

EVALUATION OF THE IMPACT OF MUSCLE DREAM EXPERIENCES

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A mixed-methods retrospective evaluation of the
impact of the Muscle Help Foundation's Muscle Dream
experiences for beneficiaries and their families



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SUMMARY OF BENEFITS FOUND

Benefits of the Muscle Dream experience:



EXECUTIVE SUMMARY

Introduction

1. The Muscle Help Foundation (MHF) aims to deliver 657 Muscle Dreams to young people with a diagnosis of Muscular Dystrophy (MD), which is one life-changing experience for every muscle in the human body. As of November 2016, 239 Muscle Dreams have been fulfilled.
2. In line with the presentation of the condition, the majority of muscle dreams have been delivered to young British males between the ages of 11 and 15, living in the South East. However, there is much diversity overall amongst the beneficiaries of Muscle Dreams.

Quantitative analysis

3. Questionnaires indicated that the majority of beneficiaries were satisfied to an excellent degree with their Muscle Dream experience. This was fully supported by the qualitative analysis, which highlighted an appreciation of the Muscle Dream experience, all the extra treats, activities, gifts and surprises and the thoughtfulness of the Muscle Help Foundation team.
4. Questionnaires indicated that the Muscle Dream experience has benefits for beneficiaries and families on a relational and social level (including making new friends, having opportunities to share information and knowledge with others and being inspired to 'join in' socially), potentially increasing support networks; this could be a fruitful direction for further study. This point was elaborated on by the qualitative analysis, where families described how developing friendships with other families with children with MD, and joining the MHF 'tribe' through identifying with the Muscle Warrior identity, staying in touch through social media and giving back to the charity all strengthened the sense of community. The kindness, compassion and understanding received from Michael and Sue McGrath seem particularly to enhance individual families' sense of belonging in relation to the charity.
5. The majority of beneficiaries indicated that through taking part in the Muscle Dream experience they grew in confidence and self-esteem, and were clearer about their life goal. These findings suggest longer-term benefit of the Muscle Dream experience for a beneficiaries sense of identity. There was some further support for this from the qualitative analysis.
6. Almost two thirds of beneficiaries also indicated that they had learned a new skill or took up a new activity following the Muscle Dream experience, indicating a change in purposeful activity. Again, there was some support for this from the qualitative analysis.
7. Questionnaires indicated that some beneficiaries felt more unsure ('*don't know*' responses between 10-20% across these questions) about making links between their Muscle Dream experiences

and broader life changes (including for example; increase in confidence and self-esteem, learning new life skills or trying new activities and feeling clearer about their life goals) than about other parts of the questionnaire at the time of its completion. Possible reasons could include that this was not part of their

expected outcomes for the Muscle Dream experience or that these changes take longer to manifest in a young person's life. It might be useful to consider how these impacts could be strengthened further before, during and after the Muscle Dream experience. It is suggested that this could be a focus for further research.

Qualitative analysis

8. The qualitative analysis highlighted the fact that a number of beneficiaries and family members particularly appreciated the Muscle Help Foundation's full understanding and consideration of disability and the lengths that the team went to in order to enable the beneficiaries.
9. Some beneficiaries described particularly valuing the mobility, physicality and physical playfulness that formed part of many Muscle Dreams.
10. The Muscle Dream experience provided families with a 'pocket of smiles' in between many life and MD-related challenges, time when parents could see their child happy, relaxed and having fun; time when they could connect around positive experiences away from hospitals; and a time to make precious memories that could sustain them in difficult times – this could be seen as especially meaningful given the life-limiting nature of especially Duchenne MD.
11. Most families and beneficiaries described a strong ongoing connection with the Muscle Help Foundation. This connection seemed particularly strengthened through the inspiration they found in their contact with Michael McGrath as a person like them, living with MD himself. Michael is an inspiration and role model to many of the young people.
12. There are indications in the qualitative data that the experience of the Muscle Dream has potential long-term affects for beneficiaries and families that included:
 - new confidence, seeing new possibilities, and being inspired to try something new;
 - an expansion of sense of identity, both for self and others, allowing for aspects beyond the illness- or disability-identity to come more to the fore;
 - finding hope.

These aspects could be further explored through research focusing on the lasting impact of Muscle Dreams.

Recommendations

- 1.** The Muscle Help Foundation is already providing successful, enjoyable and meaningful Muscle Dream experiences to young people with a diagnosis of Muscular Dystrophy and their families. This success could be built upon by providing further such Muscle Dream experiences.
- 2.** This analysis highlighted particular aspects of Muscle Dreams that were valued by beneficiaries and families, enabling the Muscle Help Foundation to continue to reinforce these in future Muscle Dreams. These include: getting to know beneficiaries and families well before the Muscle Dream in order to thoughtfully select tailor-made surprises and gifts to enhance the experience; provide families with opportunities to meet other families living with MD where appropriate, and to build on the Muscle Warrior 'Tribal' family and brand, thus developing a sense of community and providing beneficiaries with a sense of belonging and broader group identity.
- 3.** The Muscle Help Foundation has a particular advantage in having a CEO living with Muscular Dystrophy himself and this has been shown to be particularly meaningful to young people taking part in Muscle Dream experiences. Therefore, the very personal way in which Michael McGrath (and also Sue McGrath as a person understanding the experiences of family members) is involved in each Muscle Dream is a central part of what the charity offers - these key roles lie at the core of the charity and are mirrored in the people it serves. It appears an important enduring future dimension for the charity to consider.
- 4.** This personal experience of life with MD also enables the team to fully consider and accommodate disability related to MD, allowing beneficiaries to feel enabled and for the family and beneficiary to relax and enjoy the Muscle Dream. It is important for the team to continue to be aware of the importance of this aspect of the Muscle Dream for beneficiaries and family members.
- 5.** For many beneficiaries the feeling of mobility and physicality were highlighted as particularly meaningful. This awareness could enhance future Muscle Dream experiences, while holding in mind that a small minority found speed and physicality a little overwhelming.
- 6.** It is suggested that the Muscle Help Foundation could use this report (as well as the limited existing research about Dream fulfilment) to review the questionnaire completed by beneficiaries and families at the end of each Muscle Dream in order to ensure that the benefits highlighted in the report may be fully captured and further evaluated by the questionnaire (e.g. including items on hope; enhanced positive emotions).

7. Evaluation questionnaires are sent to beneficiaries and families within 48 hours after a Muscle Dream Experience has been delivered. Qustionnaires could be sent out within a one month period, allowing for additional reflection, to enable the capture of longer term benefits that could take time to become visible to beneficiaries and family members.



8. It is recommended that the Muscle Help Foundation consider how the more fundamental or long-term impacts of the Muscle Dream experience could be even further strengthened and enhanced before, during and after the Muscle Dream experience. This could include highlighting these potential benefits when promoting the Muscle Dream experience to potential beneficiaries, encouraging volunteers to use opportunities during Muscle Dream experiences to build on these aspects and to follow up Dream experiences with further opportunities for building confidence and hopefulness, e.g. through purposeful activities, etc.



9. Further research, specifically in relation to fully understanding the long-term benefits for beneficiaries in relation to identity and purposeful activity, is recommended.



1. INTRODUCTION

1.1 Muscular Dystrophy and its impact

It is estimated that 49,000 children aged 0-18 are living with a life-limiting or life-threatening condition in the United Kingdom; 55,000 young adults aged 18-40 are living with a life-limiting or life-threatening condition in England [data for other areas not readily available] (Norman & Fraser, 2014). Of the 5,000 children that die each year in England and Wales, 2,500 die as a result of a life-limiting or life-threatening condition (Sidebotham, Fraser, Fleming, Ward-Platt & Hain, 2014). One of the life-limiting conditions diagnosed in young people is Muscular Dystrophy.

Muscular Dystrophy (MD) refers to a range of neuromuscular diagnoses linked to mutated X-chromosomes, characterised by progressive skeletal muscle weakness and defects in muscle proteins (National Institute of Neurological Disorders and Stroke, n.d.). There are many forms of MD within nine main categories, namely Duchenne, Becker, Limb-girdle, Facioscapulohumeral, Congenital, Oculopharyngeal, Distal, Myotonic and Emery-Dreifuss MD. It is estimated that over 70,000 people are diagnosed with MD or related conditions within the UK (Muscular Dystrophy UK, n.d.).

MD affects approximately 1 in every 7250 males between the ages of 5 and 24 years (Romitti et al., 2015). Although MD typically affects males, some categories of MD also affects females and also, around 8-10% of female carriers of the gene have some indicators of the disease. There are approximately 2500 young people that

have a Duchenne Muscular Dystrophy (DMD) diagnosis in the UK. Most MD conditions are progressive, causing the muscles to gradually weaken over time and, despite advances made in neuromuscular research, there is currently no known cure for MD.



The impact on the quality of life for individuals with MD and their families can be great (Bach, Campagnolo & Hoeman, 1991; Baiardini, et al., 2011; Grootenhuis, de Boone & Van der Kooi, 2007). Alongside significant physical and medical challenges for individuals and their families (e.g. pain, loss of mobility, etc.), there are also many social concerns. These include the need for quality care (Kohler et al., 2005), maintaining personal independence (Munn, 2010), access to meaningful educational and vocational opportunities (Abbott & Carpenter, 2014; Skyrme, 2015), meaningful

social and intimate relationships (Rahbeck et al., 2005) and a positive sense of self (Buchanan, LaBarbera, Roelofs & Olson, 1979) and the future (Abbott & Carpenter, 2014; Gibson, Zitzelsberger, & McKeever, 2009). It has been found that parenting a child with a MD diagnosis can be a long and lonely struggle (Gravelle, 1997) for many parents. Families also face difficult decisions around information sharing and communication about MD (Fitzpatrick & Barry, 1990), managing potential stigma from the wider society (Gagliardi, 1991), as well as future planning (Abbott & Carpenter, 2014). Thus, all in the family face significant challenges over an extended period of time.

1.2 Wish fulfilment

The rising awareness of the psychological impact of coping with life-limiting and life-threatening illnesses in children and young people has led to the development of different community orientated programmes to enhance the quality of life of these young people and their families. One type of intervention has been that of 'wish fulfilment'. However, very little research exists that helps us understand the immediate or long-term effects of wish fulfilment (Shoshani, Mifano & Czamanski-Cohen, 2015). What we do know from the very limited research base is that wish fulfilment can potentially empower young people and their families, can give young people a sense of agency and normalcy, can generate positive emotions and create a sense of hope for the future, can

provide validation for the young person's illness, can improve health-related quality of life and psychological wellbeing and can potentially have an enduring positive impact (Shoshani, et al., 2015; University of Sterling, 2015). Furthermore, it can strengthen family relationships and create meaningful memories. These studies have highlighted the importance of evaluation of such interventions to develop our understanding of the short and long-term impacts for young people and their families (Galinsky, 2014).

1.3 The Muscle Help Foundation

CEO Michael McGrath set up the Muscle Help Foundation (MHF) to organise and facilitate personalised events, experiences and activities for young people with MD and their families. MHF is unique in the world because of its goal to deliver 657 Muscle Dream experiences. That is one life-changing experience for every muscle in the human body. As of November 2016, 239 Muscle Dreams have been fulfilled.

1.4 Muscle Dreams

The process of having a Muscle Dream experience is normally begun via a nomination. The nomination can be received from anyone who knows the young person with a MD diagnosis. In order to receive a Muscle Dream, the nominee must be aged between 8-28 years old, must live in the UK and have a diagnosis of MD or one of its variants.

All effort is made to ensure nominees receive their Muscle Dream. The process starts with the MHF team getting to know the young person and their family. A tailor-made event is then designed to fit with the young person's likes and temperament. This Muscle Dream experience takes full account of the young person's needs in relation to disability. Volunteers support the young person and family throughout. The Muscle Dream experience always includes many gifts and surprises and photos and DVDs form important ways to remember the day by.

Following a Muscle Dream experience, each family rates the day and the impact of the experience by completing a questionnaire.





2. RATIONALE, AIMS AND OBJECTIVES

2.1 Rationale

There is a clear commitment from CEO Michael McGrath and the Muscle Help Foundation to assess and validate the impact of Muscle Dreams for beneficiaries and their families. The MHF has collected feedback forms for every Muscle Dream that has been delivered. Further, the MHF captures additional personal feedback received from cards, letters and emails sent by beneficiaries and family members following their Muscle Dream experiences. Retrospective analysis of this information could furnish the MHF with further valuable information about the impact and experience of Muscle Dreams among participants.

2.2 Aims and Research Questions

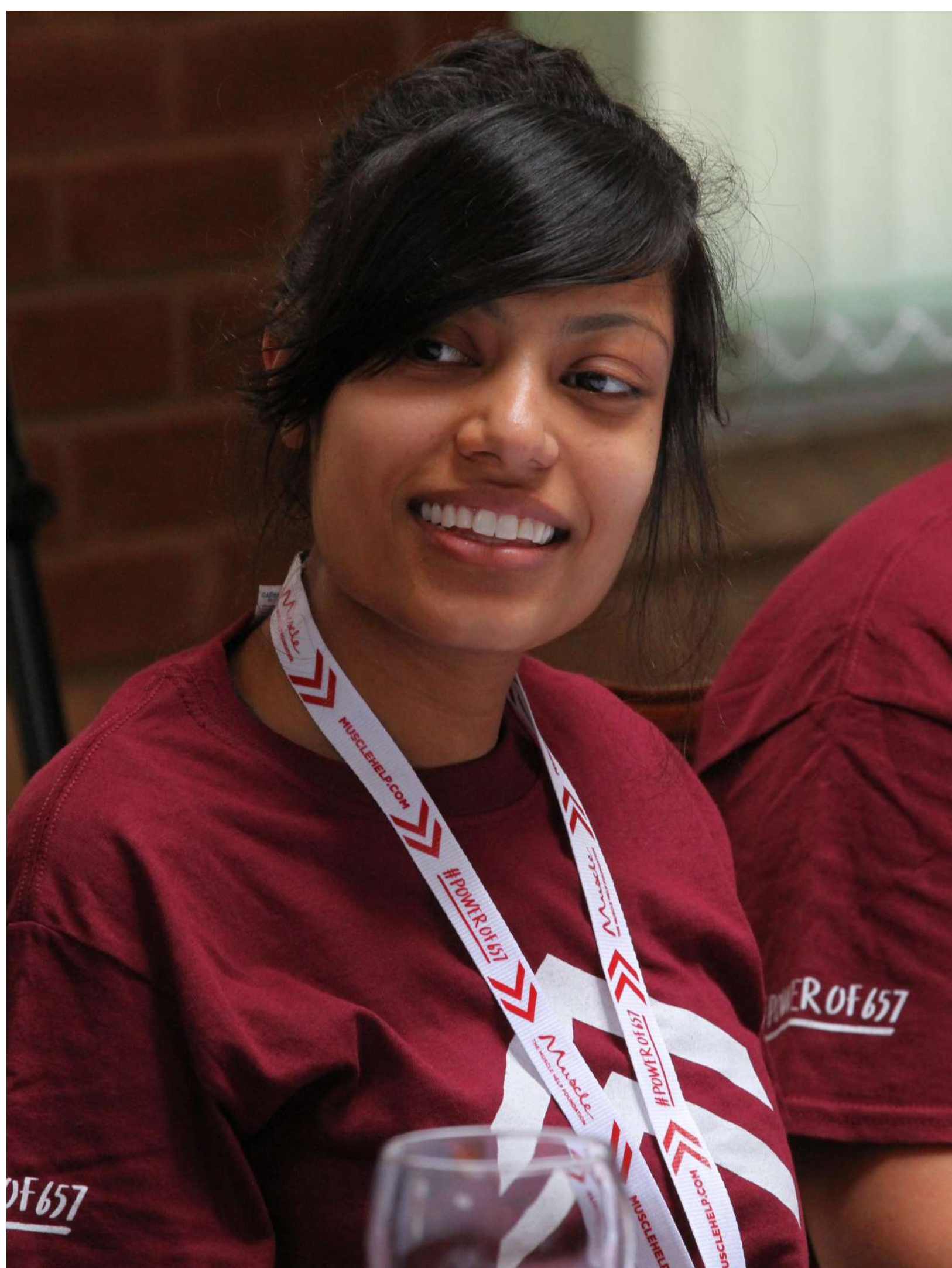
The aim of the current service evaluation is to establish the impact of the Muscle Help Foundation's Muscle Dreams for beneficiaries' lives and for their families.



Research Questions

1. What is the level of satisfaction beneficiaries and their families have of the Muscle Help Foundation following a Muscle Dream experience?
2. What can the qualitative feedback tell us of the impact of Muscle Dreams for beneficiaries and their families?





3. METHOD

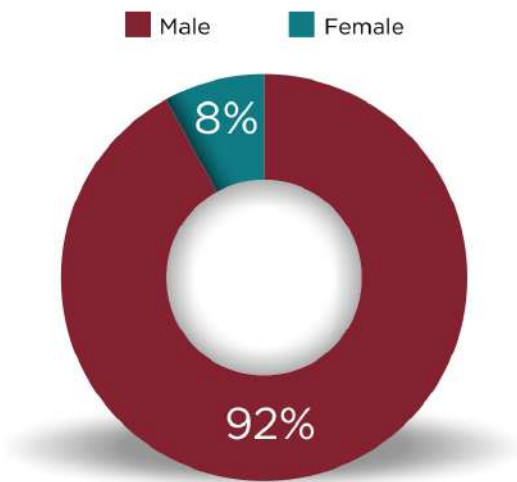
3.1 Design and Data Sources

This service evaluation used a mixed-method retrospective design. Data was obtained from all available beneficiary and family feedback forms for Muscle Dreams up until January 2016 (100% return rate). Additionally, many beneficiaries and families have written to the charity following a Muscle Dream experience. This data was also available for analysis.

3.2 Overview of Sample

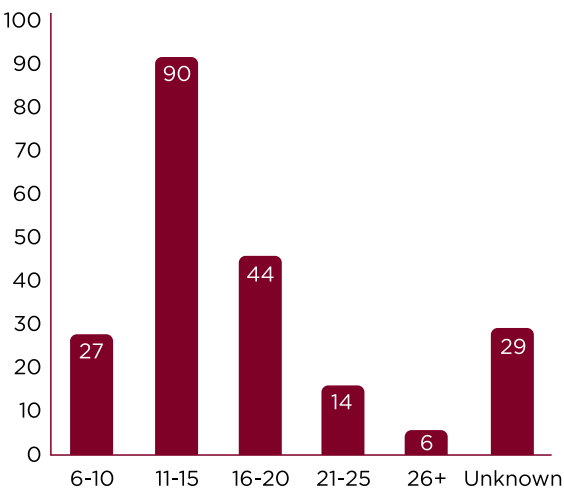
The majority of the sample (92%) were male, which is in line with what is known about MD, namely that it typically affects males (Romitti et al., 2015) (Graph 1). The ages of beneficiaries ranged from age 6 to 26+, with the largest proportion of beneficiaries aged between 11-15 (Graph 2). The majority of beneficiaries were of White British ethnicity (Graph 3). The graphs below show a full breakdown of demographic data (raw data in Appendix 1). Additionally, Figure 1 shows where beneficiaries live, in relation to the Foundation base. The majority of beneficiaries were from the South East region of the United Kingdom.

Gender Demographics



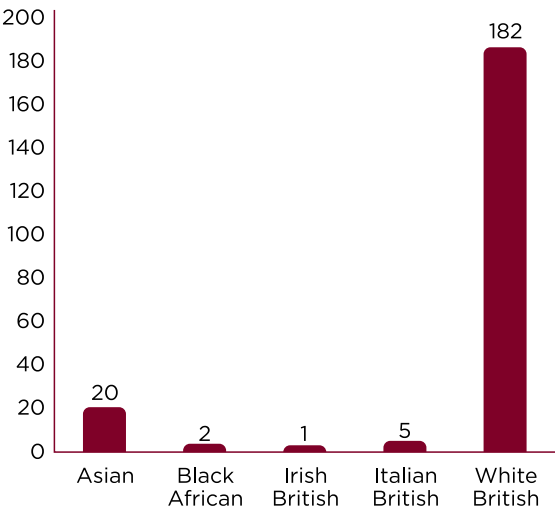
Graph 1: Pie chart showing the gender demographics of beneficiaries

Age Group of Beneficiaries



Graph 2: Bar Chart showing age groups of beneficiaries

Ethnicity of Beneficiaries



Graph 3: Bar Chart showing beneficiary ethnicity

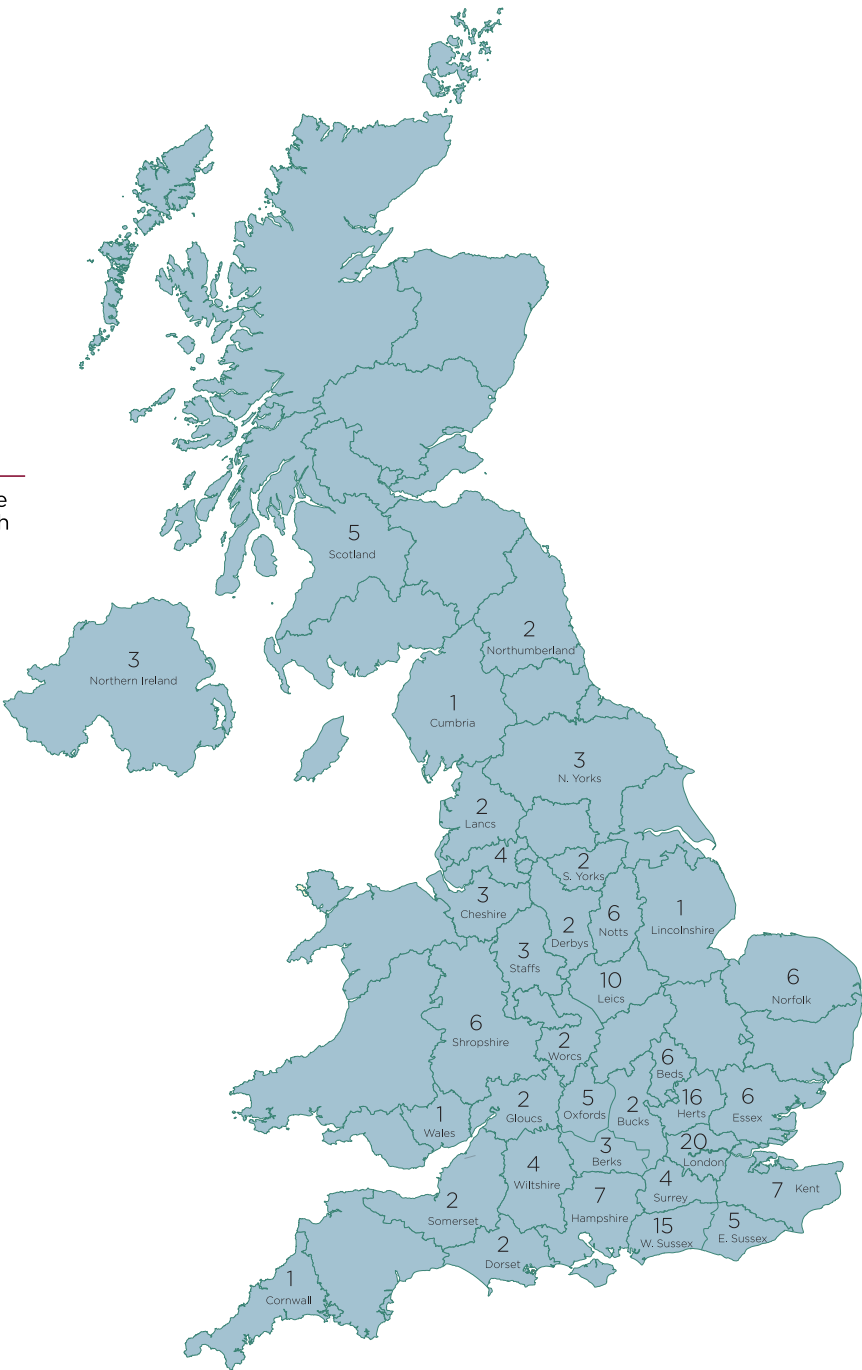


Figure 1: Map showing the numerical distribution of beneficiaries throughout the United Kingdom by domicile county.

3.3 Measures

The feedback form, devised by the MHF (Appendix 2), is a 14-item questionnaire that asks beneficiaries to rate on a 5-point Likert scale their experience of the Dream. There are also four additional qualitative questions that allow beneficiaries to share what they enjoyed most and least about their experience.

The MHF has received cards, letters and emails since the birth of the foundation and the delivery of Muscle Dreams. These may provide an additional resource of information subject to ethics approval.

3.4 Procedure

Information sheets (Appendix 3) were provided to previous beneficiaries and their families. These explained the nature of the research and set out information on how they could opt out of their data being used in the study if they wished. Additionally, a public post was placed on the Foundation website, notifying beneficiaries and their families of the research. Beneficiaries were given two weeks to opt out before being sent to researchers in order to protect individual privacy. All data was anonymised and all identifying information removed by the MHF before being sent to the researchers. Additionally, a formal agreement (Appendix 4) was made between the University of Hertfordshire and the MHF in relation to data management.

Once data was received, analyses were conducted on the quantitative and qualitative data.

3.5 Ethical Issues

University of Hertfordshire (UH) ethical approval was sought as this analysis was to be carried out on letters and cards received from beneficiaries and their families not originally intended to be used as data by the charity. Although ethical approval was sought, it was decided by the Chairman of the Health and Human Sciences Ethics Committee with Delegated Authority (ECDA) that UH ethics approval was not required (Appendix 5), provided permission to access the data had been granted and the data was used confidentially. This was managed by giving families the option to 'opt-out' of the study. Furthermore, all data was treated with utmost respect and confidentiality. All non-anonymised data was held and securely stored by the Foundation and the researchers only received data once it had been anonymised.

3.6 Data Analysis

As the questionnaires (82) were post-experience questionnaires, without a comparison and data was numerical, descriptive statistical analyses were carried out.

Thematic analysis was carried out on qualitative data. This was chosen to gain a deeper understanding of beneficiaries' experiences and to identify what impact the Muscle Dream had on them and their families. Sixteen percent (n=29) of the qualitative data set were letters received from primary school students relating to a talk given by Michael McGrath, founder

and CEO of the organisation. These were not included in the analysis as they did not relate to the aims of this research, which were focused on the Muscle Dream experience.

Themes were extracted from the remaining data using Braun & Clarke's (2006) guidelines for Thematic Analysis. This included the six phases of data analysis:

- 1. Familiarisation with data
- 2. Generating initial codes
- 3. Searching for themes
- 4. Reviewing themes
- 5. Defining and naming themes
- 6. Producing the report

Analysis was completed by one researcher (LN), while another researcher (RR) who was familiar with the data, checked codes.



4. RESULTS - QUANTITATIVE ANALYSIS

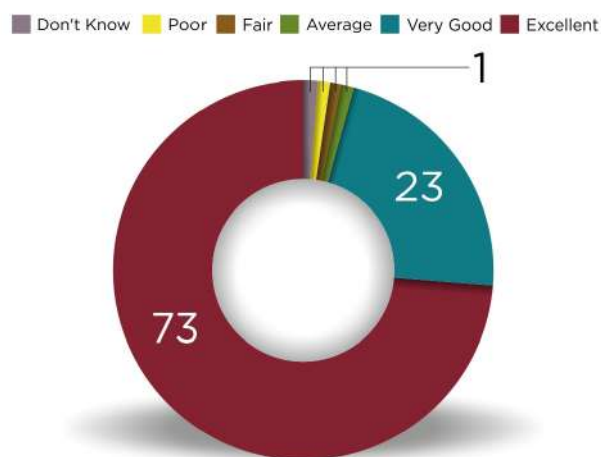
The results show the findings for the 14 separate statements (Appendix 2) requiring a Likert scale response. In order to best capture the data, the analysis was broken down by statement (raw data can be found in appendix 6).

Although feedback forms were received after every Muscle Dream experience, earlier data was not backed up electronically and original documents were not found. Thus, 82 feedback forms were received from the MHF (from 2010- 2016).

4.1 Breakdown of Individual Statements

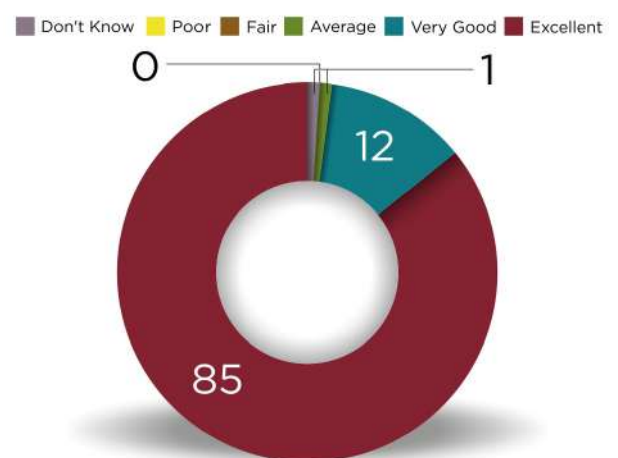
Numerical data shown in all individual statements is expressed as a percentage.

Statement 1 Responses



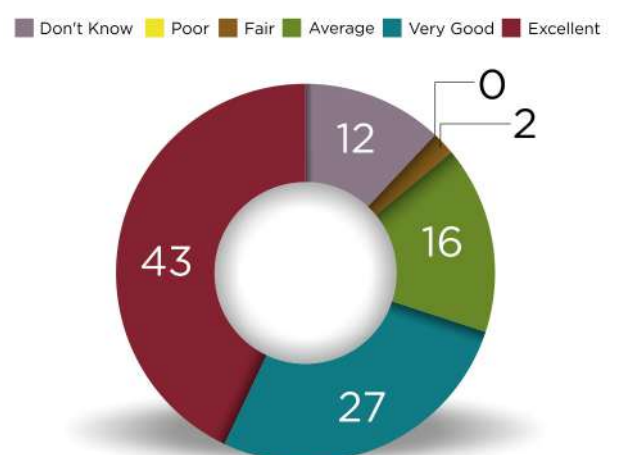
Statement 1 refers to the pre-event information being sent in advance. The pie chart shows how this statement was rated. The figures shown are percentages and it can be seen that 96% of responses rated this statement as *Very good* or *Excellent*.

Statement 2 Responses



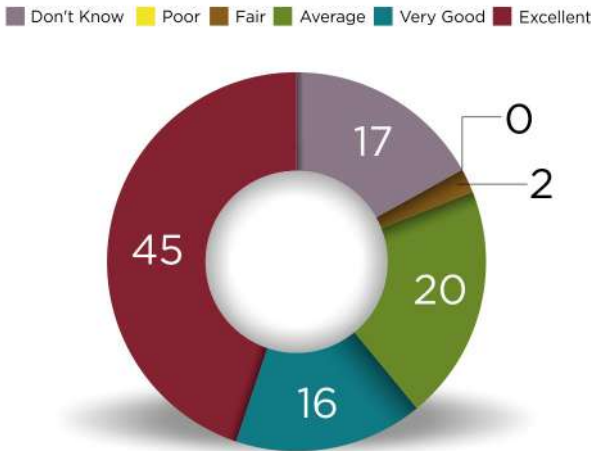
Statement 2 refers to the actual delivery on the day. The figures shown are percentages and it can be seen that 85% rated the delivery as *Excellent* and 12% rated *Very good*, with 0% rating *poor* or *fair*.

Statement 3 Responses



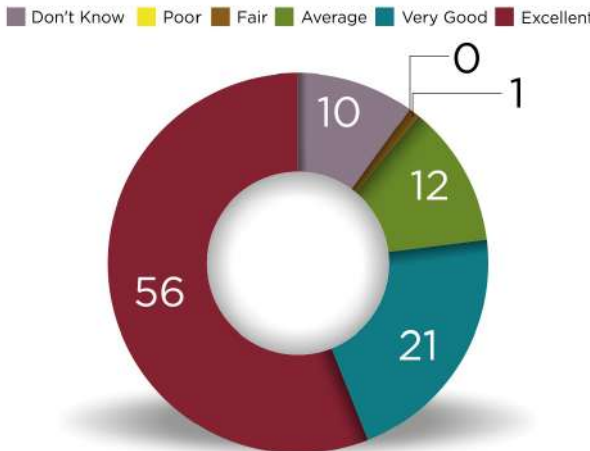
Statement 3 refers to improving confidence. The figures shown are percentages and it can be seen that 43% rated *Excellent* and 27% rated *Very good*. It is interesting to note that 12% of respondents rated this statement as *Don't know*, and 16% rated *Average*.

Statement 4 Responses



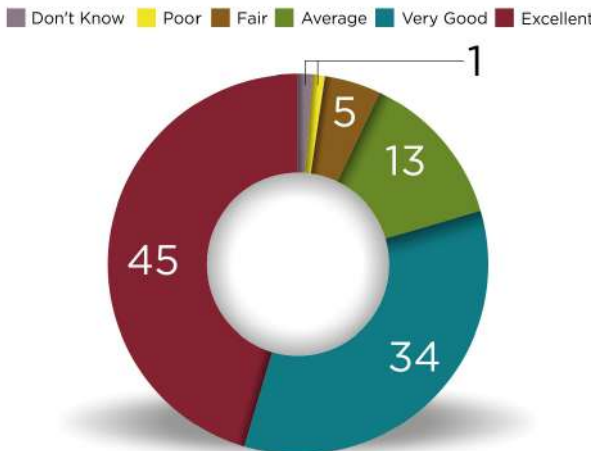
Statement 4 refers to learning a new skill. The figures shown are percentages and it can be seen that 45% rated *Excellent*, 16% rated *Very good* and 20% rated *Average*. Furthermore, 17% of responses rated this statement as *Don't know*.

Statement 6 Responses



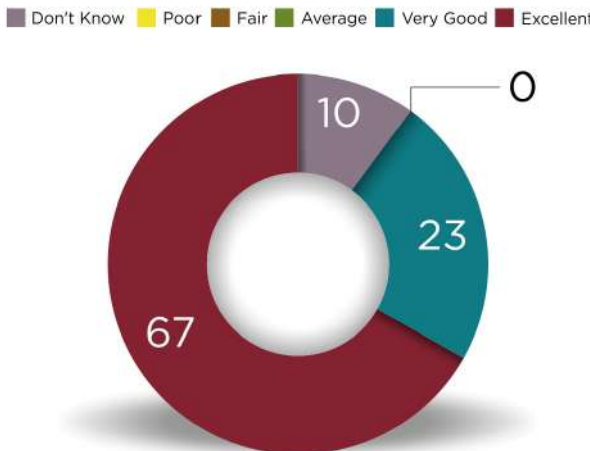
Statement 6 refers to improving self-esteem. The figures shown are percentages and it can be seen that 56% rated *Excellent*, 21% rated *Very good* and 12% rated *Average*. There were 10% of responses rated as *Don't know*.

Statement 5 Responses



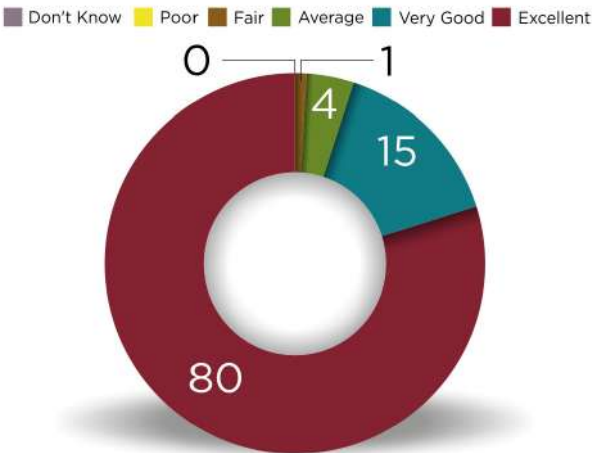
Statement 5 refers to making new friends. The figures shown are percentages and it can be seen that 45% rated *Excellent*, 34% rated *Very good* and 13% rated *Average*.

Statement 7 Responses



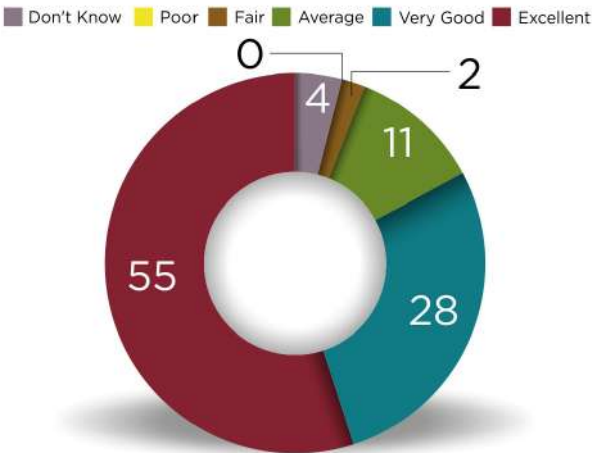
Statement 7 refers to how their experience has compared to other events separate from the MHF in which respondents have participated. The figures shown are percentages and it can be seen that 90% of respondents rated this as *Excellent* or *Very good*.

Statement 8 Responses



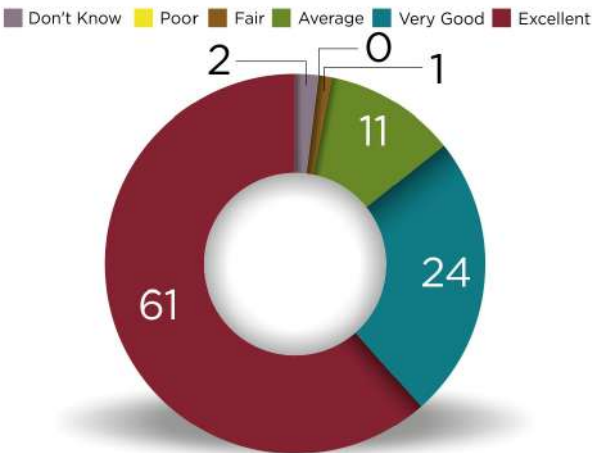
Statement 8 refers to the family's participation and enjoyment of the experience. The figures shown are percentages and it can be seen that 95% of respondents rated this statement as *Excellent* or *Very good*.

Statement 10 Responses



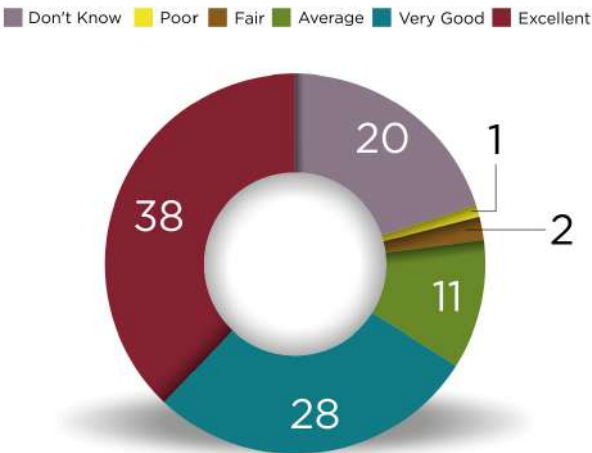
Statement 10 refers to inspiring beneficiaries to join in with others. The figures shown are percentages and it can be seen that 55% of respondents rated this statement as *Excellent*, 28% rated *Very good* and 11% rated *Average*.

Statement 9 Responses



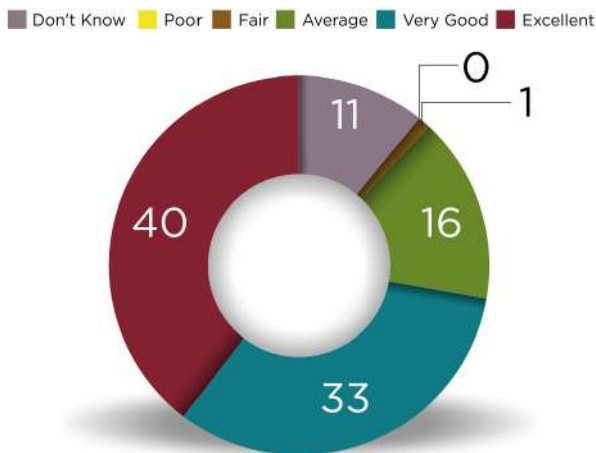
Statement 9 refers to the opportunity to share knowledge with other families/parents/carers. The figures shown are percentages and it can be seen that 61% rated this statement as *Excellent*, 24% rated *Very good* and 11% rated *Average*.

Statement 11 Responses



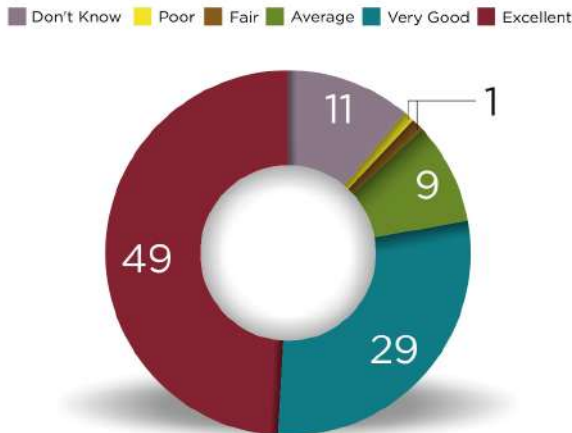
Statement 11 refers to inspiring beneficiaries to take up a new activity/sport. The figures shown are percentages and it can be seen that 38% of respondents rated this as *Excellent*, 28% rated *Very good* and 11% rated *Average*. Again, it is interesting to note that 20% of respondents rated this statement as *Don't know*.

Statement 12 Responses



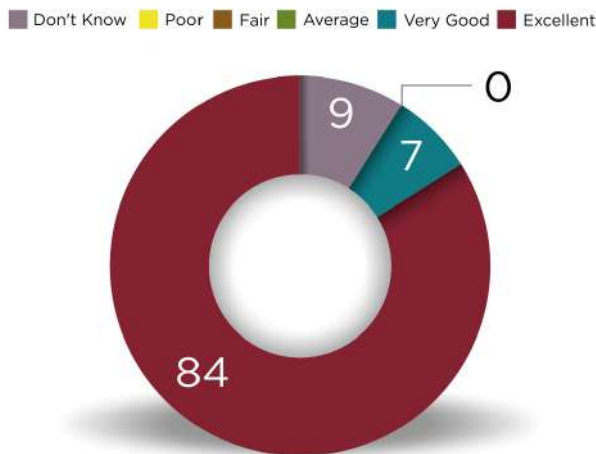
Statement 12 refers to helping beneficiaries decide what goals they may want to achieve in life. The figures shown are percentages and it can be seen that 40% of responses rated this statement as *Excellent*; 33% rated *Very good* and 16% rated *Average*. There were 11% of respondents who rated *Don't know*.

Statement 13 Responses



Statement 13 refers to helping improve family life. The figures shown are percentages and it can be seen that 49% of respondents rated this statement as *Excellent*, 29% rated *Very good* and 9% rated *Average*. There were 11% of respondents who rated this as *Don't know*.

Statement 14 Responses



Statement 14 refers to their overall Muscle Dream experience. The figures shown are percentages and it can be seen that 91% of respondents rated this statement as *Excellent* or *Very good*.

4.2 Overview of quantitative results

The statistics indicate that overall the Muscle Dream experiences were rated positively on the 14-statement questionnaire. Statements 1, 2, 8 and 14 were of particular note as they yielded excellent responses from at least 73% or more of the total sample. These statements refer to the information sent beforehand, the delivery on the day, the family's participation and enjoyment and the overall Muscle Dream experience. They refer specifically to the Muscle Dream experience and it could therefore be said that the majority of beneficiaries were satisfied to an excellent degree with their Muscle Dream experience.

The positive ratings for statement 5 (making new friends – 79% very good to excellent), statement 9 (opportunity to share knowledge with other families/parents/carers – 85% very good to excellent) and statement 10 (inspiring beneficiaries to join in with others – 83% very good to excellent) indicate that the Muscle Dream experience has benefits for both beneficiaries and families on a relational and social level, potentially increasing support networks. There appeared a strong indication that the Muscle Dream experience improved family life, with 78% indicating that this was the case to a very good or excellent degree. This points towards relational benefits within families too.

It is very encouraging that the majority of beneficiaries indicated that, through taking part in the Muscle Dream experience, they grew in confidence (70%) and self-esteem (77%), and were clearer about their life goals (73%). These findings may indicate a longer-term benefit of the dream experience for young people's sense of self.

Almost two thirds of participants also indicated that they had learned a new skill (61%) or took up a new activity (66%), indicating a change in purposeful activity for these respondents.

While the overall ratings were very strongly positive on these aspects of identity and purposeful activity, it is interesting to note that statements 3, 4, 6, 11 and 12 (referring to improving confidence, learning a new skill, improving self-esteem, inspiration to take up a new activity and helping to decide what goals to achieve in life), yielded more don't know responses than the other statements. One could argue that these statements refer to more fundamental changes in the young person's life, confidence and identity and some beneficiaries might not be able to make these connections immediately after the event. Furthermore, it would be interesting to consider to what extent these aspects were hopes these families had for their Muscle Dream experience beforehand and thus, whether these questions fitted with their expectations of the Muscle Dream experience. Finally, it would be interesting to consider how the MHF could strengthen these aspects before, during and after the Muscle Dream experience.



5. RESULTS - QUALITATIVE ANALYSIS

5.1 Thematic Analysis

The qualitative analysis involved a thematic analysis (TA) (Braun & Clarke, 2006) of the 4 qualitative questions at the end of the questionnaire as well as the thank you cards, letters and emails received by the MHF.

Four themes were identified, namely Appreciating ‘everything from start to finish’, Valuing a positive experience, Belonging to the Muscle Dream community, and Lasting impact of Muscle Dream (see Table 1). Each of these themes with their subthemes will now be discussed and illustrated with anonymised quotes from the data.

Appreciating “everything from start to finish”	<ul style="list-style-type: none">• A dream come true• Feeling special• Being enabled
Valuing a positive experience	<ul style="list-style-type: none">• Joy for parents of seeing their child happy• A ‘pocket of smiles’ in difficult time• Making memories
Belonging to the Muscle Dream community	<ul style="list-style-type: none">• Like a second family• There should be more people like you• Feeling inspired
Lasting impact of Muscle Dream	<ul style="list-style-type: none">• Gaining confidence• More than my disability• Finding hope

Table 1: Table of themes from qualitative analysis of cards, emails, letters and drawings

5.1.1 Appreciating “everything from start to finish”

This theme refers to how participants expressed deep gratitude for all aspects of the Muscle Dream, beyond the Dream experience itself, including all the extra treats and surprises, the kindness and thoughtfulness of the MHF team and volunteers and the fact that everything was arranged with an awareness of, and responsiveness to, their needs and disabilities.

A MUSCLE DREAM COME TRUE

Beneficiaries as well as family members expressed deep gratitude for the Muscle Dream experience itself, using words like “*amazing*”, “*fantastic*”, “*wonderful*”, “*fabulous*”, “*incredible*”, “*great*”, and many commented on how overwhelming the experience was and how inadequate words felt in capturing their experiences and gratitude.

Thank you so much for organizing such an unforgettable, fantastic experience... It really was a dream come true... Family 11¹

I just wanted to thank you all so very much for such a fabulous dream day out for (son) and for us. (Son) still says it was the best day of his life. Family 18

Many were thankful for having a dream come true that they had held for a long time, making it an unforgettable experience.

Thank you so much for such an unforgettable, fantastic experience... It really was a dream come true for (son). Family 1

(Son) actually said that ‘Christmas had come early’! We will never forget the day we spent with you... Family 22

Beneficiaries expressed that they felt very excited, felt privileged and were often slightly in disbelief that they could have had such a wonderful experience.

FEELING SPECIAL

Beneficiaries and family members specifically pointed out that they did not expect all the special touches, little surprises and gifts they could keep and treasure. Many commented on the thoughtfulness of the MHF team who had “thought of everything”.

We all thoroughly enjoyed every moment and seeing (son) having the time of his life in the cars, and his delight at the many surprises throughout the day and night warmed our hearts. Family 4

Thank you for the fantastic day at [Rugby club] I enjoyed the food, especially the pudding. I loved watching them play rugby. I love my rugby shirt, my signed book, and my hat. I am thrilled with my HMV voucher and my goody bag. It was very kind of you. Beneficiary 16

Beneficiaries and family members talked about how this thoughtfulness made them feel very special and some described feeling nurtured and looked after.

We would like to thank you for making (son)’s dream come true at [Football Stadium]. He was truly amazed and felt like a VIP film star!! He loved seeing his photos all over [XX] Hotel and everyone at the [Hotel] made him feel really special. Family 19

¹ All identifying information has been removed and beneficiaries, families and volunteers have been randomly allocated a number to protect anonymity

Thank you so much for our wonderful experience in London. The fantastic [pop band] concert, the hotel, food, fun and excitement and for looking after us all so well, not forgetting XX goodies. We really appreciate everything and can never thank you enough... *Family 33*

We were so well looked after... the organizing was perfect, so we had nothing to worry about. *Questionnaire 22*

[We] felt like royalty. *Questionnaire 54*

A further aspect that was described by many beneficiaries, family members and those volunteering as helpers at events were the approach and attitude of the Muscle Help Foundation team. The personal involvement, time spent, kindness and compassion were noticed and appreciated by many.

You [Michael McGrath] spent a huge amount of time in your already very busy schedule helping me with conquering some of my issues and I will never forget this kindness. *Volunteer 2*

Our whole family are so grateful for your kindness, thoughtfulness and generosity. *Family 4*

Overall, these special treats and surprises, which had been thoughtfully selected, and in particular the kindness of the Muscle Help Foundation Team and volunteers seem to add much to the experience for all involved.

BEING ENABLED

The final sub-theme refers to the fact that disability was never an obstacle during the Muscle Dream experience. Muscle Dreams were arranged around the needs and requirements of the beneficiary from a place of knowledge and understanding and this was deeply valued by a number of the participants. It allowed them to feel enabled and for the Muscle Dream experience to be in the foreground, rather than disability or restriction.

It was a joy spending the time with you both where disability is so normal. Thank you for your kindness, compassion and understanding. *Family 9*

Excellent facilities for disabled people and very enjoyable for young people. *Questionnaire 2*

... you get involved in all the activities and [are] treated like any other child... *Questionnaire 40*

Everyone see you for you and not your disability. *Questionnaire 67*

Of all the participants only 4 mentioned an aspect of their Muscle Dream experience where there was an obstacle in relation to their disability (e.g. height of bed, type of food). The many physical challenges experienced by young people with MD was also highlighted by the question relating to the least enjoyable aspect of the Muscle Dream where, while most questionnaires indicated 'nothing' could be improved, a small number pointed out the challenges related to travel, waiting and coping with a busy day.

Part of feeling enabled seems to be a valuing of mobility and physicality that was part of many of the Dreams and also some of the formal and informal activities that unfolded around the Muscle Dream.

Thanks for a great fast day. I was very grateful for the wonderful opportunity. I loved going fast and off road. Beneficiary 13

To see the photographs of (son) on the speedboat and at the wheel was fabulous. Family 14

I enjoyed the balloon sword fight with Michael. Beneficiary 15

He loved the wheelchair races with yourself, only upset by the fact that you were faster! Family 19

The off-road experience [was what I most liked] – it was fast and mad... the chance to go fast with no one saying 'slow down'!!! Questionnaire 7

Therefore, the fact that disability was in the background, that accessibility was a given and that there was opportunity for physicality and physical playfulness seemed to be deeply valued by a number of participants. In contrast, there were a couple of beneficiaries who pointed out in the questionnaire that this physicality was a little frightening for them.

In summary, in the theme '*Appreciating everything from start to finish*' it was described how there was great appreciation for the fact that the MHF helped make a dream come true for beneficiaries. Furthermore, all the extra treats and surprises, and the thoughtfulness, kindness and compassion of the MHF team greatly added to the experience. Finally, the fact that disability was understood and fully responded to seemed particularly meaningful to a number of participants, with mobility, physicality and physical playfulness particularly treasured.

5.1.2 Valuing a positive experience

This theme refers to the Muscle Dream providing families with a positive, happy and connected experience amidst the challenges of MD and the hardships they face in their lives. Parents described how they found it particularly moving and meaningful to see their children having a happy and fun-filled experience. Often the experience was seen as a time out from many challenging experiences in their wider life and families seem to really value this. Finally, parents and beneficiaries described how they treasured making memories.

JOY FOR PARENTS OF SEEING THEIR CHILD HAPPY

This sub-theme refers to the joy it brought many parents to see their children happy and having a great time.

No words can describe the feeling we had to see our son so happy. It really was a dream come true for [son]. Family 1

We all thoroughly enjoyed every moment and seeing [son] having the time of his life in the cars, and his delight at the many surprises throughout the day and night warmed our hearts. Family 4

No words could express how wonderful it was to see the smiles on the boys' faces. Priceless. Family 17

[The value of the Muscle Dream experience for me was] the joy in (son)'s face [which was] amazing! Questionnaire 16

For a few it was meaningful to share this experience, away from hospitals and with a focus that was not on illness.

The only time that [my husband] and myself spend time just with [our son] without the other two children is when we're at hospitals so to spend such quality time with him was very special. Family 24

This joy seemed to continue beyond the actual experience of the Muscle Dream experience.

We have just watched [son]'s video of him in the Porsche racing around the track, which is fantastic and it also made me chuckle and smile. He had an absolutely incredible time. I can't thank you enough for what this has meant to me and [son]. Family 20

This subtheme highlights how the joy the children experienced was described as bringing great joy to parents, grandparents and siblings, both during the event and when they remembered it afterwards.

A POCKET OF SMILES IN DIFFICULT TIMES

This subtheme refers to the fact that the Muscle Dream experience was often surrounded by difficult times for families, related to the normal challenges of life and particularly to the challenges they had to face in relation to MD. Therefore, the Muscle Dream provides some time free from the many challenges families face.

We have been in and out of hospital with [son] who unfortunately took a down turn shortly after his Dream. The memories made on his Dream have served as a wonderful pocket of smiles in these difficult times. Family 30

It meant a lot to us as well, as [son] has had a difficult time at school over the past year and had only recently been diagnosed as dyslexic; his confidence and self-esteem took a big knock. So finally in the last couple of months he has been getting the extra help he needed and has become a lot happier in himself and at school. To finish the school

year off with a helicopter ride was just so rewarding for all this hard work and battle at school. *Family 34*

The experience made me forget all my troubles (for a while), giving me a sense of freedom from my everyday life with DMD. *Questionnaire 9*

It was wonderful quality family time and memories that will last through the harder times coming. *Questionnaire 61*

Some families reported how this 'pocket of smiles' in difficult times provided the boost needed by their child or themselves when they really needed it.

It's given [son] a real boost when he really needed it and for this we will always be grateful. *Family 22*

Thank you so much, it helped me a lot too; you have given me hope that good things do happen... your call came when I was at a low point and has restored my faith in people. *Family 31*

Finally, for a few families the Dream experience also allowed for precious opportunities to focus on the relationship with their other children and connect in a special way.

Thank you for arranging the 'mother & daughter' time at the spa and manicure session - they really enjoyed it. As you may realize, much of our time is devoted to [son] with MDI's needs, so this time was truly special for them. *Family 19*

Families described valuing the Muscle Dream experience as a positive moment in time, away from the many challenges they face day to day. They treasured these 'pockets of smiles' and it gave them the boost they sometimes needed.

MAKING MEMORIES

Most families emphasized the importance of the memories of the Muscle Dream experience for themselves.

We feel so very lucky to have been part of it and to have had the chance to create these special memories to keep forever. *Family 4*

[Son] still says it was the best day of his life - thank you everyone involved for making some very precious memories. We look forward to seeing all the photos. *Family 18*

Memories were described as important both to the young person with a MD diagnosis and to the family.

I don't know how to thank you all - (son) now has an amazing memory which will stay with him forever, thanks to you, the charity, and all the lovely people that we met. *Family 7*

[What I most liked about the day was] doing something with Dad AND Mum because I am a two parent kind of child. *Questionnaire 35*

Many families in particular emphasized the preciousness of the photos, videos and gifts that they received from the MHF as part of the Muscle Dream experience and it was described how these keep the memories of the Dream alive. It also allowed families to share the Muscle Dream with those family and friends who were not present on the day and to express their pride in their child.

I have enclosed a copy of a little souvenir booklet I put together for [son] and our family so we can all treasure the memories of the experience.

Family 26

Now we have amazing memories to cherish and he is already making friends and family jealous. *Family 20*

We have returned home safe, sound and very happy... and are busy posting photos on our Facebook walls! Many thanks for a truly fantastic and memorable experience for our boy and us, his parents! *Family 28*

The photos brought back the reality of the dream and how amazing it was. *Beneficiary 8*

My family also are happy that the photos are here and will share the pictures with friends and family. *Beneficiary 18*

Almost all the families and many of the beneficiaries highlighted the importance of making precious memories during the Muscle Dream experience and revisiting these memories through the photographs

and videos of the events. They also appreciated the opportunity to share these memories with family and friends.

In summary, the Muscle Dream provided families with a 'pocket of smiles' in between many life and MD-related challenges, time when they could see their child happy, relaxed and having fun; time when they could connect around positive experiences away from hospitals; and a time to make precious memories that could sustain them in difficult times – this could be seen as valuable in sustaining families in troubling times, and could be especially meaningful within the life-limiting nature of especially Duchenne MD.

5.1.3 Belonging to the Muscle Dream tribal community

This was the strongest theme throughout the data and describes the many ways in which both families and beneficiaries felt that they had joined a wider community by taking part in the Muscle Dream experience. They also described a particular connection with Michael McGrath, Sue McGrath and the rest of the Muscle Help Foundation team. Finally, they often described feeling inspired by Michael McGrath in particular and valued their connection with him, hoping to stay in touch over time.

LIKE A SECOND FAMILY

A strong relationship with the Muscle Help Foundation following the Muscle Dream experience was clear throughout the data. Many of the beneficiaries drew the charity logo on their thank you letters and cards, sent photos where they are giving the Muscle Warrior salute, signed off their messages with the ‘#StrongerTogether’ hashtag and talked about proudly wearing their Muscle Warrior wristband and t-shirt.

Dear Michael, a big Muscle Warrior salute to you! ... And we are wearing our "Muscle Warrior" t-shirts and wrist bands with the greatest of pride... Family 15

*Dear Michael and the rest of the Muscle Warrior crew, I just wanted to write to you to give a personal thank you to all your volunteers who made a day so special.... ☺
THANK YOU ☺ (#StrongerTogether)*

Family 24

*We are Muscle Warriors and proud xxx.
Thanks So Much! Beneficiary 6*

The Muscle Help Foundation is truly an all inspiring charity that I have embraced and I now stand proud as a 'Muscle Warrior'. Please be assured my shirt was proudly worn in my local village pub the following night and information was passed to many inquisitive friends and locals. Volunteer 4

I love the Muscle Help Foundation. Beneficiary 5

Some families also referred to the value of meeting other families at events or during shared Muscle Dreams.

We all had an amazing time and enjoyed sharing the day with (another beneficiary) and (another beneficiary) and their (family member). Family 32

It was great to meet new people and make new friends. Beneficiary 12

It was also nice to meet with (another boy) and his parents. Family 7

Because you meet new people, have fun and have a laugh. Questionnaire 3

[What I like best about the Muscle Dream experience was] meeting other families, as we all understand each other without explanation. Questionnaire 45

For many this felt like they had become part of a special family or tribe and this appeared to give many a strong sense of belonging.

You made us feel very special and we feel we have made some very special friends within the Muscle {Help} Foundation team. Family 22

I feel enormously privileged to be part of your amazing charity and having spent so much time with volunteers and families, I now really feel part of the Muscle Help Foundation tribe. Since the Paralympics, I feel this tribe has become a lot tighter and feels like a second family. Volunteer 2

Many families indicated that they hoped to stay in touch with the charity and for most this included a desire to give something back.

I would like to offer my services to you, if you ever need a volunteer for any events then feel free to ask. Would be more than happy to come and help. Family 24

We will never forget the day we spent with you and hope to see you all again. Please keep us informed of future events and if you need any help. Family 22

I do hope we can all stay in contact and help to support your charity in the future. Family 13

We would like to make a donation towards the amazing work you do to help {in} a small way towards making a Dream for someone else.

Family 30

We know [son] would like to help you whenever he can by keeping people aware of the Muscle Help Foundation and by helping raise money, especially within (his school). Family 34

This subtheme indicated the strong, and for many ongoing, relationship that the Muscle Dream established between families and the Muscle Help Foundation team and for some with other families with a child with Muscular Dystrophy. It also describes many families' desire to stay involved with the charity and give something back.

THERE SHOULD BE MORE PEOPLE LIKE YOU

A further subtheme was the strong connection people felt to Michael and Sue McGrath in particular and with the MHF team. All cards, notes and emails were addressed to the team by name, were warm and personal and often referred to specific moments shared, included humour and playfulness and an indication of specific characteristics that were appreciated.

There should be more people like you! Family 12

...you and your wife Sue and all of your team are a credit to humanity. My family and I are proud to be part of your "Muscle Warrior" family. Family 15

I really admire what you do as a charity and I am glad I have been part of what you offer.

Family 24

You and your team are stars. Family 21

Our whole family are so grateful for your kindness, thoughtfulness and generosity.

Family 4

It was great to meet your family and volunteers; {you} clearly are passionate about what you do and go the extra mile to ensure things go smoothly and that families enjoy themselves. Family 27

The warmth and kindness of the Muscle Warriors and ...team.. Questionnaire 11

This subtheme highlighted the special connection families felt to Michael and Sue McGrath and the MHF team and the value this relationship held for them.

FEELING INSPIRED

A final subtheme in this theme is the inspiration families, and beneficiaries in particular, took from Michael McGrath as CEO of the Muscle Help Foundation and as a successful and high achieving person living with a Muscular Dystrophy diagnosis himself.

Also well done in setting up Muscle Warriors. It's a great thing to do for people with Muscular Dystrophy. I hope it carries on for a long time. You are a great man who cares for lots of people. Beneficiary 2

I just want to say that you are a truly amazing person! You are an inspiration to me and many more. I love what you are doing making people's dreams come true. You are so caring and thoughtful. I liked how you made us feel special and important. It is a privilege and a pleasure to have met you and your team. Beneficiary 7

I will hopefully meet you again in the future and I hope the Muscle Warriors make other people experience the great things that you can do. I am following you on Twitter as well as Muscle Warriors and also liked the Facebook page. #StrongerTogether Beneficiary 18

Dear Michael, I wanted to write to you to express my thanks for giving me the most incredible opportunities over the last few

months... you spent a huge amount of time in your already very busy schedule helping me with conquering some of my issues and I will never forget this kindness. You have helped me to overcome a lot of my anxieties and I feel my confidence growing daily!

Volunteer 2

I loved how Michael & co were so caring... I really wish I had a dad like him...

Questionnaire 12

Each of my contacts with Michael have served to increase my confidence. Questionnaire 55

The contact with Michael McGrath was clearly meaningful for many of the beneficiaries and it made them seek out an ongoing connection with him and the MHF. The fact that he is a person with MD himself seemed particularly meaningful for the beneficiaries.

In summary, in this theme most of the families and beneficiaries described a strong ongoing connection with the Muscle Help Foundation. This connection was strengthened through a sense of community, an appreciation for the help, kindness and compassion received from Sue and Michael McGrath and the inspiration they found in their contact with Michael in particular. Furthermore, developing friendships with others, and joining the MHF 'tribe' through identifying with the Muscle Warrior identity, staying in touch through social media and giving back to the charity all further built this sense of community.

5.1.4. Lasting impact of Muscle Dream

As a point of distinction, the final theme of the lasting impact of the Muscle Dream was less well developed in the data. However, the presence of this theme within the data, where it would not necessarily be expected, makes it valuable to report.

Some ways in which the Muscle Dream experience had more lasting impact on young people's lives is therefore tentatively reported here.

GAINING CONFIDENCE

There was a sense that for a number of beneficiaries the Muscle Dream experience provided a boost to their confidence. It seems to open new horizons of possibility for them.

I thought the whole experience was perfect and gave me lots of confidence in trying new things. Questionnaire 2

I found out that things I thought was not possible now for me really are possible. Questionnaire 6

I really enjoyed meeting so many positive people and it really inspired me that I can do anything... it has left me inspired and ready to adventure... Questionnaire 12

...even in a wheelchair you can do anything... Questionnaire 14

Knowing that people with MD can achieve things. Questionnaire 24

I can now say I have driven a boat, even in my wheelchair. Questionnaire 30

[It] proved that no matter what the disability, where there is a will there is a way. Questionnaire 74

Some beneficiaries also reported doing something new or different following the Muscle Dream experience.

Hi Michael... I thought you would be interested to know that thanks to the Muscle Dream and your determination to do anything, you have inspired me to follow my dreams and gain my... racing license with a view to compete in a few rounds of the junior touring car championship (budget depending). I would like to take this opportunity to thank you once again for making me realize how much I want to follow my dreams and also giving me the determination to {do} this. Thank you once again. Beneficiary 8

We all benefitted enormously and [Son] was so thrilled. He has decided that he will start his pilot's license aged 14! Family 9

[What I most liked about the Muscle Dream experience was] flying aeroplanes because I could do it independently - it has inspired me to fly planes. Questionnaire 41

It made me want to improve my wheelchair football skills. Questionnaire 71

Therefore, for a number of beneficiaries the Muscle Dream increased their confidence, allowed them to see new possibilities and for some, led to them trying something new.

MORE THAN MY DISABILITY

There was also a sense from some families that they were feeling proud in sharing the Muscle Dream photos with family and friends and one could speculate that this potentially offers a new ‘storyline’ in the identity construction of the young person with a Muscular Dystrophy, expanding how they are perceived within their circle of family and friends beyond their health concerns.

Now we have amazing memories cherish and he is already making friends and family jealous. Family 20

It's given (son) a real boost when he really needed it and for this we will always be grateful. Family 22

[The part of the Dream I enjoyed most was] being able to walk around the (sport venue) pitch, because none of my friends have achieved this. Questionnaire 4

Therefore, there were some hints in the data that the Muscle Dream had the potential to contribute to beneficiaries seeing themselves in a new way, expanding on their sense of self. Furthermore, it seems to allow others to see them as more than their illness or disability too.

FINDING HOPE

Finally, a small number of beneficiaries and family members specifically described how the Muscle Dream experience has given them hope.

Thank you so much, it helped me a lot too; you have given me hope that good things do happen, your call came when I was at a low point and has restored my faith in people.

Family 31

[The Muscle Dream experience] made me feel that life is still worthwhile. Questionnaire 51

Therefore, for these few participants, the Muscle Dream experience provided them with hope.

In summary, there are some indication in the data that the experience of the Muscle Dream could have long-term affects for beneficiaries and families. These include new confidence, seeing new possibilities, and being inspired to try something new. Furthermore, there was some indication in the data of an expansion of sense of identity, both for self and others, allowing for aspects beyond the illness- or disability identity to come more to the fore. Finally, for some participants, the Muscle Dream experience contributed to hope.



5.2 Summary of findings of Thematic Analysis

In this thematic analysis four themes were described, namely *Appreciating “everything from start to finish”*, *Valuing a positive experience*, *Belonging to the Muscle Dream community* and *Lasting impact of Muscle Dream*.

In *Appreciating “everything from start to finish”* families indicated that they felt that the Muscle Dream did make their child with Muscular Dystrophy’s dream come true. However, beyond this experience all the special extras, unexpected surprises and thoughtfully chosen gifts made families feel special and cared about and greatly enhanced their experience of the Muscle Dream. There was also indication in the data that disability and the needs of young people with a Muscular Dystrophy diagnosis were understood and meaningfully responded to during the Muscle Dream experience. This was particularly meaningful and important to some families. This can be understood within the context of a society that is not always not geared up to be accessible and inclusive for people with disabilities.

In *Valuing a positive experience* parents powerfully described the joy they found in seeing their child happy, excited and having a special time. For parents who have to deal with seeing their child suffer at times and with the knowledge that many life experiences taken for granted by society might never be available to their child, this might be particularly meaningful. Furthermore, parents described the Muscle



Dream as a ‘pocket of smiles’ within what can at times be highly stressful, complex and challenging life circumstances living with Muscular Dystrophy. Families appreciated this joyful Muscle Dream experience and the often caring and nurturing treats surrounding the Dream as some precious time away from the struggles and away from hospitals. Finally, the opportunity for special memories to be made was highlighted by many. This was highlighted both for the young person, potentially in order to provide hope at difficult times in the future; and for the family, possibly in order to sustain them through the challenges, and for some to hold on to when they lose their loved one.

In *Belonging to the Muscle Dream community* it was suggested that the Muscle Dream experience starts an ongoing relationship with the Muscle Help Foundation for many. Families and

beneficiaries embraced the Muscle Warrior identity, connected with other families and also with the charity (e.g. through social media) and hoped to stay in touch with Michael McGrath, Sue McGrath and the MHF team, including wanting to give back to the charity. A specific aspect of this theme involved the inspiration many beneficiaries took from their relationship with Michael McGrath. An important part of this might be the fact that this is a person who is both living with a Muscular Dystrophy diagnosis and is also successful, active, entrepreneurial and adventurous. Regular events, the Muscle Warrior identity and salute, the charity emblem (e.g. on t-shirts), the social media presence (e.g. through the hashtags '#StrongerTogether' and '#powerof657'), etc. all enable beneficiaries and their families to feel part of the Muscle Help Foundation 'tribe'.

Finally, in *Lasting impact of Muscle Dream* some tentative consideration was given to the potentially ongoing impact of the Muscle Dream for beneficiaries. For example, some beneficiaries talked about gaining in confidence, seeing new potential and about changes they made or new activities they sought out following the Muscle Dream experience. Furthermore, there was some indication

in the data pointing towards the potential for identity expansion or enrichment of 'storylines', to include or expand on aspects beyond Muscular Dystrophy. Finally, some data indicated that the Muscle Dream experience could potentially increase or restore hope.

In summary, this thematic analysis captures some of the impact that the Muscle Dream experience has upon beneficiaries and their families. The analysis also points towards areas for further qualitative research, in particular consideration of the longer term impact of the Muscle Dream, e.g. in relation to identity development and hopefulness.



#POWER OF 657

6. DISCUSSION AND RECOMMENDATIONS

This service evaluation aimed to establish the satisfaction with and impact of the MHF Muscle Dream project for beneficiaries and their families.

The Muscle Help Foundation is already providing successful, enjoyable and meaningful Muscle Dream experiences to young people with a diagnosis of Muscular Dystrophy and their families. A number of key elements of successful Muscle Dreams were highlighted by both the quantitative and qualitative analysis. These included the personalised and tailor-made nature of the Dream experience and all the surprises and gifts that accompany the Dream; and the personal touch and involvement of Michael and Sue McGrath and the MHF team. This success could be built upon through providing further such Muscle Dream experiences and appears central to the notion of the charity's sustainability.

The focus on a single diagnosis, namely MD, has been highlighted as a strength in a number of ways. Firstly, the fact that Michael McGrath as CEO lives with a diagnosis of MD himself, was particularly inspirational for beneficiaries. Furthermore, the charity's understanding of the needs of young people with MD and effectively accommodating these during the Muscle Dream was highly valued by parents in particular. Finally, families valued meeting others who understood their circumstances where no explanations were needed. This final point is understandable, given the indication in the literature that an MD diagnosis not only affects the young person, but also those around them (Baiardini, et al., 2011; Grootenhuis, et



al., 2007; Gagliardi, 1991). It was evident that feeling a sense of belonging with a wider community was significant, both to beneficiaries and family members. As a point of sustainability, the charity could consider building on this further by providing further opportunities for families to be in contact with one another where they so desire. Research suggests that such supportive contact can provide a number of benefits, such as providing social and emotional support, as well as practical information and helpful guidance (Munn-Giddings & McVicar, 2007).

The literature highlights the fact that young people with MD often struggle with pain and lose their mobility over time (Munn et al., 2010). Furthermore, the literature points out that young people with MD often feel they do not have the same opportunities as their contemporaries (Abbott & Carpenter, 2014). Within this context, it is notable how many participants highlighted the joy they found in feeling mobile and physically active and challenged. However, a small minority did find the speed and physicality of their Dream experience a little overwhelming. It appears valuable for these elements to be central to Muscle Dreams, within a safe and supportive environment.



It was particularly meaningful to note indications in both the quantitative and qualitative analysis of more fundamental and long-term changes for both beneficiaries and their families in relation to sense of self, confidence and purposeful activity, which are all areas indicated in the literature as areas that could present those with MD with challenges (Abbott & Carpenter, 2014; Bach, et al., 1991; Buchanan, et al., 1979; Skyrme, 2015). One could therefore argue that the Muscle Dream experience provides one way to respond to these challenges faced by MHF recipients. Further research to fully understand these benefits of the Dream experience would be of interest.

While this analysis points towards these more fundamental and long-term impacts of Muscle Dreams for the majority of beneficiaries, neither the quantitative nor qualitative data fully illuminated these aspects in detail. It has also been highlighted that statements related to these more fundamental impacts in the questionnaire data received slightly more don't know responses than others. However, this analysis does not provide insight into the reasons for this. Furthermore, while both the quantitative and the qualitative data provided some evidence for the nature of such changes, due to the nature of the data (cards, letters and emails to thank MHF), this evidence was not as strongly developed in the data as other aspects.

Strengths of the study

It is a strength of this study that both quantitative and qualitative data could be included. *The charity is commended for its commitment to validate and improve what it offers - the 100% return rate powerfully highlights the unique relationship the MHF forms with its beneficiaries and families.* The feedback form does seem to capture the different elements relating to the impact of the Dream experience and the qualitative data supported the quantitative analysis.

Limitations of the study

It has to be acknowledged that the majority of qualitative data was made up of thank you cards, letters and emails received by the MHF. By definition this will be positive feedback and may exclude anyone who had a more negative experience. *However, this is incontestably counteracted by the 100% return rate of the questionnaire and the significant agreement between findings from the qualitative aspects of the questionnaire and the rest of the qualitative data.* It is important that these aspects are taken into account when drawing conclusions from the analysis.

Conclusion

In conclusion, the Muscle Help Foundation's work is commendable and has yielded positive results from both datasets. The analysis has highlighted specific strengths of the Muscle Dream experience, both for beneficiaries and families. This report provides both strong supportive evidence for the work of the charity and validation for its approach.



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APPENDICES

Appendix 1: Demographic Data

		Count	Percentage
Sex	• Male	• 193	• 92
	• Female	• 17	• 8
Age Group	• 6-10	• 27	• 13
	• 11-15	• 90	• 43
	• 16-20	• 44	• 21
	• 21-25	• 14	• 6
	• 26+	• 6	• 3
	• Unknown	• 29	• 14
Ethnicity	• Asian	• 20	• 9.5
	• Black African	• 2	• 1
	• Irish British	• 1	• 0.5
	• Italian British	• 5	• 2
	• White British	• 182	• 87

Table 2. Demographic data for beneficiaries

Appendix 2: Feedback Form

Beneficiary Name:

How did you hear about *Muscle Dreams*?

To what extent did your *Muscle Dream* meet your expectations? (tick 1 box below)

☐ Well below

☐ Below

☐ Met Expectations

☐ Above

☐ Well Above

Please give your *Muscle Dream* a mark for the following factors:

0 Don't Know	1 Poor	2 Fair	3 Average	4 Very good	5 Excellent
The pre-event information sent to you in advance					
The actual delivery on the day					
Improving your confidence					
Learning a new skill					
Making new friends					
Improving your self esteem					
In comparison to other events you've participated in separate to <i>Muscle Dreams</i>					
The family's participation and enjoyment of the experience					
The opportunity to share knowledge with other families/parents/carers					
Inspiring you to join in with others					
Inspiring you to take up a new activity/sport					
Helping you decide what goals you may want to achieve in life					
Helping improve family life					
Your overall <i>Muscle Dream</i> as an experience					

What did you most like about your ***Muscle Dream*** experience and why?

What did you least like and why?

In one sentence, tell us what you thought of your ***Muscle Dream*** experience and its impact

Would you recommend Muscle Dreams to other children and young people affected by Muscular Dystrophy and allied neuromuscular conditions? **Yes / No** – tell us below why

Thanks for completing this form – please post it back to the charity ASAP in the enclosed envelope

Appendix 3: Information Sheet to Beneficiaries and their families

MUSCLE DREAM FOUNDATION LETTERHEADED PAPER

Dear _____,

The Muscle Help Foundation has recently embarked on an exciting research collaboration with the University of Hertfordshire Clinical Psychology doctoral team. As part of this collaboration we are undertaking a robust outcome study to look at the impact of the Muscle Dream experience for beneficiaries and their families. It is hoped that this study will help us provide the best possible experience to our future beneficiaries, while also supporting us in future funding applications, which are so vital to enable us to continue our work.

The study will analyse the data collected over the years through the Muscle Dream Evaluation Feedback Form, the Beneficiary feedback form and the Muscle Dream profile form. However, we know that those forms do not always fully capture the richness of the feedback you have given us and often, following participation in Muscle Dream experiences, beneficiaries and their families have sent cards, letters and drawings to express their feelings about the experience. We feel that we will not get a full picture of the impact of the Muscle Dream experience, unless we also include these expressions of experience in the analysis.

Some information about the study:

The Research Team

The researcher in this study is Romila Ragaven, a Trainee Clinical Psychologist on the University of Hertfordshire Doctorate in Clinical Psychology training course. She will work closely with Lizette Nolte, Clinical lecturer on the course and Romila’s supervisor for this project and myself, Michael.

What will the research involve?:

Romila will carefully analyse all information that can shed light on the impact of the Muscle Dream experience, namely Muscle Dream Evaluation Feedback Forms, Beneficiary feedback forms, Muscle Dream Profile forms, letters, cards, drawings and other forms of feedback sent to the Muscle Help Foundation Team on completion of a Muscle Dream experience. She will look for themes that highlight the impact of the experience and will write this up in a report that will be used by the Muscle Help Foundation and might also be published on the Foundation website and in an academic journal.

Our guarantee to you:

All information will be handled with the utmost respect and, in addition to the Muscle Dream team, only Romila and Lizette will have access to it. All information will be fully anonymized to protect confidentiality and we will ensure that you cannot be identified in the report or any other use of the analysis. Finally, you have the right to choose for your or your family members’ data not to be included in the study.

Your right:

You have the opportunity to decline for your letter, card or drawing to be included in the analysis. Should you wish for us not to include your contribution, please contact us on <<Telephone number>> or <<email>> by << DATE>>. If we do not hear from you by then, we will assume that you are happy for us to include any information we have received from you or your family members. However, should you change your mind at a later stage, you are welcome to contact us at any time and we will remove your data from the study.

A big Muscle Warrior salute to you!

Michael McGrath

Appendix 4: Permissions to Data

MUSCLE DREAM FOUNDATION

Doctorate in Clinical Psychology Course
Department of Psychology
School of Life and Medical Sciences
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB

01/06/15

Dear Lizette,

Re: Analysis of beneficiary and family member feedback following Muscle Dream experiences

We look forward to collaborating with the University of Hertfordshire Doctorate in Clinical Psychology Course on the above research project assessing the impact of Muscle Dream experiences for beneficiaries and their family members. The study has been considered by <<Michael/the group/the Board????>> and we hereby give permission for Romila Ragaven and yourself to have access to the following information for analysis:

- MHF Evaluation Feedback Forms
- Beneficiary feedback forms
- MHF profile forms
- Letters, cards, drawings and other forms of feedback sent to the Muscle Help Foundation Team on completion of a Muscle Dream experience (excluding those from beneficiaries and their families who have opted out of the study)

We understand that all data will be anonymized to protect confidentiality. We also understand that Romila will produce a report based on her analysis that can be used by the Muscle Help Foundation to inform the provision of future Muscle Dream experiences, as well as in future fundraising applications.

<<Signed as appropriate>>

Appendix 5: Emailing confirming ethical approval not required

On 15 Jun 2016, at 10:03, hhsecda, uh <tv13xaa@herts.ac.uk> wrote:

Dear Lizette,

The Chairman of the Health and Human Sciences ECDA has considered the additional information you have provided and has confirmed that an application for UH ethics approval is not required provided permission has been granted to access the data/information and the researcher commits to using the data/information confidentially.

Kind regards,

Lesley Powell

Academic Services Officer (Ethics)
Academic Services
MacLaurin Building
de Havilland Campus
University of Hertfordshire

Appendix 6: Raw qualitative data

Statement	Rating											
	Don't Know		Poor		Fair		Average		Very Good		Excellent	
	n	%	n	%	n	%	n	%	n	%	n	%
1	1	1	1	1	1	1	1	1	18	22	60	73
2	1	1	0	0	0	0	1	1	10	12	70	85
3	10	12	0	2	2	2	13	16	22	27	35	43
4	14	17	0	2	2	2	16	20	13	16	37	45
5	1	1	1	5	4	5	11	13	28	34	3	45
6	8	10	0	1	1	1	10	12	17	21	46	56
7	8	10	0	0	0	0	0	0	19	23	55	67
8	0	0	0	1	1	1	3	4	12	15	66	80
9	2	2	0	1	1	1	9	11	20	24	50	61
10	3	4	0	2	2	2	9	11	23	28	45	55
11	16	20	1	2	2	2	9	11	23	28	31	38
12	9	11	0	1	1	1	13	16	27	33	32	40
13	9	11	1	1	1	1	7	9	24	9	40	49
14	7	9	0	0	0	0	0	0	6	7	69	84

Table 3. Frequency and Percentages of responses to Statements

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The University of Hertfordshire research team would like to thank the following individuals from The Muscle Help Foundation charity for their invaluable support in the completion of this research:

Michael McGrath

Founder & CEO

Sue McGrath

Trustee

Sonali Kumarakulasinghe

Governance & Organisational Development

Kate Barnbrook

Trust & Grants Fundraiser

Rosemary Adams

Beneficiary Evaluation, Data & Impact Analyst

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Michael McGrath's brother, for his editorial input and comment.

Martin Barrett

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The Muscle Help Foundation is a unique, multi-award winning, small charity, rooted in family values, delivering transformational experiences in the UK called 'Muscle Dreams' for children and young people (8-28yrs) with the muscle wasting disease, Muscular Dystrophy (MD) and allied neuromuscular conditions.

Since inception in 2003, the charity's vision has grown from a big idea, to a life changing reality, touching the lives of thousands of people across the UK. Today, it's impact and reach continues to grow.

With your support, the charity will surpass its target of delivering 657 'Muscle Dreams', that's one life changing experience for every muscle in the human body. To learn more about its impact, get involved and discover how your support can help change lives and give hope, contact us today – as we say, that's the #powerof657

For more information, please contact:

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