of brand identity and developed brand identity models/prisms are authors, David Aaker (1996) and Jean-Noel Kapferer (1992).

Aaker and Joachimisthaler's Brand Identity Model (2000) looks at three key elements of a brand; *strategic brand analysis*, *strategic identity system* and *brand identity implementation system*.

The first section which is *strategic brand analysis* looks at three areas of analysis; *customer analysis*, *competitor analysis* and *self-analysis*.



Figure 1: Aaker and Joachimisthaler's Strategic Brand Analysis (2000)

The second section, *strategic identity system*, looks at the characteristics of the brand, being the *essence* of the brand, the *core* and *extended* brand identities. According to (Ciceo, 2013), Aaker alludes to the *core* brand identity as the very 'essence of the brand, its fundament that should remain constant no matter what strategies should involve the brand' (e.g. brand extension). The *extended* brand identity on the other hand, consists of 'elements that provide texture and completeness, as well as adding details in order to portray what the brand stands for in a better way' (Ciceo, 2013). These characteristics have four perspectives on the concept of a brand; *brand as product*, *brand as organisation*, *brand as person* and *brand as symbol*. For the purpose of this study, the researcher believes that this section in particular may be best suited for the development of brand identity of RDSA, because it will allow the researcher to unpack its brand identity in light of its brand *essence*, *core* and *extended* activities which are important in developing a strong and clear brand identity.

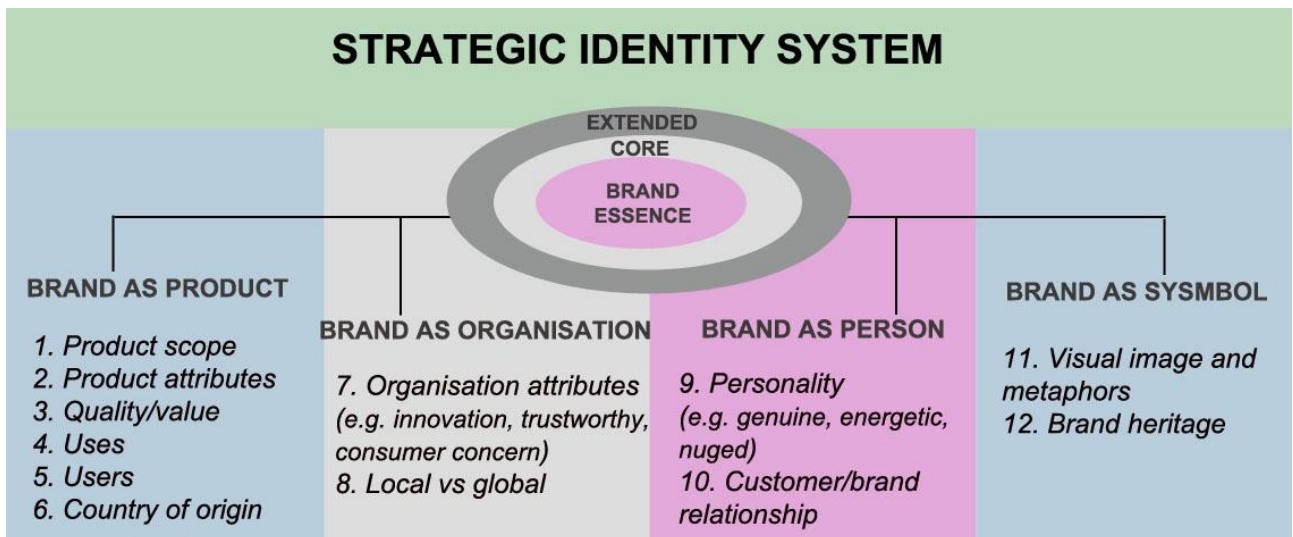


Figure 2: Aaker & Joachimsthaler's Strategic Identity System (2000)

The third and last section within Aaker and Joachimsthaler's brand identity model (2000) is the *brand identity implementation system*, which looks at *brand identity elaboration*, *brand position*, *brand building programs* and *tracking* of brand growth.

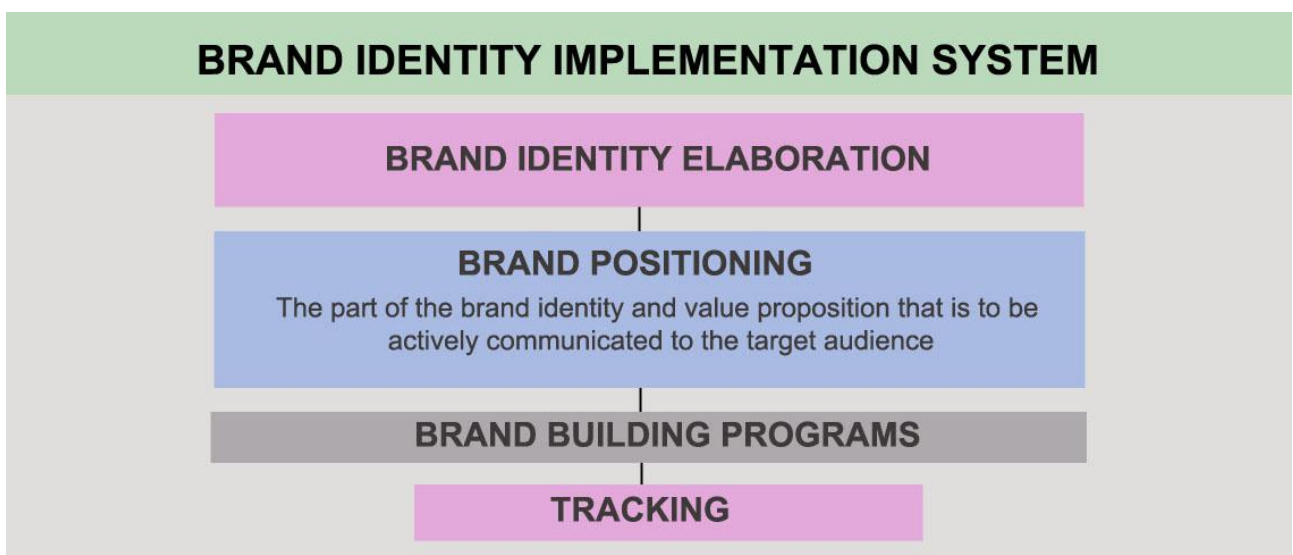


Figure 3: Aaker & Joachimsthaler's Brand Identity Implementation System (2000)

Together, these characteristics (see Figure 4) contribute to the credibility and the value proposition of the brand which may contribute to the relationship between the customer and the brand.

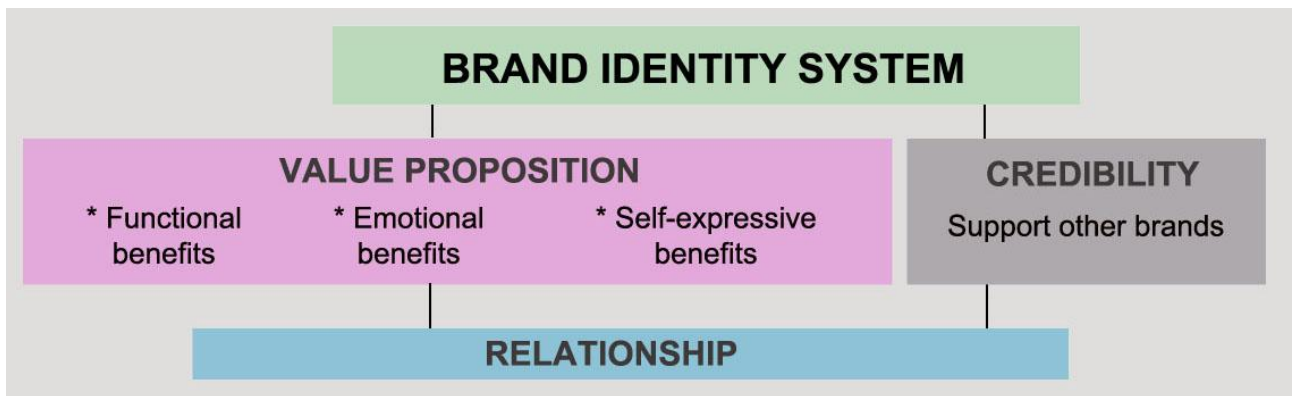


Figure 4: Aaker's Brand Identity System: Value Proposition, Credibility and Relationship (2000)

Aaker (1996) and Kapferer's (1992) brand identity models have similarities but are not identical. For instance, there is a contradiction between Kapferer (1992) and Aaker (1996) in regard to brand personality definition. Aaker (1996) regards brand personality as a whole 'set of human characteristics attributed to a brand', whereby Kapferer (1992) alluded that brand personality would also 'include other three facets of his brand identity model (1992): *physique*, *culture* and *reflection* of consumers', which are also human characteristics (Ciceo, 2013).

The researcher's brand identity model of choice for this study was Aaker and Joachimisthaler's brand identity model (2000), because the researcher believed that their brand identity model allowed for better unpacking of RDSA brand identity.

2.2 Non-profit organisations

An NPO is defined as a 'trust, company or other association of persons established for a public purpose and of which its income and property are not distributable to its members or office bearers except as reasonable compensation for services rendered' (Department of Social Development, 2016). On March 2015, South Africa had 136 453 registered NPOs, to which 8% were health NPOs totalling 11 966 (Department of Social Development, 2016). The subject of this study, RDSA is a health NPO and it finds itself in competition not only with other health NPOs but rather with all NPOs in South Africa. This makes it even more pivotal for the RDSA to have a strong presence and solid brand identity, in order to stand out from other NPOs.

According to (Sargeant, et.al., 2008) 'non-profit branding appears to have come off age'. For example, the United States of America's NPO, the Habitat for Humanity brand was valued at 1.8 billion dollars, reinforcing the significance of the practice of branding to NPOs (Sargeant, et.al., 2008). They furthermore, add that this is well over due.

Non-profit organisations have been relatively 'slow to adopt branding practices as a result of difficulties in committing internal stakeholders to the process, and a perception on the part of some NPO managers that branding is too 'commercial' or even immoral' (Ritchie, et.al., 1998).

Tapp (1996) explains that despite the resistance to use 'commercial' terminology, NPOs have long been concerned with maintaining 'a consistent style and tone of voice and conducting periodic reviews of both policies and actions to ensure that a consistent personality is projected'. And this practice, according to Tapp (1996) is the very essence of brand management, whether organisations management choose to call them such or not.

According to Sargeant, et.al., (2008), this is now ample evidence to suggest that 'an explicit consideration of NPO branding by charity managers is warranted, and not least because it appears that it can impact on income generation'.

'Existing work demonstrates that branding can convey the values and beliefs of an NPO to potential donors and suggest very compelling reasons why it may be worthy of support' (Sargeant, et.al., 2008).

Earlier in this paper, the researcher indicated that she had identified that the subject of this study, RDSA does not seem to have a strong brand identity. However, the researcher believes it is possible for RDSA to develop a brand identity that reflects its values and beliefs, as well as a personality that may be compelling enough to display its worth for support by stakeholders and sponsors.

2.2 Research Paradigm

As cited by Du Plooy-Cilliers (2014), the historical Thomas Kuhn is responsible for coining the term 'paradigm' and he describes it as "a cluster of beliefs which may in a particular discipline influence what should be studied, how research should be done, and how results should be interpreted". A paradigm can therefore, be explained as a structure of assumptions, ways of thinking and beliefs about how the world is perceived, it also includes methodologies that are commonly accepted by researchers in order to guide their behaviour in the process of a research (Wahyuni, 2012). The two main dimensions to distinguish paradigms are *ontology* and *epistemology* (Laughlin, 1995). *Ontology* and *epistemology* 'relate to the nature of knowledge and the development of that knowledge respectively' (Saunders, et.al., 2009). *Ontology* is the view of how one perceives a reality, and where one can perceive that existence of reality is external and independent of social players and their interpretations of it, as described by (Saunders, et.al., 2009).

In light of the subject of this study, RDSA, this may imply, for example, that consumers and stakeholders of RDSA can form brand perceptions outside external influences and existing brand perceptions that may be known to them. However, (Neuman, 2011) on the other hand, believes that 'reality is dependent on social actors and assumes that individuals contribute to social phenomena'. This, in terms of RDSA, may imply that consumers and stakeholders of RDSA would probably not be able to form brand perceptions without either common sense as accumulated from social norms, related media exposure, or prior exposure to social actors in regard to NPOs in general, or RDSA in particular. Furthermore, it is more likely that each individual could form a different perception around the same subject or issue, because people ascribe different meaning to their own experiences and interactions (Du Plooy-Cilliers, 2014).

Epistemology is the beliefs on how to generate knowledge that is understood to be valid and acceptable, as well as how to understand and utilise that knowledge (Saunders, et.al., 2009). For example, common sense guides people in daily living (Du Plooy-Cilliers, 2014). Therefore, one can say that if you want to understand human behaviour, one needs to grasp what people view as common sense, because this may be an essential source of information for understanding people and their perceptions of a brand (Du Plooy-Cilliers, 2014). Researchers utilising the *epistemology* dimension, challenges the idea of objective knowledge and objective truth (Du Plooy-Cilliers, 2014). They see facts as fluid, and embedded within a meaning system (Du Plooy-Cilliers, 2014). For example, should there be a distribution of knowledge that NPOs in South Africa misuse donor funds and steal from beneficiaries – this may be believed as fact and discourage sponsors from making financial contributions towards NPOs. However, should this information later on be changed and South African NPOs now deemed as the best structured, and service oriented NPOs in world, what was seen as factual would therefore have changed (Du Plooy-Cilliers, 2014). Researchers utilising the *epistemology* dimension believes that facts are not objective and neutral, especially in the social sciences. Instead, 'what is factual depends heavily on the context and people's interpretation of information (Du Plooy-Cilliers, 2014). The two main paradigms to be discussed for the purpose of this paper are *positivism* and *interpretivism*. Both (Neuman, 2011) and (Taylor, 2013) explains that *positivists* strive to 'investigate, confirm and predict law-like patterns of behaviour by conducting value-free research to measure social phenomena'.

Positivists 'possess a common belief on the existence of a universal generalisation that can be applied across contexts' (Neuman, 2011). This common belief on the existence of universal generalisation is the reason the researcher does not believe that *positivism* may be suitable for this study.

The researcher believes that *positivism* paradigm has the potential to meet challenges should the subject's brand be approached in the same way as all other NPOs, because *positivists* hold the 'view that there is a single, objective and stable social and physical external reality that is governed by laws' (Du Plooy-Cilliers, 2014). According to the researcher, different NPO brands require different approaches, whereas, *positivists* are of the opinion that a given cause has the same effect on all people, and do not consider the effect that the social, psychological, historical or cultural context can have on behaviour (Du Plooy-Cilliers, 2014).

Interpretivism paradigm developed as a reaction to the shortcomings and limitations of *positivism* (Du Plooy-Cilliers, 2014). *Interpretivists* reject objectivism and a single truth as proposed in *positivism* - they subscribe to what is called *constructivism* (Wahyuni, 2012). *Interpretivists* believe that reality is constructed by social actors and people's perception of it. And they recognise that individuals with their own different experiences and backgrounds contribute to the continuous development of reality existing in their wider social context through social interactions (Wahyuni, 2012).

In reviewing both paradigms, the researcher believed that *interpretivism* paradigm was best suited for this study, because the researcher aimed to understand the social world around the RDSA issue from the experiences and subjective meanings that the people attached to its brand identity. This paradigm allowed the researcher's intention to interact with people and to have a dialogue with participants around the subject issue, in order to uncover inside perspectives and meaning of social phenomena, as opposed to the generalisation approach adopted by *positivist* researchers (Wahyuni, 2012).

CHAPTER 3

3. RESEARCH DESIGN

It was important for the researcher to select a suitable and relevant research design approach prior to conducting this research study. According to Creswell (2009), there are three main research design approaches that could be utilised for a base of a study. However, the applicability of these research designs are dependent on the type of study, as well as the characteristics of each design approach (Creswell, 2009). These research designs are qualitative, quantitative and mixed research designs. In brief, the distinction between quantitative and qualitative approaches refers to 'how the researcher chooses, collects, analyses and interprets data that will serve as evidence', and it also determines the data collection and analysis methods to be used (Bezuidenhout, 2014). Bezuidenhout (2014) furthermore, adds that 'quantitative methods present numerical or statistical data, while qualitative research presents interpretive data'.

For the purpose of this study, the researcher undertook a cross-sectional and exploratory study in order to gather information from primary and secondary research, applying the qualitative research design. These methods and research approaches were selected because they accommodated the data collection tool that was utilised for this study (in-depth interviews), and also because this study was done over a short period of time. Qualitative research design was used because the researcher wanted to understand the qualities of a specific field of inquiry which in this study is the importance of brand identity for RDSA (Visocky O'grady & Visocky O'grady, 2009). Creswell (2009) similarly alludes that the qualitative approach comprises of 'quality data' which is directly pertinent and reliable to serve the specified purpose. This research design approach is especially utilised when the researcher's objective for a study is to understand, explore or describe people's behaviour, themes in behaviours, attitudes or trends, relationship between people's actions, beliefs, motivations and perspectives about a particular phenomena. The key consideration for the researcher was to ensure that the approach warranted *trustworthiness* for research findings (Bezuidenhout, 2014).

The study is exploratory because it aimed to gather information about a topic that had not been undertaken for RDSA and also, the researcher wanted to unpack the elements of RDSA brand identity with the intention to explore the importance of brand identity for RDSA as an organisation (Du Plooy-Cilliers, 2014).

This exploratory research approach focused on gaining insights and understanding and generation of new ideas and assumptions (Eugene & Lynn, 2017).

This study is cross-sectional because it entailed collection of data at and concerning one point in time and the study was also relatively inexpensive and required little time to conduct. The sample selected for this study was not random, as opposed to a longitudinal study which follows the same sample over time and makes repeated observations which may enable the researcher to track changes over time and to relate them to variables that might explain why the changes occur (Eugene & Lynn, 2017).

The selection of these research methods, techniques and approaches were best suited for this study and complemented the research paradigm that the researcher applied, which is the *interpretivism* approach. *Interpretivism* researcher as discussed (see point 3) believes that reality is constructed by social actors and people's perception of it. And they recognise that individuals with their own different experiences and backgrounds contribute to the continuous development of reality existing in their wider social context through social interactions (Wahyuni, 2012).

3.1 Research Population

A population is defined by Wiid and Diggins (2013) as “the total group of people or entities [social artefacts] from whom information is required”. It can therefore be said, that the population was all the individuals or units of interest. According to Vonk (2016), the definition of the study population and the sampling process can affect the validity of the research, that if the study population suffers from sampling error, the study population may not correctly represent the target population. And if the researcher's operational definitions of the target population differ, findings might differ across studies, and this may lead to apparent contradictions among results of study (Vonk, 2016).

The population parameters of this study were as follows:

- *The nature of the population:* a non-profit organisation
- *The size of the population:* a health non-profit organisation
- *The unique characteristics of the population:* The organisation is an NPO and belongs in the category of health NPOs.

Since the researcher had already identified a subject for this study, the target population for this study was RDSA. Accessible population was those members of RDSA based at RDSA Head Office in Fourways, which the researcher actually reached and questioned.

A target population is defined as 'everyone or everything that falls within the population parameters, whereas the accessible population refers only to the section of the population that the researcher will actually include in the study' (Pascoe, 2014).

3.2 Sampling

Sampling is the process of reducing the number of the accessible population to a more manageable number (Pascoe, 2014). A sample represents the members of the study population from whom data is collected (Vonk, 2016). There are two methods that can be used to draw a research sample from a study population:

- *Probability sampling*: Every member of the study population has a known and equal opportunity of being selected for the research sample (Vonk, 2016). According to Pascoe (2014), this method is preferred and therefore often used in quantitative studies, because it removes human bias from the sampling process by using methods that are random and systematic, following a step-by-step procedure.
- *Non-probability sampling*: The probability of a person being selected is unknown (Vonk, 2016). Non-probability sampling is used when it is nearly impossible to determine who the entire population is or when it is difficult to gain access to the entire population (Pascoe, 2014).

A sample chosen, using the non-probability method is different to the sample selected by means of probability sampling, because the elements in the population will not all have an equal opportunity to form part of the sample (Pascoe, 2014). For this reason, the sampling method that best suited this study was non-probability sampling, simply because the sampling method that the researcher applied for this study was purposive sampling. There are 6 main non-probability sampling techniques:

- *Accidental sampling*: this method of sampling 'does not use a sample frame instead; the sample consists of elements that were included purely because they happen to be in the right place at the right time' (Pascoe, 2014).
- *Convenience sampling*: this method of sampling is most used to pre-test questionnaires, and the reason for this is that a sample gathered using convenience sampling can be heavily biased towards the social or professional context of the research (Pascoe, 2014).
- *Purposive sampling*: this method of sampling allows the researcher to 'purposefully choose the elements that she wishes to include in the sample, based on a set list of characteristics' (Pascoe, 2014).

- *Quota sampling*: this sampling method is similar to purposive sampling in that the researcher purposefully chooses her sample (Pascoe, 2014). But differs from purposive sampling on how the sample is drawn to match the ratio of different characteristics of the target population and then allocate proportions to these characteristics (Pascoe, 2014). Pascoe (2014) furthermore, adds that 'this sampling method may assists in making sure that the characteristics stipulated in the target population parameters are represented proportionately in the final sample' (e.g., if RDSA population indicates that females were double the number of males, then the ratio of the study would reflect a 2:1 sample)
- *Snowball sampling*: this method of sampling is used in qualitative research, and similarly to other non-probability sampling methods, the results obtained cannot be generalised to a larger population (Pascoe, 2014). This sampling method makes use of referrals in order to increase the sample size, where participants provide suggestions of others who also fit the population parameter of the study (Pascoe, 2014).
- *Volunteer sampling*: this method of sampling as the name suggests, is 'a sample put together from people who volunteer to participate in the research (Pascoe, 2014). Pascoe (2014) also alludes that this method is not very reliable and tends to provide a lot of flawed research results.

A non-probability purposive sampling method was chosen for this study because the researcher aimed to purposefully select a sample that was easily accessible, and served a specific purpose for the study - based on a set list of characteristics and representation of the population of interest. The sample size was 5 participants who were all members of RDSA based at the Head Office in Fourways, Gauteng.

3.3 Data collection method

Data collection is one of the most important aspects of any research study. The researcher needed to take great care when collecting data, because data that is collected incorrectly may have lead to invalid results and findings (Strydom & Bezuidenhout, 2014).

There are several data collection methods that a researcher can consider when undertaking a qualitative study. Data collection methods are tools in which the researcher considers in order to collect information required for a research study.

For the purpose of this study, data was collected utilising a qualitative data collection method (n-depth interviews) and therefore, quantifiable measurements were not appropriate for researching the lived experiences and experiential meanings of individuals at RDSA (Strydom & Bezuidenhout, 2014). In-depth interviews are a form of conversations, with the primary aim of obtaining information based on open-ended questionnaires, allowing questions to be posed to participants with the aim of learning more about their views, opinions and beliefs about a specific phenomenon (Strydom & Bezuidenhout, 2014).

By using a qualitative data collection method, the researcher obtained a richness and depth of data gathered from RDSA participants.

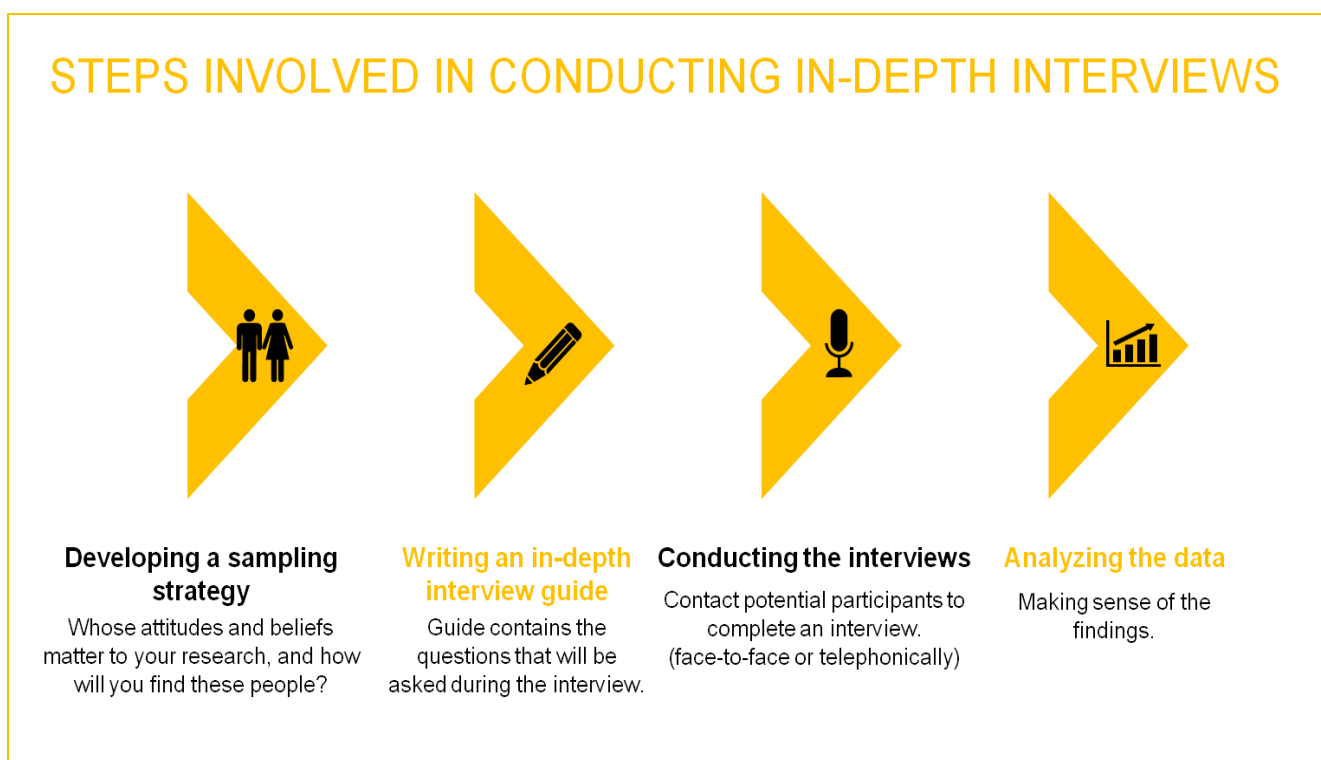


Figure 5: Wallace Foundation (2017): Steps involved in conducting in-depth interviews

In-depth interviews also allowed flexibility and afforded the researcher an opportunity to ask for clarity on points and views made by the participants (Strydom & Bezuidenhout, 2014). The advantages of using in-depth interviews included: the possibility to uncover valuable insights and enabled the researcher to find out the “the real story” from the people in the know; the participants were also able to open up on a one-on-one basis and in-depth interviews allowed for data to be collected faster than other research methods (e.g. focus group, questionnaire) (Wallace Foundation, 2017).

Prior to conducting in-depth interviews, the researcher requested consent of participation and informed the participant of the details on the study and the interview. The 'researcher also modelled the interviews after a normal conversation rather than a formal question and answer exchange,' because the questions that were asked were semi-structured, open-ended and aimed to gather data from a natural perspective of the participant's view and opinions (Taylor, et al., 2015). Semi-structured open-ended questions provided an opportunity for the participants to elaborate further on the topic as they saw fit (Strydom & Bezuidenhout, 2014).

In the effort to make the interview process comfortable for the participants, the researcher met with the participant at the venue and time most convenient to them. The researcher had compiled an in-depth interview guide sheet that assisted both the researcher and participants to stay within the confinements of the topics and themes related to the interview and the research study. The researcher used the in-depth interview guide as what it actually means (just a guide). In commencing the interview, the researcher started with lower intensive questions in order to gain trust of the participant and to develop some relationship. The researcher increased the intensity of the questions gradually and moderately, so as to avoid the participant from feeling attacked and answering defensively. The researcher considered the following, prior and during in-depth interviews:

- Introduced herself and the study.
- Established good 'relationship' with the participant them at ease.
- Listened and observed as the participants were guided through the conversation until all the important issues on the interview guide are explored.
- Became interactive and sensitive to the language and concepts used by the participant, and kept the agenda flexible.

During the interviews, the researcher had the freedom to follow the respondent's train of thought, and recorded the questions when it had suited the flow of the discussion. Questions included suggested probes, follow-up questions in an attempt to explore specific aspects of an issue.

3.4 Data analysis methods

According to (Wahyuni, 2012) data analysis involves the process of filtering raw data, which can involve a number of methods that are applied sequentially, and is called methodological triangulation. Qualitative data analysis is defined by Bezuidenhout and Cronje (2014) as ‘the process of bringing order, structure and meaning to the mass of data’.

For the purpose of this study, the process for analysing collected qualitative data involved reducing the volume of raw information (opinions, words, perceptions, views, beliefs, motivations etc.) by dismantling, segmenting and reassembling data in an effort to identify significant patterns, and to form meaningful findings to which the researcher was able to draw conclusions (Wahyuni, 2012). The researcher conducted qualitative content analysis using the *deductive approach*, because the argument the researcher intended to make was from a general to specific which was achieved by doing several cycles of analysis and interpretations.

When conducting this deductive qualitative content analysis, the researcher used a conceptual framework from Aaker and Joachimisthaler’s brand identity model (2000) in order to identify specific codes within the text which were grouped into specific themes (Bezuidenhout & Cronje, 2014). The researcher also used determined research questions to categorise data, therefore highlighting similarities and differences of sifted data. This approach for data analysis best suited this study because it allowed the researcher to use the second section of Aaker and Joachimisthaler’s brand identity model (2000) - *Strategic Identity System* [please see Figure 3] in order to group the data and identify the surfacing relationships as intended, and in order to achieve research objectives. Data was analysed using the following process of data analysis:

STEP 1: Preparing data

- The researcher organised and transcribed collected raw data (from notes and recordings);
- Transcribed even some data that looked irrelevant at first glance, just in case it could have gained significant in the second or third cycle of coding.

STEP 2: Defining the coding unit

- The researcher then started labelling/coding relevant pieces (e.g., words, phrases, symbols, sentences or paragraphs, actions, activities);

- The researcher also made codes on repetitions of some things and modified codes where necessary.

STEP 3: Developing categories and a conceptual framework

- The researcher decided which codes were most important;
- Created categories/themes by bringing several codes together and also went through codes created on the previous step with a pen to create new codes by combining two or more codes. Some codes were dropped where necessary.

STEP 4: Coding all text

- The researcher labelled categories and decide which are the most relevant and kept those;
- Decided how these categories were connected to each other and described the connection between the categories.

STEP 5: Assessing the coding consistency and results

- The researcher rechecked consistency with which the coding was conducted and described how the categories were connected.
- The researcher used a neutral voice and at this stage data was not interpreted as yet.

STEP 6: Interpretation of data

The results were discussed in detail and interpreted in light of similar previous studies published in relevant scientific journals in the same field, theories, frameworks and concepts.

CHAPTER 4

4. RESEARCH FINDINGS

This chapter presents a report on participants' comments in regard to the topic of the study 'The importance of brand identity for non-profit organisations,' and this is done in consideration of the research questions to this study. This chapter reflects the researcher's attempt to extract knowledge and understanding of the concept of brand identity and its importance for Rare Disease South Africa as an organisation.

The following results to the finding were arrived at through the process of coding that was conducted, and which reflected participants' knowledge and understanding about each question asked in providing answers to the research questions. The process that was followed in the analysis of data alongside determined categories relevant to the research questions is outlined in [section 3.4].

4.1 Understanding Brand Identity

The objective of this section and the research question related to it – "Does RDSA have a relevant brand identity?" was an attempt to extract views that would answer the research question, by gathering information that would allow the researcher to determine whether RDSA understands what brand identity is, and furthermore, what they think is their organisation's current brand identity.

When asked about the concept of Brand Identity, of the five participants that were interviewed, two participants showed a significant understanding about what brand identity means, while the other two participants struggled to clearly express their understanding about the concept of brand identity. Only one participant of the five seemed to have good but somewhat scattered idea and understanding about the concept of brand identity.

With regard to the participants' knowledge about what the current brand identity for RDSA is; three participants (P1, P3 and P4) attempted to provide an answer, but the answers they provided showed no relevant knowledge of the current RDSA brand identity. When asked about the current brand identity of RDSA, participant 1 stated: *"Well, i mean we just launched Living Beyond, so i think aspirational, inspirational, yeah, i think it will be inspirational...is it the kind of answer you are looking for, like what message we are trying to say?"* while Participant 3 stated: *"I think, obviously we've got that whole sort of keyhole look and feel and the reason for that is to almost provide perspective to what's behind the obvious."* Participant 5 thought that there is no brand identity currently, and that what exists is a "wishy-washy" brand identity that needs to be worked on.

Participant 2 had a good understanding about what the current RDSA brand identity means, however, the participant could not specifically state what the organisation's current brand identity is. She responded: *"I am not too involved on the whole brand side, but i think then it says a lot about what we aim for, what our goals are, what we want to achieve, what we want to put out there to the general public."* This display of a lack of knowledge about the specific RDSA brand identity may be an outcome of the NPO paying limited or no attention to its brand identity. This could be credited to the fact that as much as for example, NPOs in First World Countries are coming of age in terms of branding, NPOs in general have been relatively slow to adopt branding practices because of difficulties in committing internal stakeholders to the process and a perception on the part of some NPOs that branding is too commercial (Sargeant, et al., 2008).

4.2 Strategic Brand Identity System

The objective of this section of the study is to explore the elements of brand identity for RDSA within the framework of Aaker and Joachimisthaler's second section of their Brand Identity Model (2000) – *Strategic Identity System*, which looks at brand elements from the perspective of *brand as product*, *brand as organisation*, *brand as person*, *brand as symbol*, as well as the value proposition and relationship as indicated on [figure 2 and 3].

When asked about RDSA as an organisation and the services it renders, all five participants indicated a good and relevant understanding of RDSA's *raison d'être*. In response to the question about RDSA *brand as service*, Participant 3 stated *"providing an organisation where patients can feel supported, and as an organisation we aim to improve the quality of life and provide treatment, life saving treatment. So really, as action, we provide access or we fight for access and to improve the quality of life, but as a service, it is providing that level of support."*

In response to the question about the organisation's attributes, the word that was used in repetition by three participants to explain the main attribute of RDSA *brand as organisation* is 'support' for patients with rare diseases and affected families. Participant 4 felt that 'professionalism' was the ultimate attribute, whereas Participant 5 believed that 'patient advocacy' was the main attribute for RDSA. With regard to the value that RDSA is adding to its stakeholders, all five participants have a mutual understanding of what those values are.

Participant 5 stated that RDSA provide 'happiness' to its patients and affected families, whereas Participant 3 responded: *"We are definitely improving our patient's lives, and we help professionals as well by referring them, because they may not know how to treat these specific patients. Then we can refer patients to them, and having the caregivers know that we are there to support them as well. It's not just about the patients; it's about the whole units."*

In response to the question about the perception about RDSA, both globally and locally; two participants felt that as much 'as they are global leaders for the African continent, they are considered lagging and an underdog in comparison to First World countries'. Participant 3 stated: *"I think in terms of the African continent, we are considered leaders. We are well advanced in comparison to other organisations focusing on rare diseases in Africa."* Participant 2 responded: *"I think initially we were perceived as being the underdog, and now they actually realise that we have a lot to offer."* The other three participants showed no relevant understanding of where RDSA stands globally. The response about the perception locally, showed to be mixed and somewhat contradictory. While three participants could not provide answers because they feel that RDSA is relatively unknown in South Africa, two other participants feel that locally, RDSA is considered an opinion and information leader when it comes to rare disease issues and it is a respected organisation in that regard. Participant 1 stated: *"We haven't really got figures about how people feel about the brand, maybe it's an exercise that we need to do."* Participant 3 responded: *"Definitely as opinion leaders when it comes to rare diseases. We are often thought of for comments and we are probably the most identified group in terms of rare diseases."*

As a person, the personality traits that the participants allocated to RDSA were vast and unique to each participant. This means that the participants each relate differently to the brand. The traits include; strong, fun, ethical, ambitious, brave, creative, juvenile, kind, caring, loud, humble and family oriented. Participant 4 stated: *"Professional, fun, understanding, puts stakeholders first,"* while Participant 2 thought that RDSA personality is: *"Loud, well we try to be loud, creative, family oriented...caring and supportive."* The list of roles that RDSA would play within the relationship with stakeholders were indicated by all five participants as being that of a mother, mentor, supporter, advocate, loving, comforter, educator and collaborative.

As a symbol, all five participants feel that the reason behind the selection of the genetic strand for the logo is literal, because most rare diseases are genetic. Four of five participants did not think there is a metaphor behind the logo but just a literal indication of what their cause is about. When asked if there is meaning behind the selection on the colours, Participant 3 who chose the colours, indicated that teal is her favourite colour and that is the reason behind the colour selection. She stated: *“I like this colour, and that’s what it was when we started...the dark elements are really just to provide a little bit of stability and it can’t be all flair, so it needed a bit of a foundation and stability. So that’s really what it was.”* The other two participants thought that the colours are medically related. Besides Participant 3 who chose the colours - the other four participants who did not participate in the design of the logo and the selection of colours feel that the colours are soothing, calm, inviting, cool, relatable, kind and welcoming. Participant 5 stated: *“Turquoise and grey for me are very common colours and i think they are very soothing, and i think for our patients that’s what we’re trying to do. We are trying to calm and soothe them in every difficult time or space.”* Participant 2 was able to explain the metaphor behind the logo which is a genetic strand. She explained that the different grey shades that are seen inside the genetic strand indicate *“that we are all different, that all the patients are different but still within RDSA, within one family”*. Otherwise, the other four participants found the logo to have no metaphor attached to it but just a literal meaning of a genetic strand.

4.3 The importance of Brand Identity

When asked about their view on the importance of brand identity for RDSA, all five participants felt that it was indeed important for RDSA to have a strong brand identity. The terms used to express the level of importance were vital, hugely, fiercely and very important. All participants feel that a strong brand identity would make RDSA to stand out and by growing its brand awareness and recognition for patients and sponsors, and by generating various support from all stakeholders. Participant 5 stated: *“I think it’s vital and i think it stands for every brand, you need to stand out from the clutter because the less you stand out, the more diluted the support becomes, the more diluted what you do becomes, and the less people will know and recognise you as a brand.”* When asked about what would be the disadvantages of having a weaker brand identity, all five participants felt that a weaker brand identity would result in a lack of awareness and recognition, decreased support and a diluted brand.

Four of five participants also added that a weaker brand identity would lead to RDSA not being able to reach patients that they want to help, that patients would not be able to register with them, so that they would be able to receive help.

CHAPTER 5

5. INTERPRETATION OF FINDINGS

5.1 Understanding Brand Identity

With regard to the concept of brand identity and the current brand identity for RDSA; the findings to this study indicate that members of RDSA have a good understanding of what the concept of brand identity is. According to Aaker (1996) brand identity is defined as those exclusive traits of a brand, that were intentionally created in order to construct an identifier of a particular brand, and to which that brand aims to maintain within the minds of the people. The findings therefore, show that in connection to Aaker's definition of brand identity, members of RDSA understand the concept of brand identity to be relating to an identifier and something that is intentionally created to make an organisation stand out.

It is however, have to be noted that as much as RDSA members understand the meaning of brand identity, none of them had specific knowledge about what the current brand identity of RDSA is. This was credited by one participant to be a result of the infancy stage of the NPO, while the other four participants were not able to provide a relevant answer to the question. This study shows that members of RDSA do not know what the current brand identity of RDSA is. Not knowing the organisation's brand identity means that RDSA does not have an identity which they can use to clearly position themselves in the minds of stakeholders and sponsors. Knowing the service offering of an organisation does not mean knowing the heart and essence of an organisation.

5.2 Strategic Brand Identity System

The following brand identity elements were unpacked in order to determine the current elements to RDSA brand identity. When looking at RDSA brand as an organisation, the findings indicate that three participants feel that 'support' is the main attribute for RDSA. However, based on each participant's entire interview, all of the participants have mentioned the word 'support' more often than any other word throughout their interviews, and this indicates to the researcher that as an organisation the major attribute for RDSA is support. This is because all other attributes mentioned by two participants, such as 'patient advocacy' and 'fighter' could still be covered under the term 'support' because advocating and fighting on behalf of someone is a form of support. Therefore, this study shows that the attribute that defines RDSA as an organisation is that of a supporter.

Instead of looking at RDSA *brand as product*, as it is referred to within the framework of Aaker and Joachimisthaler's brand identity model (2000), the researcher deals with this element as a service, because the organisation is an NPO and renders services to the people in order to improve their quality of life. From the findings, the primary service offering by RDSA is support. The services that are rendered by RDSA under the umbrella term 'support' are; providing diagnosis, access to medical specialists and treatment, advocacy, education and financial support. Support does play a dual role for RDSA, being that of an attribute and a service. This is because RDSA does not offer a product and is rather dealt with from the context of *brand as service*. The elements covered for 'support' as an attribute and as a service are different as indicated because of the variation in context. The value that RDSA is adding to the stakeholders, their primary stakeholder in particular is "relief". This value was not specified as a term by any participant in their responses. However, from the context of their answers, the researcher deducted that the emphasis was on how RDSA provided "relief" to their patients and affected families (relief from feeling alone, relief from high medical bills, relief from getting diagnosis, relief from having access to treatment etc.).

According to Aaker (1996) a brand can be perceived as having a distinctive personality. Aaker (1996) alluded that in the process of putting together an Identity System, a brand would also have to be viewed as if it is a person and allocated personality characteristics, in order to make it relatable to humans. The findings indicate that the way in which the participants relate to the brand as a person is somewhat unique to them. This can be attributed to Aaker's self-expressive benefit, because it appears as if each participant allocated personality traits to RDSA in relation to the value proposition that applies to them and is unique to the relationship they have with the brand. This indicates a failed attempt by RDSA to reach each participant with one message, one focus, one aim and one identity, which then would have been received at least in a similar manner by the participants. Personification of a brand is important because if the brand is viewed in human terms, not only will it inspire people with its desirable human characteristics, it makes it possible for them to develop a 'human' relationship with it (Sergeant, et.al., 2008). The fact that four of five participants identified the brand to be creative, juvenile, loud and fun is concerning to the researcher because of the nature of service that the organisation is rendering and the target audience it wants to reach.

An NPO brand should not want to be seen as juvenile because it may be viewed as incompetent within its field of service (Sergeant, et al., 2008). This may negatively impact the trustworthiness and reliability of the brand. Also, for an NPO brand of the nature of RDSA, the researcher does not feel its personality should be focused on being that which is creative and fun – at least not as an identifying characteristic. According to (Sergeant et.al., 2008), the personality traits of importance that are regarded as appropriate ‘charity’ traits or traits that are ‘charitable’ in nature, are considered to be ‘benevolence’ and ‘progressive’. (Sergeant, et.al., 2008) furthermore, stated that the benevolent characteristics associated with the notion of charity are that of being caring, trustworthy, ethical, supportive, fair, compassionate, honest and helpful. In consideration to the list provided by (Sergeant, et.al., 2008), the researcher believes that having a creative personality would not pull the heartstrings of the people as alluded by Participant 2 to have been the intention of RDSA. The most common traits as identified by all five participants to which the researcher feels would serve the purpose of RDSA is that of having a strong, caring, kind and brave personality with sound values. These traits based on the list provided by (Sergeant, et.al., 2008) and also considering the services rendered by RDSA, would assist in building trust and credibility for the brand. This could result in additional support and brand recognition. Although, there is no indication that the presence of these traits would drive the absolute support or amount that sponsors and individual donors would be willing to give, it is clear as stated by (Sergeant, et.al., 2008) that the presence of these values would be a prerequisite to giving or at least including an organisation within the target audience’s consideration set.

In terms of customer-brand relationship, the findings indicate that RDSA assumes the maternal role, because the organisation appears to be an educator, advocate, mentor, protector, caregiver and supportive. Traits such as compassionate, understanding, welcoming and helpful are typically applied to human-service organisations, irrespective of whether an individual has had a direct experience with the brand or not (Sergeant et.al., 2008). Therefore, in this regard traits mentioned by all five participants concur with what (Sergeant, et.al., 2008) found to have been traits that are typically applied to human-service organisation such as RDSA. A mother is a person who embodies the mentioned roles and as stated by Participant 5: *“a mom wears different hats, and that is what we do depending on who we are dealing with”*.

According to Aaker (1996), a strong symbol can provide a structure and cohesion to a brand's identity and would make it easier to gain recall and recognition. The presence of a strong symbol can be a key ingredient when developing a brand. Aaker and Joachimisthaler's Brand Identity Model highlight two types of symbols to be considered when putting together an Identity System or exploring an existing one and these are: *Visual imagery* and *metaphors*, and *brand heritage*. The logo for RDSA is clear and easy to comprehend. The logo has a literal symbol which is a genetic strand that reflects the cause. The genetic strand instantly informs the receiver that the organisation is within the medical sphere and is dealing with DNA. The colour teal and grey are soothing and calm. With regard to Aaker's and Joachimisthaler's second symbol, *brand heritage*, RDSA brand appears to have a weak brand heritage as it was recently established and it is still trying to find its place within the industry and as a brand.

5.3 The importance of Brand Identity

This section explores the knowledge and understanding of the importance of brand identity for RDSA. The findings show acknowledgement and understanding of the importance of brand identity by the participants. Although, all five participants do not know what the current brand identity of RDSA is, they show a significant understanding of the benefits of having a strong brand identity, as well as the disadvantages of having a weaker brand identity for RDSA. The two benefits that all five participants mutually agree on are, brand awareness and recognition, which they believe once those have been acquired, more of their objectives would be able to be achieved. This concurs with Aaker (1996) view on brand awareness. Aaker (1996) alluded that 'brand awareness, which is often an undervalued asset, has been shown to affect perceptions, liking and even behaviour towards the brand'. Brand awareness can also indicate the success of a brand, its commitment, attribute and substance which can be essential to sponsors and individual donors (Aaker, 1996). It appears that people like the familiar and are most often prepared to allocate all sorts of positive attributes to items that are familiar to them.

The findings shows that a strong brand identity is pivotal for RDSA, although as it stands, is has no clear or relevant brand identity in place. It also appears that RDSA is starting to pay attention to its brand identity and it is an issue they are currently working on. The logic of the matter in regard to brand identity and brand awareness is that if a brand is recognised, there must be a reason for that (Aaker, 1996). Awareness can affect whether a brand is recalled, most especially at a key time in the donating process (Aaker, 1996).

The findings also show that as an NPO, RDSA appears not to have the budget to source the service of a professional to address the brand identity system issue, but they are doing the most with the current team they have. They have also alluded to have received good ideas from Vega students during the *Brand Challenge* presentations that they are working on implementing for their brand identity system.

6. TRUSTWORTHINESS OF THE STUDY

Qualitative research is conducted to promote understanding of particular phenomena within a specific context, and it is not used for the purpose of generalising results to broader populations. Qualitative researchers do not use numerical data as evidence, they use different criteria to determine the *trustworthiness*, or *credibility* of research findings. Qualitative researchers use *credibility*, *transferability*, *dependability* and *confirmability*, in order to measure the *trustworthiness* of a qualitative study (Koonin, 2014). Quantitative researchers measure their research studies based on the validity and reliability of the study, whereas, the overreaching term that is used for validity and reliability in qualitative research is '*trustworthiness*' (Koonin, 2014). There are four criteria of research '*trustworthiness*' developed by Lincon and Cuba (1985) and are discussed as follows:

- *Credibility*: refers to the accuracy with which the researcher interpreted the data that were provided by the participants (Koonin, 2014). This study is credible because it measured what was intended, and was able to answer determined research questions; the researcher selected a relevant case study to answer determined research questions; the sample was selected from the relevant population which in this case was RDSA members whom the researcher needed answers from; relevant research methods and design were also selected and coupled with a relevant data collection method and paradigm that best suited this study.
- *Transferability*: refers to the ability of the findings to be applied to a similar situation and delivering similar results (Koonin, 2014). Although this study was conducted in a short period of time, the researcher believes that this study is somewhat transferable and may allow for generalisation of the findings across health NPOs in South Africa, and also trusts that the results acquired from this study may be applied beyond this specific research project.

While it is certain that data from qualitative study is not reproducible, it is not impossible to apply a qualitative study in a different setting with some adjustment that can be done in the setting, therefore, findings of this study have the possibility of being transferred into a different study within the NPO sector (Wahyuni, 2012).

- *Dependability*: refers to the quality of the process of integration that takes place between the data collection method, data analysis and the theory generated from the data (Koonin, 2014). Dependability corresponds to the notion of repeatability or replicability of a study (Wahyuni, 2012). Because dependability can be achieved by a detailed explanation of the research design and process to enable future researchers to follow a similar research framework, however, the researcher is not confident in the dependability of this study because this study was conducted over a short period of time and on a smaller sample (Wahyuni, 2012). Even though, the researcher believes that the data collection method is relevant and appropriate for this study, as well as careful attention was paid into analysing collected data, and best suited qualitative data analysis method and process were also utilised for this study.
- *Confirmability*: refers to the extent to which others can confirm the findings in order ensure that the results reflect the experiences and understanding of the participants and not the researcher's preferences (Wahyuni, 2012). The researcher believes that this study is confirmable because the researcher has described the research process fully and clearly in order to assist other interested researchers in scrutinising the research findings of this study.

7. ETHICAL CONSIDERATIONS

For the researcher, ethics are a moral or professional code that sets a standard for the researcher's attitude and behaviour (Louw, 2014). For this study, the researcher sent an email to RDSA to request permission to conduct this study, and was given authorisation by the Chief Executive Officer and Founder of RDSA, Kelly du Plessis (see Annexure 2).

7.1 Ethical issues: participants

According to Louw (2014), there are a number of important ethical issues that affect the participants when undertaking a research to which the researcher should respect and uphold at all times.

The researcher started by briefing the participants about the study and the voluntary nature of their participation; informed participants about what the interview was about and emphasised on the confidentiality and anonymity of the study; the participants were then given a consent form that was signed by both the participants and the researcher.

Lastly, the researcher asked the participants for permission to record the interview. In the process of data collection, the researcher prioritised on participants' physical and psychological comfort by being gentle and friendly; avoided keeping them for long in the interviews; communicated effectively with participants and managed the research process sensitively and with respect; no harm was done to the participants in any way; and at the end of the interview, the researcher provided an opportunity to the participants to add to the interview or make additional comments about information that they may have wanted to share and was not covered during the interview.

7.2 Ethical research: the researcher

According to Louw (2014), apart from ethical issues concerning research participants, there are several ways in which the researcher's approach to data analysis and data reporting can be unethical. For the purpose of this study, the researcher did not falsify information or changed data to get a desired research outcome or for any other reason; the researcher kept to the interview guide and themes related to the topic of the study and did not emphasise certain aspect of the study over other aspects of equal significance which could have distorted interpretation of data; did not utilise data collected from participants of this study for any other purposes other than what it is meant for; understood the responsibility to protect the participants of the study, and the researcher did not use research methods that were harmful to participants or unsuited to the stated purpose of results.

8. RESEARCH LIMITATIONS

Limitations are described as restrictions or limits in a study that are out of control of the researcher, such as time, financial resources and access to information (Enslin, 2014). The limitations for this study that the researcher encountered were time and number of participants. The biggest limitation with in-depth interviews data analysis lies in being overwhelmed by the quantity of 'verbal data' there is to analyse, and the time required for data analysis. This study was conducted over a short period and provided limited time for data collection, transcribing, data analysis and interpretation, and presentation in the final report.

The researcher would have preferred to have had a larger sample and enough time for data analysis and interpretation, so that this study would be more robust, especially in regard to the sample size and *transferability* of the study.

Because as alluded by Lincoln and Guba (1985), the enhancement of the *transferability* of 'a qualitative study requires a 'rich' and 'thick' explanation of research sites and characteristics of case organisations'.

9. CONCLUSION

This study found that in terms of the current brand identity for RDSA, the organisation does not have a brand identity that can be used as an identifier for their brand. The members of RDSA do not know what the current RDSA brand identity is and this should be a concerning matter of RDSA. The study showed that members of RDSA have a good understanding of what the concept of brand identity is, and were able to articulate the benefits of having a strong brand identity and the disadvantages of having a weaker brand identity for an NPO. This indicates that the reason behind the lack of knowledge about RDSA current brand identity is not that members do not know or understand what brand identity is, but could be credited to failure to paying formal attention to RDSA brand identity and in understanding its importance for their organisation, as alluded by (Sargeant, et al., 2008) that the slow adoption of branding by NPOs is because of the difficulty in getting internal stakeholders to commit or that some NPOs find branding to be a commercial issue and not necessarily something that is of importance or priority for NPOs. The other factor for RDSA could be the lack of funds to outsource a professional in helping them put together a relevant brand identity.

The unpacking of this study provided an indication of traits for RDSA that can be utilised in creating a strong brand identity. When RDSA brand identity elements were unpacked within the framework of Aaker and Joachimisthaler's brand identity model (2000), RDSA as a person appeared to be strong, brave, caring and kind with sound values; playing a maternal role in the relationship with stakeholders by providing vast support an advocacy as a service to the public, and to which its value-proposition is 'relief'. From this suggested brand identity, RDSA will be enabled to communicate its brand identity in one voice to its target audience and stakeholders, because as alluded by (Sargeant, et al., 2008), the personification of a brand is critical, because when a brand is viewed in human terms, not only does it inspire people, it makes it easier for them to relate to the pseudo-human characteristics reflected by the brand.

A stronger brand identity will gain RDSA brand awareness and recognition, which will help them in their efforts to increase funding, increase patient registrations, acquire credibility and trustworthiness (Aaker, 1996).

The purpose of this study was to explore the importance of brand identity for NPOs and RDSA in particular. Research questions and objectives were determined in the beginning of this study, which gave this study a direction in terms of answers that this study needed to provide. In this study, the research objectives were reached, the research problem was also solved, and all three research questions were answered.

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Annexure 1: Consent Form

CONSENT TO PARTICIPATE IN A QUALITATIVE RESEARCH STUDY IN-DEPTH INTERVIEW

**Please Initial
box:**

I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any question or questions, I am free to decline.

☐

I understand that my responses will be kept strictly confidential. I understand that I will be anonymous, that my name will not be linked with the research materials.

☐

I agree for this interview to be digitally recorded. I understand that the audio recording made of this interview will be used only for analysis and that extracts from the interview, from which I would not be personally identified, may be used in any conference presentation, report or journal article developed because of the research. I understand that no other use will be made of the recording without my written permission, and that no one outside the research team will be allowed access to the original recording.

☐

I agree that my anonymised data will be kept for future research purposes such as publications related to this study after the completion of the study.

☐

I agree to take part in this interview.

☐

I have read and understood the information provided above.

AKA of participant

Date

Signature

Researcher

Date

Signature

Once this has been signed by all parties the participant should receive a copy of the signed and dated participant consent form. A copy of the signed and dated consent form should be placed in the main project file which must be kept in a secure location.

Annexure 2: Permission email

PERMISSION EMAIL: RDSA

From: **Mimi Sithole** mims.sithole@gmail.com

Good evening Kelly,

Thank you for your response, much appreciated!

Yes, Skype is ok, when would you be available for the interview, I will require up to an hour with you?

I need to interview 5 people from RDSA. Would you perhaps recommend 4 other people I can interview as well? I will accommodate the venue and time they are available on.

Kind regards,

Mimi

From: **Kelly du Plessis** info@rarediseases.co.za

Maybe it will be easier then for you to come to our office in fourways one day and do us all on the same day?

Kind Regards,

Kelly du Plessis

Rare Disease South Africa: CEO

INTERVIEW GUIDE

Introduction

Hi, my name is **Mirriam Lethole** I am an honours student at Vega School of Brand Leadership, and i am doing an academic qualitative research on 'Exploring the importance of Brand Identity for Non-Profit Organisations', to which this interview is about.

I would like to thank you for agreeing to meet with me, and for allowing me to conduct this interview. Before we begin, please may i ask you to sign the consent form?

Interview time: 1hr max

Please be open, honest and free to express your opinions and feelings of the questions being asked. There are no right or wrong answers because I am just looking for different perspectives and views. And if you have questions or additional comments, you can do so at any time during the interview. Please note that your participation is voluntary and that you can freely withdraw at any time without giving any reason and without there being any negative consequences.

I would also like to ask for your permission to record this interview. The recording is for the purpose of capturing all the details of the interview, and for me to be able to continue on an attentive conversation with you. All your personal information will remain confidential and I will be compiling a report which will contain all comments, but please note that all your responses will be kept anonymous.

A. PARTICIPANT'S INFORMATION

Firstly, I would just like to ask you some basic questions relating to your 'employment':

1. What is your 'job' title here at RDSA?
2. How many years have you been with RDSA? (participating/working/volunteering)

B. EXPLORING CURRENT RDSA BRAND IDENTITY

3. What do you understand about the concept of brand identity?
4. As a person who in involved with RDSA, what would you say is the current brand identity of RDSA?

C. UNPACKING ELEMENTS OF RDSA BRAND IDENTITY

RDSA Brand as a product/service

5. According to you, what is the service that RDSA gives to the people?
6. What would you say are the attributes of RDSA's service offering? In other words, what does RDSA wants to achieve by rendering these services?
7. From the services that RDSA is offering, what value would you say this organisation is adding to everyone who is somewhat involved with it? (e.g., beneficiaries, sponsors, caregivers, volunteers, health practitioners)

RDSA Brand as organisation

8. What would you say RDSA is more concerned about as an organisation when it comes to the perception it wants to put across to everyone? (e.g., innovation, stakeholder concerns, trustworthiness)
9. I believe that RDSA participates in global activities (such as Rare X and the International Conference on Rare Diseases), how would you say RDSA is perceived globally as an organisation?
10. How would you say RDSA is perceived locally as an organisation?

RDSA Brand as person

11. When you think of RDSA as a person, how would you describe its personality?
12. Again, when you think of RDSA as a person that is in a relationship with its stakeholders, how would you describe the role it would play within the relationship? (e.g., nurturer, confidant, companion, friend)

RDSA Brand as Symbol

13. (first show the participant the logo) Do you think that there is a meaning or reason behind the visual image of RDSA?
 - a. Logo
 - b. Colours
 - c. Metaphors

(Probe: would you say there is a metaphor behind the design and selection of the logo and colours?)

- (RDSA founder): Is there any special story behind the design and selection of RDSA visual images?

(Probe: would you say there is a metaphor behind the design and selection of the logo and colours?)

D. THE IMPORTANCE OF A RELEVANT/STRONG BRAND IDENTITY FOR RDSA

The following is a list of questions designed to gather information about the knowledge or understanding of the importance of brand identity for RDSA.

14. There are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, especially in comparison with other NPOs in South Africa?
15. What benefits to RDSA do you think may come about from having a strong brand identity in the NPO market?
16. What do you think may be major disadvantages/implications for any NPO with a weak/irrelevant brand identity?
17. Based on our discussion, what would be your key view or understanding about the importance of brand identity for Non-Profit Organisations?

Annexure 4: Participant 4 Interview

INTERVIEW: PARTICIPANT 4

Researcher: Firstly, I would just like to ask you some basic questions relating to your employment. What is your jo.8b title here at RDSA currently?

P4: I'm an Intern for the Communication and PR section.

Researcher: Tell me, how did you choose RDSA by the way, to intern at?

P2: They came to school and we had to submit our CVs, and then they called me for an interview and i got the job.

Researcher: So how many months have you been with RDSA?

P4: 4 months.

Researcher: For our first question. What is your understanding about the concept of brand identity? When you think brand identity, what do you think about?

P4: Ok when i think about brand identity, i think about the organisation itself, how the people from outside see it.

Researcher: As a person now who is involved with RDSA...because you are still new, what would you say is the current brand identity?

P4: In terms of?

Researcher: I don't know if you know about their elements so far...have you been able to view their blueprint?

P4: Not really but then I have read about their strategic document, strategic communication plans.

Researcher: I think let's try to put it this way. What would you say RDSA as an organisation is, if i were to ask you a question?

P4: I would say RDSA is organisation that helps people with rare conditions to get improved lives, in terms of medication, to get medication.

Researcher: ok, According to you, what is the service that RDSA gives to the people?

P2: It donates to people who have rare diseases but cannot afford. They provide medical assistance to the people who cannot afford. So basically they are all about health and medical.

Researcher: What would you say are the attributes of RDSA's service offering? In other words, what does RDSA wants to achieve by rendering these services?

P4: Ok, they want to achieve for patients to get more improved health. And they want people with rare diseases living much longer. Because most of the people, they don't live longer depending on the diseases

they have.

Researcher: So, from the services that RDSA is offering, what value would you say this organisation is adding to everyone who is somewhat involved with it, like the stakeholder group? What value do you think they are adding to the beneficiaries or the patients, or the families or the Drs, or the caregivers or the activists?

P4: I think they want to see people living healthy. I can say they want to see people being happy, especially the people with rare diseases.

Researcher: What would you say RDSA is more concerned about as an organisation when it comes to the perception it wants to put across to everyone? Like when you guys are sitting down and planning whatever the case, the marketing team, the communication team, putting together communication messages, adverts...what perception are you trying to build within the mind on an ordinary South African?

P4: Ok, i think we're trying to get RDSA to get exposure. Firstly for people to know about RDSA, education and for the people who do not know about RDSA to know, especially people with rare diseases in South Africa. Because people are focused on cancer, like those diseases that are known but then they do know about rare diseases. So, we're trying to get the word out there.

Researcher: Just to add further to that. What do you think people think about when they see RDSA or hear about them as an organisation, as a brand? What do you think comes to mind to an ordinary people or stakeholders?

P4: I think they see a professional organisation firstly, because everything in RDSA is in order. So i think professionalism.

Researcher: And how would you say RDSA wants to be known for by the people?

P4: Professionalism and people to know what is RDSA.

Researcher: So RDSA participates in global activities, i'm not sure if you are aware or not, but I believe that RDSA participates in global activities (such as Rare X and the International Conference on Rare Diseases), how would you say RDSA is perceived globally from the little knowledge that you could have picked up so far?

P4: I think it is perceives as an organisation that is firstly professional and it helps people. They put people first, because it's all about helping people.

Researcher: And how would you say it's perceived locally?

P4: I think most people don't know about RDSA, so don't have knowledge about it, so i can say they are perceived as still professional.

Researcher: We gonna talk about RDSA as if it's a person. Like it's that lady over there, sitting there and her name is RDSA, something like that. How would you describe RDSA's personality, when you think of it as a person and you had to allocate personality to it?

P4: Ok i can professional, fun, understanding, put its stakeholders first, more especially patients because it's all about giving patients the quality of life.

Researcher: Again, when you think of RDSA as a person that is in a relationship with its stakeholders, what

role do you think it would play within the relationship?

P4: I'd say, it would play the main role, the responsible role because it wants to see its stakeholders all happy.

Researcher: So i dont know if you like me to give you an example, to make it easier. A role could be a motherly role, it could be a friend you know, for people to feel like they have support. Are you then able to think about roles that RDSA could possibly paly within that relationship?

P4: Yeah, but then i think that with patients it would play like a motherly role and then with sponsors it would play more like a friendship because we all want to see each other happy.

Researcher: And with medical professionals?

P4: I think it will play..., i think a friendship thingy because we refer patients to a specific Dr and the Drs wants them to be happy and they also want patients to be happy. So i think for patients it will be motherly but then for sponsors it will be more like friendship.

Researcher: For activists?

P4: For activists it will be like motherly because we give activists like...let's say we have an event we have so if you wanna ride for 947 you can do this and do that. So, for activists we like give orders but not directly.

Researcher: So more like a mentor?

P4: Yes.

Researcher: Alright. You do remember RDSA logo? Its teal and grey i believe. Do you think that there is a meaning or reason behind the visual image of RDSA?

P4: I think so, because this is more like genetic thingy, so with rare disease, i think like an actual rare disease it comes form the genes and everything. So, i think like genes and genetic they go along so it has a meaning.

Researcher: Anything about the colour? Do you know why they chose teal and grey?

P4: Ok, the colours i don't know.

Researcher: When you looking at this logo, do you think or feel as if there is a metaphor behind the design of the logo. Like an underlying kind of meaning behind the logo and the colours?

P4: I'd say, when you see genetic stuff on tv or anywhere they put up something like this, especially the colours like greyish and blue. Because rare disease are rare and all about genetics.

Researcher: Thank you so much. There are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, especially in competition with other NPOs in South Africa?

P4: Ok, i think it's very important because as you've said, there's so many competition out there with NPOs and people are trying to get funding. So we need to come out as very professional, as very unique form others to like stand out from other NPOs in SA.

Researcher: Yeah. And what do you think would be the benefits of RDSA by having a strong brand identity?

P4: I think the benefit would be, we'd attract more sponsors and patients would know about us. There are more patients in SA as a whole, because not everyone in SA know about RDSA. That would also benefit us to getting more patients registering with us.

Researcher: What would you think may be major disadvantages or implications if at all for any NPO that may find itself with a weak or irrelevant brand identity?

P4: I think the disadvantage would be not everyone will know about RDSA, and we'd not get sponsors because brand identity is important when you like market yourself, people see you from outside.

Researcher: Based on our discussion, what would be if at all your key view or understanding about the importance of brand identity for Non-Profit Organisations in general?

P4: Ok, for my understanding i think each and every NPO needs to have a very strong brand identity to stand out from other people, to be unique from other NPOs.

Researcher: Would you think that RDSA as an organisation takes brand identity important?

P4: Yeah, i think we take brand identity important because Kelly our boss is not strict but professional and wants to see RDSA to be known as a professional organisation. When people think about RDSA they must know that it is a very professional NPO.

Researcher: Thank you so much i appreciate your time. The interview was very lovely and insightful.

Annexure 5: Ethical Clearance Letter

ETHICAL CLEARANCE LETTER


IIE **vega**
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23/10/2017

Dear Mirriam Sithole

ETHICAL CLEARANCE LETTER

Your research proposal and ethical considerations were reviewed by your supervisor and moderated by the campus research panel.

☒ Your research proposal posed no significant ethical concerns. We hereby provide you with ethical clearance to proceed with your research methodology.

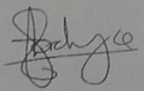
OR

☐ Your research proposal posed the following minor concern:
Please mention how your research design will address this issue:

In the event of you deciding to change your research methodology in any way, kindly consult your supervisor to ensure all ethical considerations are adhered to and pose no risk to any participant or party involved. A revised ethical clearance letter will be issued.

We wish you all the best with your research!

Supervisor Name: Althea Fordyce

Supervisor Signature: 

Campus Anchor Name: _____

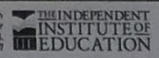
Campus Anchor Signature: _____

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Annexure 6: Participant 2 Interview

INTERVIEW: PARTICIPANT 2

Researcher: Firstly, I would just like to ask you some basic questions, what is your 'job' title here at RDSA?

P2: Patient advocacy project assistant. And I run all Rare Bear projects.

Researcher: That's a nice concept that you have. How many years have you been with RDSA?

P2: Just over 1 year.

Researcher: Tell me, what do you understand about this concept, brand identity?

P2: It's like having a fingerprint. So it's really like having something specific about a brand, so then like when people see it they will recognise Rare Disease or Rare Bear because it's unique to them.

Researcher: What would you say is the current brand identity for RDSA? You have a blueprint...have you been able to be in possession of your blueprint?

P2: I am not too involved on the whole brand side, but I think then it says a lot about what we aim for, what our goals, what we want to achieve, what we want to put out there to the general public.

Researcher: And that is?

P2: That our patients are number one, and we are there to provide support and love and do what we can to make their world a better place.

Researcher: Thank you. According to you what is the service that RDSA is giving to the people?

P2: Providing support and advocacy for them. Helping our patients to get through treatments, and just letting them know that they are not alone in their struggle.

Researcher: What would you say are the attributes of RDSA's service offering? In other words, what does RDSA want to achieve by rendering these services?

P2: We want all our patients to be able to get the best possible treatment that's out there, and at the moment that is not possible because it might not be authorised by their medical aids, or they may not be able to afford it. They might not know about the treatment, they might not have found diagnosis. So that's why we want to be able to help them.

Researcher: Thank you so much. So, from the service that RDSA is offering, what value would you say this organisation is adding to everyone who is somewhat involved with it? It could be the caregivers, patients, the medical practitioners you are working with...What value would you say RDSA is adding?

P2: Well, we're definitely improving our patients' lives, and we help professionals as well by referring them because they may not know how to treat these specific patients. Then we can refer the patient on, and having the caregivers know that we are there to support them as well. It's not just about the patient it's about the whole units.

Researcher: Thank you so much. What would you say RDSA is more concerned about as an organisation when it comes to the perception that it wants to put across? Either by marketing or communication messages...What is the perception that RDSA wants to put across out there to the public of SA?

P2: That, everyone needs support and love and you might not see that someone is battling or fighting a battle that we need to be more understanding. Support our patients, support their families. To try and

understand that they are fighting a battle.

Researcher: Just to be on that again, when someone outside RDSA thinks of RDSA what is it that you want them to think about? When they think RDSA?

P2: Awareness and support.

Researcher: And that's awareness for rare diseases?

P2: For all the different ones, over 7000 of them.

Researcher: That's a lot and I am sure that there are some that are not diagnosed...I also believe that RDSA participates in global activities such as Rare X and the International Conference on Rare Diseases, how would you say RDSA is perceived globally?

P2: I think initially we were perceived as being the underdog, and now they actually realise that we have a lot to offer and that we are not that far behind. And...we are not a first world country but we are doing the absolute best that we can with what we have available. And now they are realising that we are learning year by year, so yeah...

Researcher: That is awesome. And how would you say RDSA is perceived locally?

P2: A lot of people don't know about us which is quiet sad. They did like a market research thing and 70% of the people did not know about us.

Researcher: 70%, that's a lot?

P2: Yes, so that's like a whole other avenue that we could be helping.

Researcher: Yeah, that's true hey. And that's more people with rare diseases continuing to struggle as well.

P2: So we need to get out there so that more people get to know about us.

Researcher: Yeah, that's true. So, now we gonna talk about RDSA as if it is a person. So, When you think of RDSA as a person, how would you describe its personality?

P2: Loud, well we try to be loud, creative, family oriented...that's quiet a tricky one. Caring and supportive.

Researcher: Yeah. And again, when you think of RDSA as a person that is in a relationship with its stakeholders, like a person in a relationship with another person. How would you describe the role it would play within the relationship?

P2: With the stakeholders?

Researcher: Yeah, with stakeholders, patients, you know just everyone who is included under the stakeholder group, it could be the caregivers...

P2: I think it's almost that we take on the mothering role. That we try and take care of them, and be the one that they turn to when they are having a bad time. The moment they know that we'll give them a hug and sort of pat them on the back and do what we can to fight for them and protect them.

Researcher: That's really nice. This is you logo right? (shows her the logo) Do you think that there is a meaning behind the visual image of RDSA, the logo, the colours, the turquoise blue and grey...?

P2: The logo is a genetic strand, so obviously that has a lot of meaning. Because a lot of our diseases are genetic in origin. And i don't know the reasoning behind the colour.

Researcher: Just by looking at it, would you say there is a metaphor behind it? Looking at the turquoise and

there are strands of grey, and there's like a gradient on the grey, it's dark, it's light, do you think there is a metaphor behind that?

P2: I think it's like the teal colour is kind of calming, but the different grey say that we are all different, that all our patients are different but they are still within us, within one family.

Researcher: So, the outside teal colour says we can be different, lighter shade, darker shade but at the end of the day we are all as important.

P2: Yeah.

Researcher: That's very lovely. So for our last part of the questions we gonna talk about the importance of brand identity for RDSA. There are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, and especially in comparison to other NPOs or its competition because i mean, they are your competitors in a way?

P2: I think it's so important. Like i said there are over 7000 rare diseases, think about how many patients there are with those, they don't know about us, not all of them. We haven't been able to reach all of them. So we need to reach out to them, so that we can help them to have a better life, to have a longer life, for the parents and families to know that they are not alone.

Researcher: And what would you say are the benefits of having a strong footprint for RDSA?

P2: Well, our ultimate goal is to look after our patients and to make their lives better. To do what we can to help them in everything that we can, so yeah.

Researcher: Ok, just to probe a little further on that. What would you think would be other benefits especially in regard to sponsorships and the public at large? What would you think RDSA may be able to benefit from having a strong brand identity?

P2: Well obviously with more sponsorship we'll be able to do more projects, more fund raising, more assisting our patients and the lives of all of them. And obviously sponsorship make a massive of difference and we all fighting, all the NPOs are fighting over sponsorship.

Researcher: It is a competition and there are a lot of them. And what would you think may be implications for any NPO that either does not have a brand identity, or has a weak one or an irrelevant one? What would you think that they may be able to suffer from having a weaker brand identity?

P2: I think you almost fall into the background. Like for example, when you think about the Smile Foundation, everyone knows about them and their brand identity is so strong they have that impact and i think that's what we all strive for. We want to pull all the heart strings and to be able to have an impact. We want people look at us and say wow i want to help them, i want to support them.

Researcher: Based on our discussion, what would be your key view or opinions about the importance of brand identity for Non-Profit Organisations, any NPO?

P2: I think you have to know your goals and know what you want to do. Don't just go out there and be like, well might want to do this, we might want to do that . You have to let people know what you want to do, know that you want to make a difference and do what you can for that.

Researcher: Thank you so much, it has been a lovely interview, very insightful.

P2: Sorry, i am a patient, that's why i battle with my talking sometimes.

Annexure 7: Participant 1 Interview

INTERVIEW: PARTICIPANT 1

Interviewer: These are basically very simple questions for me to get a view about your View about the importance of brand identity. Ok, firstly I would just like to ask you some basic questions relating your employment. What is the title of your job here at Rare Disease South Africa?

P1: I am a graphic designer.

Interviewer: Oh, you have loveliest job.

P1: And a social media marketer.

Interviewer: Oh,...and a Social Media marketer.

P1: And I work on a freelance basis.

Interviewer: That is nice, and how many years have you been with RDSA?

P1: Just the one.

Interviewer: Ok, just one... ok, and are you an employee, a volunteer, an activist?

P1: A little bit of both, I probably let's say a volunteer.

Interviewer: Volunteer right?

P1: let's say volunteer slash employee because I do the graphic design on a reduced rate.

Interviewer: Oh ok, alright, for the first section of our interview, what is your understanding about the concept of brand identity? When you think of brand identity what is your understanding?

P1: well, is basically and identifier right? So when people think rare diseases they feel a certain way about the company about what they portray. So i mean we have recently undergone a brand exercise with rare diseases where we kind of redone everything. So our message is "Living Beyond", so Living beyond rare diseases, not letting the umh... disease get to you, you kind of live beyond that. We implemented that in all of our marketing so that we have an identity...

Interviewer: So that is the new campaign that you are running now?

P1: Yes, it's called Living Beyond. Yeah... and it's on all our touch points. We make sure that's in the messaging that we...

Interviewer: Put across...?

P1: Yes, that we put across because the people then see that..., they identify, i mean is the word brand identity, they identify that with us. So we make sure that it is in all our collateral. You know, from our pull us banners to our business cards. Have you seen our business cards?

Interviewer: Not yet.

P1: Uhm, from our business cards to everything that we portray. Even to social hour hashtag is Living Beyond. So yeah, so brand Identity is very important for a company. I think NGOs don't always get it right, you can keep that. They don't always get it right because they don't have the funds for it. You know and...

Interviewer: So, you think it's because they don't have funds?

P1: I think, i think, yeah, i think when people start NGOs...., I mean this is my opinion, but I think when people start NGOs, the most important thing for them is to, is what they are starting it for, for either patients....so i think for them the priorities aren't not always brand. I think people always see brand identity as a luxury, as something they will tackle later on, let's start NGO let's get it going and kind of stumble through it, until they get a point where they can afford or where somebody who volunteers their services to actually.. you know, the NGOs are there to serve the patience, the animals, you know what I mean... brand identity is not in the list of priorities and it does need to be because I think people take..., you know, sponsors take brands way more seriously or NGOs way more seriously if they have a certain look and feel. Unfortunately it's a very shallow way of looking at this, I mean graphic design really is, but the purpose that it serves is to say we are serious, this is our messaging, we, you know take things serious and we are across all borders. We make sure that we can do that. I don't know if that answers your question, but that's my opinion on it.

Interviewer: My second question is..., as person who is involved with rare disease South Africa what would you say is your current brand identity, as it stands?

P1: As a person? Rare Diseases as person?

Interviewer: No, not Rare Diseases as person, i mean you right now? If you were to tell me the current rare diseases brand identity as it is now what would you say?

P1: Well, i mean we just launched living beyond, so i think aspirational, inspirational. Yeah, i think it will be an inspirational..., is it the kind of answer you are looking for, like what message are we trying to say?

Interviewer: Not necessarily the message, but when people think of Rare Disease South Africa, in this particular instance yourself, what do you think is the brand identity behind rare diseases?

P1: That's a tough one, because, you know brand identity can mean different things. Give me an example what you...

Interviewer: Have you ever seen Rare Diseases blue print? Do you have the blue print because you are a graphic designer in your possession?

P1: We do, we've actually just gone through the exercise of a strategic plan, so we've got key objectives and that type of stuff. So, i don't know...

Interviewer: So as it stands now, do you think that you guys have a strong brand identity?

P1: I think so, i definitely think so, like i mean it has taken 5 years to get here, but i think now it's much that with everything that we do, we go back to the key objectives, does it serve those key objectives. If it doesn't then we chuck it, but if it does then we know that we are going in the right direction. So i think we do follow our blue print to a point. I mean there are still some things we can obviously improve on. But i think we are getting there, i think we are putting the right things in place to get there.

Interviewer: Oh, It's still pretty young.

P1: It is young, it is still very young. So, we are, but i think we definitely doing the right exercises to get to that.

Interviewer: So, now in terms of the brand identity blue print that we have just discussed right? I would like us to unpack the elements that you were talking about of RDSA. But now i am going to give you guidance as to how i would like us to do that. RDSA brand as product, but in this instance brand as a service, because you are not selling products but you are rendering a service. So according to you what is the service that RDSA gives to the people?

P1: Uhm, I think, like I mean, I'm still very young, Kelly will be able answer this way more than I can. But i think just from what I've seen over this past year. I think patient advocacy, like that's a big thing. , like that is like the root of why Kelly does what she does, I mean she's the CEO. That's like the root of it. A bigger, maybe an offset of that would be like support i think. You know, like when somebody is diagnosed with the rare disease, I mean this is how it all started with Kelly, you will hear her story, but there is not enough support for a rare disease, because it's rare. So people kind of feel unsupported, unloved, they don't have knowledge. So it's very much place where we disseminate knowledge. We educate people on what is a rare disease, what are the different types of rare diseases, those types of things, but I think support it's a big thing. They have a at least somebody they can call you know, if they are diagnosed with something rare. They have at least I like a support base.

Interviewer: so, are these two elements of your services, are they meant for patients only or you extent it to families and...?

P1: Yes, so basically we've got a bereaved members group, we've got family members group, caregivers group to caregivers leg, we've got the patients' leg and we've got a Doctors' leg. So, we connect doctors with patients. Where before, i mean, we kind of just roamed around what to do. So we find Doctors, we really have quiet a nice Doctor base, where we can say this patient is suffering from this, here's the Doctor for it. So, we kind of put people together. We kind of like the Tinder for rare diseases, let's put it that way. So, i think yeah, that's a big thing. I know Kelly does a lot of lobbying because a lot of these rare diseases aren't..., i mean it goes with the patient advocacy, because a lot of this rare diseases aren't really knowledged by the medical aids and the medical profession. So, there is a lot of like support in that.

Interviewer: So what would you say are the attributes of RDSA service offering? So, in other words what does RDSA wants to achieve by rendering these services?

P1: I think the biggest thing, you know awareness. Its' always about awareness, getting our brand name out there, because, you know, the more people that are aware that we are here, the more we'll grow and the more people we will reach. But i also think for people in the medical industry to take us seriously you know, like that RDSA is actually a serious cause.

Interviewer: So, would it be correct to say consideration of rare disease issues. And from the services that RDSA is offering, what value do you think that RDSA is adding to everyone who is somewhat involved with it? It could be the sponsors, the families, the beneficiaries.

P1: I don't know if i have answered it already, but i think that the value is the support for me. Like the biggest thing is the support. Like, I have recently had a family member diagnosed with a rare disease and the support that you receive. I mean, people that are here aren't just doing it, you know, they are actually involved. I mean Kelly has a son who's got Pompe disease, Megan is suffering from Myasthenia Gravis. People that are actually living the disease, is not just people that are employed here. They are people that are actually dealing with a rare disease. From that point of view you feel like they actually understand. It's not

just numbers to them.

Interviewer: Would you also say that you are adding value to, for instance the patients, in that you improve their livelihood or access to Doctors. How would you explain that one?

P1: Massively, absolutely, like definitely. I mean, the thing is they don't always have access to that and we've got a data base to that. I guess like on a more technical term we do give them access to Doctors and all of that, but also on the patient like support side of things. I know i keep going on the support, but we've got like the rare bears program where people can donate a rare bear, and we actually give that when people are in the hospital. So, there's that care element as well, that you are not just on our data base, we actually care about you. I don't know if that answers your question. You know, we are constantly doing research, there is a research leg as well, i don't know if you'll speak to Helena, i don't know if she's on the list there, but there is a research leg and there are....

Interviewer: So you guys are getting there?

P1: Yeah, we are getting there but there more you grow, the more things kind of like adds on. But it's good, its' great, i think we are heading in the right direction.

Interviewer: What would you say RDSA is more concerned about as an organisation when it comes to the perception it wants to put across to everyone?

P1: Patient advocacy.

Interviewer: So, you would like South Africans to know you for...?

P1: For patients. Patient advocacy is the core.

Interviewer: Now, to extend a little bit on the perception that i am asking about RDSA, let me put it this way, when someone thinks of RDSA or your social media or a banner or bill board. What perception do you want to build to South Africans when they think about RDSA?

P1: We want to build a caring, honest, open, approachable..., yeah. I think we want to, I mean if you look our..., just in terms of like, the fonts that we use and the colours that we use , it's very friendly, very..., i would say that it is soft at all, but i think it is very much a friendly open type of approach to the design.

Interviewer: Alright, i will extend on that. Obviously, this is your logo (displayed on the table), alright, so do you think there is a meaning or reason behind the visual image of RDSA?

P1: Of course there is, i would be a bad graphic designer if i said no, definitely.

Interviewer: The logo, the colours.

P1: The colours, look i mean, i wasn't here when they chose the colour, but if i had to look at the colour, it's a medical colour, so we are saying that we in the medical sphere of things. But i don't think it's a harsh medical colour. I think it's an inviting cool...you know, in my opinions, and the fonts are rounded. They want people to feel welcomed, you know, we don't want our brand to say...We don't want to be harsh and clinical, because we are not clinical. We speak in terms that are relatable you know. I mean, if you've meet all of us, like we are all honest and open, what you see is what you get, we don't have any easels and graces. So we put that forth in our branding as well.

Interviewer: Looking at this logo here, would you say there is a more metaphor behind it or not?

P1: I don't think it's that deep, i just think it's a DNA strand, so we've literally because rare diseases are mostly genetic, so we've taken...I didn't design the logo, i only came on board after the logo was designed. But if i can look at it, i think it's more literal than it is metaphorical in my opinion. I mean, look your gene is your life, so your DNA is your core, it's what makes you, where it's a rare disease or not.

Interviewer: I believe that RDSA participates in global activities (such as Rare X and the International Conference on Rare Diseases), how would you say RDSA is perceived globally as an organisation?

P1: I wouldn't be able to comment on that, like not intelligently. I've just came on board, so think that someone else probably will be able to answer that more accurately.

Interviewer: Any idea locally? Stakeholders, sponsors, how do you think they perceive you locally?

P1: That's a tough one to say as well, because we have just launched this brand and we haven't really put figure about how people feel about the brand. Maybe it's an exercise that we need to do. We do polls regularly maybe that out next poll. Maybe that's something that we can do. We just kind of done research more on the patient side and not actually on the public side of things. So, that is something that we need to do and see what that perception is. Maybe one of the other can answer you better than i can.

Interviewer: When you think of RDSA as a person, how would you describe its personality?

P1: Strong, sound values, kind, brave. The Living Beyond is a brave statement, because we say yes i have a rare disease but i'm going to chose to live beyond that. Or to the person who doesn't have a rare disease, living beyond your circumstances to support somebody. So, i would say brave.

Interviewer: Again, when you think of RDSA as a person that is in a relationship with its stakeholders, how would you describe the role it would play within the relationship?

P1: Supportive, educator, advocate.

Interviewer: There are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, especially in comparison with other NPOs in South Africa?

P1: It's very important, we want to achieve our goals, our key objectives. We need to have a strong brand identity you need people to say rare diseases, I know who you are so that I can support you. It's all awareness and getting our identity out there so that we can do the work that we do. I mean NPOs and NGOs, everybody think they all take the money for themselves, that's the perception. So, i think for us to show that we are actually having an impact, it's very important. We want to be recognised, everybody wants to be recognised so that we can be supported so that we can do the work that we do.

Interviewer: What benefits to RDSA do you think may come about from having a strong brand identity in the NPO market?

P1: The benefits i mean are far reaching i think because once people start recognising as they will be like hey that's Rare. I mean we did Walk the Talk and, we wore tutus in our colours and people recognised us, so were top of mind. I think for us people can go and donate money and resources and volunteer to a lot of charities. So its competitive and we need to start thinking like a business and thinking like a brand because its competitive. And if we are not competitive and we just say we are just here to support, whatever. It's a business at the end of the day and if we don't have that income coming in, we cannot do the work that we want to do. So brand identity is fiercely important in that sense, because it sets us up for recognition for people to support us.

Interviewer: What do you think may be major disadvantages/implications for any NPO that may have a weak/irrelevant brand identity? What do you think it can suffer in the market.

P1: Not be top of mind. Not stand out, because i think like a wishy-washy identity, that they all over the place, then portray that they are business that is all over the place. Remember i am attacking it from the graphic design point of view, you are obviously gonna get other opinions as well. For me, if i see a strong brand identity and i see people have actually taken their time and effort to do that, i feel more confident. It's like businesses that don't have a website, i don't trust them, because you should a website, you know what i mean. Its little things like that because we are in the digital age where we believe more in things that are pretty, solid and well designed. I think that i won't have the confidence in supporting an NGO that doesn't have a relevant brand identity.

Annexure 8: Participant 5 Interview

INTERVIEW: PARTICIPANT 5

Researcher: Firstly, I would just like to ask you some basic questions relating to your employment. What is your 'job' title here at RDSA?

P5: Office Manager

Researcher: And how long have you been with RDSA?

P5: Officially two, three months...short.

Researcher: You participation has been since?

P5: But I've been working with them for about 3 years in my own capacity I've got my own company, so, i have a radio sales agency and i did campaigns and stuff for them on radio, at the universities. Because i do university radio station so it's my core business. So i met the Rare Disease team 2014 and i've been working on and off with them, and in August this year i started assisting more with in the sense that now i am handling traffic, office management, and i do a lot of marketing stuff for them.

Researcher: So, the 3 years was it like on a business level or was it like a relationship?

P5: Both. I found what they do very compelling personally, and obviously i met them through business but it became a personal relationship.

Researcher: I know hey. Because we had to do a Brand Challenge for RDSA at school and you know during my brand homework and stuff that's when i realised that i am actually interested in this NPO.

P5: It's a great NPO. And what Kelly has accomplished blows my mind and that's why i've gotten more involved.

Researcher: And in this short time frame, because i mean it's still a pretty organisation young but the impact is huge.

P5: Yeah, it's a baby... it's awesome.

Researcher: Now getting to the questions. First question, what would you say is your understanding about the concept of brand identity?

P5: Brand identity is in my opinion, is when somebody...well first of all is making sure that a brand becomes known as something that the general public when they hear the name it's what they think of. If i take a brand like KFC, its known for Colonel Santos, its known for finger lickin good. It's got iconic elements that makes it specific. So brand identity is for me but building a brand that people can relate to, whether you understand marketing and that whole field or not. And it's something that allows the brand to stand out amongst the clutter of so many brands in this industry, in this country, world.

Researcher: thank you. As a person involved with RDSA, what would you say it's RDSA's current brand identity?

P5: Sorry i am getting distracted with what is happening outside.

Researcher: What are they known for?

P5: So, Rare diseases is obviously know...it's still very small and it's not very known at all. I think when people hear the name they don't necessarily know what we do. Those who do know, the rare bears has become something that people identify with and people are learning about the brand, they are starting to understand the impact that we are having within the rare community. But i think the lack of identity is why it's not that well known and it's something that we are focusing on and working on, on a daily basis. At the moment i think too wishy-washy and that a big problem. So,there isn't really a brand identity, certainly not out in the general public. Within the health care sector, patient advocacy and support and awareness is what we do and we're known for that within the commercial sector but not the general public.

Researcher: Ok, thank you so much. According to you right, what is the service that RDSA gives to the people?

P5: So, its support for patients, and when i say support, i mean putting them in touch with other support groups, other patients with the same disease, support when it comes to educating them about their own disease, about who to speak to, you know, maybe what medical aids cover, or which medical aid to be on, assisting them in fighting with medical aids where necessary. Kelly has just spend time in court doing exactly that. So, patient advocacy is a very broad umbrella term for what we do in general and then obviously we do a lot of financial support and then you know, its education for our patients, for caregivers, for the industry. It's about educating pharma companies on what is happening internationally and trying to help them bring stuff in here. There's a hell of a lot that we do. But its really support patients as a big umbrella term.

Researcher: Thank you so much. What would you say are the attributes of RDSA's service offering? In other words, what does RDSA wants to achieve by rendering these services?

P5: We obviously want to make the lives of our patients and their caregivers or broader support structure, we want to make their lives easier. Because living with a rare disease is hell of a difficult. And we are talking financially easier, education easier, medication, just in every way possible making their daily struggle easier. Giving then support and educating the general public on these diseases because there are so many illnesses that are invisible. And so people don't necessarily get the same support or sympathy if you've got an invisible disease. I don't know if you've met Megan as yet? So, Megan has an invisible disease, unless she is really battling you would never know she is sick. And you get other people whose diseases are very apparent because they are an amputee or they are in a wheelchair or they are deformed or whatever. You get a lot of sympathy when it's visual. So educating the general public on how many different diseases there are and to be sympathetic towards everyone, and everyone struggle in life in general is i mean very important.

Researcher: From the services that RDSA is offering, what value would you say this organisation is adding to everyone who is somewhat involved with it?

P5: Well, obviously we are giving support to our patients, which is huge. And those who do know about rare diseases are beyond grateful for the support they are getting. And, it is a daily fight that Kelly and the team fight for all these patients and for their families. Just letting people know that they are not going through this really difficult patch. Whether its a periodic thing, whether they are brand new thing, whether they've been on it for years and years, knowing they are not doing it alone. I think it's the biggest thing, because you can feel very lonely, especially with a rare disease where there might be one or two other people in the entire country fighting that disease. You kind of feel like you are going at it alone because the medical aids often don't even know it exists. So you phone to get support or to get a procedure approved and these guys don't even know what you are talking about, and it can feel like a very lonely difficult struggle.

Researcher: thank you. What would you say RDSA is more concerned about as an organisation when it

comes to the perception it wants to put across to everyone?

P5: I think the biggest concern is that want people to feel like can approach us with their problems and it doesn't matter how big or small your disease is. to know that you can come to us and that there will be people to help you.

Researcher: So, when you guys as a team, rare disease team, are sitting around the table discussing communication messages, your campaign, your ads or everything else. What perception is it that you want to build within the minds of ordinary South Africans?

P5: Well, within the minds of the patient it's one of fighting...we've got a campaign called Living Beyond, and it's about getting up every day and fighting the fight being positive about it and not getting weighed down by your disease because that's half the battle won already if you can get up every day and be positive and focus on how you gonna win that day. So, i think that's the general message that we are trying to put across everything, whether it's to our patients or to the general public. It's one of being positive, of hope, of knowing that i might be sick but i'm not gonna let it get me down today, and i'm gonna keep on fighting, and i'm gonna keep on living. There's days when i'm sick and i feel like shit and there's days where i don't even feel sick and i feel like a normal happy healthy South African going about my day.

Researcher: So generally what would you want RDSA to be known for?

P5: Being a positive support system and a positive influence on the lives of our patients and all of us stakeholders really.

Researcher: I believe that RDSA participates in global activities such as Rare X and the International Conference on Rare Diseases, how would you say RDSA is perceived globally as an organisation?

P5: I don't really know the answer to that, i don't really think i'm the right person to answer that question. I know that Kelly is within the medical community and within rare diseases internationally. She is very well respected for what she does, for her knowledge, for the fact that she fights in what she does and what she knows. I mean she talk all the time as an international speaker. I mean she is really respected and i think that she and the brand RDSA are one and the same, one doesn't go without the other. And i think there is massive respect for what she are RDSA are doing in this country.

Researcher: And how would you say RDSA is perceived locally?

P5: There is definitely that same respect for her and for the company certainly from the healthcare sector, all the pharmaceutical companies. I think all the medical aids are quiet scared of her, simply because it's not easy to blindside her or put wool over her eyes. And i think more and more they are realising that she is a force to be reckoned with. Like i said, i think that RDSA has got a long way to go as far as the general public knowing about us and what we do. But i think that those who do know about us, who know what we do are very grateful that we are here and we doing all we can. All the communication and correspondence that i've had in the last couple of months of being here is just, it's really people saying oh my gosh thank you so much or i had no idea you exist please help. But there is a general feeling of relief and gratitude certainly from patients as far as the fact that we exist.

Researcher: I can imagine. So, i would like us to talk about RDSA as a person. When you think of RDSA as a person, how would you describe its personality?

P5: Someone who is positive, ambitious, driven, the small guy who refuses to stay down in a fight if that makes sense. And it's juvenile, its learning new stuff every day and it's just growing in leaps and bounds, but definitely growing and expanding daily like a teenager. Lots to learn but also quiet humble and grateful and respectful. Because everybody is just so grateful to every person who donates or support or offers to help in

some way is met with the same gratitude. Whether you're donating a bag of toys or R30 000, the gratitude is the same because we understand that when someone is donating, they are donating what they can. The fact that they are, whether it's time or money or whatever means their hearts are in the right place.

Researcher: Again, when you think of RDSA as a person that is in a relationship with its stakeholders, how would you describe the role it would play within the relationship?

P5: The maternal role, because a mom can be loving and caring and supportive and positive, and help you grow and all of that but she can also put her foot down and be strict, put you in your place and give you parameters and boundaries. So whether we are dealing with patients or we are dealing with the pharma companies, a mom can wear different hats. And i think that's what we do depending on who we are dealing with. Changing the hats.

Researcher: Thank you so much. So this is RDSA logo. Do you think that there is a meaning or reason behind the visual image of RDSA?

P5: Absolutely. The genetic strand speaks volume, because so many rare diseases are genetic. Cut from a genetic stand point, that it will immediately, certainly in my mind draws one's attention to remind one that rare diseases are genetic. So, the DNA strand everybody knows it, it's a very recognisable thing and we all talk about our DNA. And whether it's a medical thing because it's a medical thing, because they a tinkering with DNA all the time and we are hoping they can tinker some of these genetic diseases out of the DNA. So i think visual its 100. As for the turquoise and the grey. Turquoise and grey for me are very common colours and i think they are very soothing, and think for our patients that's what we're trying to do. We're trying to calm and soothe them in a very difficult time or space. So i think the colours and the DNA strand were very well put together.

Researcher: And would you say there is like a metaphor behind the logo and the colours?

P5: Not really.

Researcher: An indirect meaning?

P5: Well i think genetic diseases are rare, and DNA, rare diseases...

Researcher: Like a literal meaning behind the logo and stuff. Thank you so much. So, there are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, especially in competition with other NPOs in South Africa?

P5: I think it's vital and i think it stands for every brand. You need to stand out from the clutter because the less you stand out, the more diluted the support becomes, the more diluted what you do becomes and the less people we'll know and recognise you as a brand. So, for example, we've got the 947 coming up and a brand like choc, when the guys are riding down the road you know they a Choc rider from miles away because they are riding in a cow suit, you cannot miss it. And that cow has become synonymous with Choc. That brand identity is so strong for them and they've done a phenomenal job for them and i think it's really important that we grow our brand identity and that we grow our brand identity and we find something, and i think it's the rare bears to really help RDSA to stand out from the clutter because if we stand out more people are gonna know about us. From the general public perspective which then obviously needs a patient's perspective. The more people who know about us the more support we can get, so then the more good work we can do.

Researcher: Definitely. And what do you think may be major disadvantages or implications for any NPO that may find itself with a weaker brand identity?

P5: Well i think, it all just get so diluted. If people don't know who you are, they can't come to you, whether is a patient or as a sponsor or as a supporter. So, it's as simple as that really.

Researcher: Thank you so much. Based on our discussion, what would be your key view/understanding about the importance of brand identity for Non-Profit Organisations?

P5: It goes for any brand and not just NPOs, but i think NPOs struggle more because what we do...because we don't necessarily have a product, you got to educate so much more. So, if you are a food brand for example, it's very simple, we're KFC we make chicken, it's easy it's very simple. So you don't have to necessarily do so much education, its more just about pushing a product. Whereas, as an NPO there is so much education that's required in order to succeed in gathering support and assisting your target audience. So, that brand identity needs to be even stronger in order for people to know you exist. NPOs need to focus on the heart, because people support them because you tap on the heart strings. The Smile Foundation has done a fantastic job, because they put up pictures of kids with a damaged smile. Nobody wants to see a kid with a damaged smile, of course you want to help that kid smile, you wanna help them with their cleft pallet, it's so easy and they have caught onto the heart strings, same as kids with cancer. And you when can find a long lasting or recurring... if you can find something like for example, cupcakes for kids with cancer, where it happens every year and you get people involved and you get that heart support. It just help grow the brand and it benefits everybody, so for an NPO, you've gotta focus on the heart. You've gotta put on those heart strings as hard as you can because that's why people support them, and without support we can't do anything for our patients.

Researcher: So would you say that its still a long road for RDSA to get to that solid strong brand identity?

P5: I think we are working on it. We have got some really nice insights from the Vega presentations. Some really nice ideas that we are fishing out for next year and i think education from a young age is so important. I mean we've got this movie coming out. We are doing a premier for a movie coming out at the end of November called Wanda, it's awesome to see Hollywood looking at rare diseases and actually highlighting the effects of having a physical disease or deformity, how they affect the patient and i think the more we can educate and pull on those heart strings to help people put themselves into the shoes of the patients, the more we will be able to grow the brand and educate more.

Annexure 9: Participant 3 Interview

INTERVIEW: PARTICIPANT 3

Researcher: For the record, what is your job title here at RDSA?

P3: CEO and Patient Advocate

Researcher: The founder as well right?

P3: How many years have you been with RDSA?

Researcher: So, RDSA officially started in 2014. We were previously functioning before but it just wasn't actually formalised. So we formalised in 2014, but there was a lot of work that was done before that point, so essentially it's been between 4 and 5 years.

Researcher: What do you understand about the concept of brand identity?

P3: Nothing, i am not marketing related at all, from what my team tells me, brand identity is like a visual sort of look and feel. Ok, not necessarily what they have said but this is from what i gathered that they do. It's a visual look and feel that people resonate with your brand. So, it's something that is recognisable, its synonymous with the work that you do and it gives an impression of what your organisation does. That is what i think brand identity is. I'm probably way off base.

Researcher: Would you say it's restricted to the visual image of RDSA or it can go beyond?

P3: It probably can go beyond it, yeah is probably can.

Researcher: What would you say is your current brand identity?

P3: I think, obviously we've got that whole sort of keyhole look and feel and the reason for that is to almost provide perspective to what's behind the obvious. So, it's seeing what is behind what you necessary can see. So obviously many of our conditions are invisible, so you don't necessarily know somebody is sick just by looking at them. So there is this whole side of their lives that you might not necessarily have idea about, and that is sort of what that keyhole look and feel is, and it's really to inspire people that there is a life beyond really what you just see and there is things that happen beyond face value.

Researcher: Thank you for that. According to you what is the service that RDSA is giving to the people?

P3: Providing an organisation where patients can feel supported at and as an organisation we aim to improve the quality of life and treatment, life saving treatment, so really as action, we provide access or we fight for access and improve quality of life. But as a service, it is providing that level of support.

Researcher: What would you say are the attributes of RDSA's service offering? In other words, what does RDSA wants to achieve by rendering these services?

P3: It is to make sure that all people that are affected by rare diseases have access to care.

Researcher: organisation is adding to everyone who is somewhat involved with it?

P3: It's about having a home. It's about having a place that you can identify with. It's about having a contact, a telephone number that you can phone. It's about providing a safe place to being the sick individual that you

may be. That's essentially what we are trying to do.

Researcher: And, what would you say RDSA is more concerned about as an organisation when it comes to the perception it wants to put across to everyone? For instance when you do your marketing, when you send out communication messages what perception do you want to build within the minds of South African?

P3: It that rare diseases can affect anybody, regardless of age, colour, weight, height, race, interest, religion, it affects everybody. And there are people out there going through battles that nobody knows about. So, it's about providing that insight, that don't be so quick to judge, or don't be so quick to dismiss because tomorrow it can be your mom, it can be your child, it can be you.

Researcher: Yeah, in terms of RDSA as an organisation. What do you want people to think about you, when they think of your organisation?

P3: Support, we want people to think of support, transparency, assistance, help, education, information. All those things that we feel our patients require.

Researcher: Thank you so much. I believe that RDSA participates in global activities (such as Rare X and the International Conference on Rare Diseases), how would you say RDSA is perceived globally as an organisation?

P3: I think in terms of the African continent, we are considered leaders. We are well advanced in comparison to other organisations focusing on rare diseases in Africa. In terms of the global landscape, we are probably lagging because of the fact that we have other disease elements such as HIV, TB and malaria that are not necessarily impacting, Europe, USA and other parts of the world. So, those are big burdens. So in terms of rare diseases in the global landscape, they probably look us and go gee they still have a lot of work to be done. But in context to how we've done with limited resources i think we really done quiet well.

Researcher: And how would you say you are perceived locally?

P3: Definitely, as opinion leaders when it comes to rare diseases. So, we are often thought of for comments and we are probably the most identified group in terms of rare diseases. I can say that confidently. So, if a Dr is needing information they will come to us first. If people are needing research information they will come to us first. If patients are needing stuff they will generally come to us first.

Researcher: Any perception from government departments?

P3: They are fully aware of what we do. Have they bought into it, no, because they have other pressing priorities. Are we a priority for them, no. Are they aware of what we are trying to do, yes.

Researcher: Now we are going to speak of RDSA as if it's a person. So, when you think of RDSA as a person, how would you describe its personality?

P3: Vibrant, creative, caring, ethical.

Researcher: Thinking about RDSA as a person again. Let's look at it from the context of RDSA being in a relationship with a stakeholder, it could be anyone within your stakeholder group. How would you describe the role it would play within the relationship?

P3: Generally that of collaboration. So, we are all for team play. Working towards common objectives and also that of mentoring. I think a lot of the relationships that we have are us sort of hand holding other groups through tough times. So, we try to be a source of comfort for them. But we're very collaborative. We are really enjoying working in teams. We enjoy working with other stakeholders and organisations towards common objectives.

Researcher: Design of the logo and selection of the colours, the entire visual image of RDSA?

P3: So, other than the fact that i like this colour, and that's what it was when we started. I think it's relatively

an unusual colour. It stands out and that's what we wanted. We wanted something that would make people take a second glance because our work is not always visually appealing. We have very unsexy conditions. We have a lot of abnormalities, like facial abnormalities and things like that. Sometimes is very difficult to look at. So we wanted something that was appealing and would bring them in even though what is behind this might not. And in terms of the dark elements, it's really just to provide a little bit of stability and it cant all be flair, it also needed to have a little bit of a foundation and stability. So, that's really what is was and i loved this colour.

Researcher: And any story behind the selection of the chromosome?

P3: So, 80% of our conditions are genetic. So a large portion of the patients that we have are born with these conditions. Whether they only started appearing later on in life, its still a genetic disorder. So, that is the symbolism behind the gene the DNA.

Researcher: There are currently over a thousand registered NPOs in South Africa. How important do you think it is for RDSA to have a strong brand identity, especially in comparison or in competition with other NPOs in South Africa?

P3: I think it is hugely important. Because as i alluded to earlier. Very often our conditions are unknown, our work is unknown, our space is unknown. So if you can have a brand that is recognisable i think it will only strengthen what we are trying to do as an organisation. And again, we are having to pull people in, who have no idea about what it is and what we do and the conditions that we cover. It is not something where the context behind this organisation is known. So, we need to be able to pull them in.

Researcher: And what would you say would be the benefits of RDSA being a known brand in South Africa. How would it be benefited?

P3: Definitely by improved support. So, if we had more public awareness, we would have more patients registering with us. It would be a much easier journey for them to get registered with us, get a diagnosis, get on the correct treatment, get the relative support. And then also from a generalised point of view, if public awareness was improved, we would have more resources to be able to do what it is that we are trying to do. So, it would be increased awareness, increases funding, increased collaboration, increased policies. Basically just improvement on all fronts.

Researcher: As Megan alluded earlier, she said that your poll indicated that 70% of South Africans don't know who RDSA is. So what would you say are the implications of being unknown?

P3: So again it comes back to a lack of awareness and a lack of understanding. So, because of the nature of the work that we do, you'll only seek out the support group for rare diseases on diagnosis or when somebody has been diagnosed, a family member etcetera. As a lay would wake up and go i want to go look for RDSA because it's not common. So, that's really it. It's about creating that increased awareness and that will improve the outcomes for patients.

Researcher: So, based on our discussion, if at all, what would say is your key understanding or view about the importance of brand identity for any Non-Profit Organisations?

P3: It's about when somebody hears about something and seeing them in their mind. It's about having that link. It needs to be easily understood so that there is that instant connection.

Researcher: So, i would be correct to say the brand positioning in the mind of the people?

P3: Absolutely.

Researcher: Thank you, i appreciate it.