CLAPA Regional Coordinators
Project in Scotland: End of Project Report
May 2018

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Report Contents

Glossary of Terms .................................................. Page 3
Lay Summary .......................................................... Page 6
Introduction ............................................................ Page 8
Outcome 1: People affected by cleft are better able to cope with their condition Page 11
Outcome 2: People affected by cleft have increased confidence Page 12
Outcome 3: People affected by cleft feel less isolated Page 13
Outcome 4: Parents are better able to support their children with cleft-related challenges Page 14
Online Survey for Project Beneficiaries Page 15
Additional Supporting Evidence Page 22
Summary of Key Achievements Page 27
Potential Areas for Development Page 28
Project Summary Page 29
Appendices Page 32
Glossary of Terms

**Cleft lip and/or palate (CL/P)** – ‘cleft’ means ‘split’ or ‘separation’. During early pregnancy separate areas of the face develop individually, and then join together. If some parts do not join properly this may result in a cleft, the type and severity of which can vary (see diagram below).

The Cleft Lip and Palate Association (CLAPA) - the only national charity in the UK dedicated to supporting all those affected by cleft lip and/or palate.

The Centre for Appearance Research – a centre of excellence for psychological and interdisciplinary research in appearance, disfigurement, body image and related studies.

Vocational Training Charitable Trust Foundation (VTCTF) – VTCTF is a charitable organisation and awarding body. VTCT also supports the health and beauty sector and under its charitable remit aims, which includes research and support for those affected by physical disfigurement.

Regional Coordinator (RC) – a member of CLAPA staff who is based in a particular region and is responsible for increasing the diversity and frequency of local activity within that region.

Healthcare Professionals (HPs) – general and specialist medical practitioners, nurses, dentists, allied health professionals and any other skilled workers providing a form of healthcare service.
CLAPA Branch — CLAPA has branches across the UK, primarily run by volunteers, offering local support to parents, patients and HPs. In April 2018 these changed to Events Groups and Fundraising Groups.

CLAPA Parent Supporters — trained volunteers who can offer personal knowledge of the difficulties that can be faced by new parents of babies born with CL/P. Individuals who are interested in speaking to a Parent Supporter contact CLAPA who match them with an appropriate volunteer.

CLAPA Peer Supporters — Peer Supporters are trained volunteers who were born with a cleft themselves. Individuals who are interested in speaking to a Peer Supporter contact CLAPA who match them with an appropriate volunteer.

CLAPA Happy Faces groups — based around the region, these informal groups are run by trained Parent Contacts. Members meet on a regular basis for the opportunity to gain “a sense of community, understanding, talk about problems, and help each other.”

CLAPA Family Days — events held throughout the region for parents, children, young people, and wider family members. The events include activities and aim to give families the chance to meet others affected by CL/P.

Scotland Children and Young People’s Council — The Council in Scotland meets 4 times a year and is made up of a group of 9-17 year olds who were born with CL/P. The members act as Scotland representatives for children and young people affected by CL/P and help to improve CLAPA’s services, raise money for CLAPA, and raise awareness of CL/P.

Adult Services Coordinator (ASC) — A full-time post to support CLAPA and increase adult participation.

Bumps and Babies groups — these groups are an initiative of the NHS Scotland cleft teams, aimed at both new and expecting parents of babies with cleft to get together and share stories, experiences and concerns.

Public Involvement (PI) - research and/or service provision that is carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (see www.invo.org.uk). Patient representatives play an active role in shaping the services and research which they benefit from.
**CLAPA Awareness raising** – sessions/presentations to Health Professionals and school children, which are usually carried out by volunteers and are aimed at increasing awareness of CL/P and CLAPA.

**Cleft Awareness Week** – held annually across the UK, Awareness Week involves a host of awareness raising and fundraising activities, aimed at raising awareness of CL/P and promoting the services which CLAPA offers.

**Cleft Surgical Review in Scotland** – separate to CLAPA, this review is being carried out by the National Services Division (NSD), which is part of the NHS in Scotland, to determine the effectiveness of the current service delivery.
Lay summary

What is cleft lip and palate?

- Cleft lip and/or palate (CL/P) is the most common congenital craniofacial condition, affecting approximately 1 in 700 live births per year in the UK.

- The cleft and its treatment pose a number of challenges for those affected and their families throughout life, and having access to appropriate support when it is needed is a vital factor in facilitating psychosocial adjustment.

- The implementation of localised support is a frequently requested and highly valued service, with proven potential to have a positive impact.

The Scotland Regional Coordinators Project

- The Regional Coordinators (RC) Project was set up to provide local support to children, young people, parents, and adults affected by cleft.

- The Regional Coordinator (RC) is responsible for organising events for people affected by cleft, as well as training CLAPA volunteers, liaising with health professionals, and raising awareness of CL/P.

- Following the success of the RC Project in England, the Cleft Lip and Palate Association (CLAPA) obtained funding from a number of charitable organisations (the Big Lottery Fund, The Robertson Trust, Edinburgh Children’s Hospital Charity, Glasgow Children’s Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust, Rathbones Trust) to run a similar project for three years in Scotland.

- This funding enabled CLAPA to employ one Senior Scotland Regional Coordinator (SRC) and one Scotland Support Officer, with the aim of improving local service provision for children, young people, and adults affected by CL/P and their families over three years (June 2015 – May 2018).

- The Centre for Appearance Research (CAR), based at the University of the West of England (UWE) in Bristol, was commissioned to conduct an independent evaluation of the project, in relation to four key outcomes. The aim of this final report is to evaluate the overall success of the SRC Project to date, in order to
supply evidence to support the continuation of existing services and the development of new services and activities in Scotland.

The project has four main outcomes:

**Project Outcomes**

**Outcome 1**
People affected by cleft are better able to cope with their condition

**Outcome 2**
People affected by cleft have increased confidence

**Outcome 3**
People affected by cleft feel less isolated

**Outcome 4**
Parents of children with a cleft are better able to support their children with cleft-related challenges

During the project, a large number and variety of events have been run for children, young people, and parents. In addition, the SRC has taken important steps to increase adult engagement in Scotland. The findings from the three years provide promising results, and evidence shows that the events are beneficial and provide important support for individuals and families affected by CL/P. In addition, a number of volunteers have been trained over the course of the project and awareness raising sessions have been carried out with schools, community groups and health professionals. In future, it may be beneficial to consider how to engage more adults with CL/P, and to incorporate activities specifically aimed at increasing problem solving and coping skills into new or existing events.

**A huge thank you to everyone who contributed to the evaluation reports.**

For more information about the Regional Coordinators Project, or to make a suggestion about how you would like to see cleft services in Scotland improve, please contact Claire.Cunniffe@clapa.com.
Introduction

Background and project rationale

Cleft lip and/or palate (CL/P) is one of the most common congenital conditions in the world, affecting approximately one in every 600-700 live births every year in the UK. For most parents, the ‘diagnostic event’ is an emotionally demanding experience, and families often express a number of concerns for their child’s future. Complex multidisciplinary care continues throughout childhood, forming an underlying and unremitting stressor in the family’s lives. The cleft and its treatment can also pose challenges for the affected individual in many domains of life, including several areas of psychological and social wellbeing. Although most individuals cease to require treatment when they reach the age of eighteen years, CL/P is often considered to be a lifelong condition. Some individuals may continue to experience difficulties into adulthood, and different life stages are likely to bring about new challenges. Unfortunately, little is known about what happens to adults once they leave the service. Access to appropriate support is vital to encourage psychosocial adjustment and ultimately improve outcomes in all areas of life for parents, children, young people and adults with CL/P.

The Cleft Lip and Palate Association (CLAPA) is the only national charity dedicated to supporting all people with and affected by CL/P in the UK. They represent the voice of patients, parents and a multitude of Health Professionals (HPs) working in the field of cleft. CLAPA’s overall aim is to further improve the quality of life of all those affected by CL/P by providing effective services in all sectors of the community.

CLAPA is already well-established throughout the UK, providing a number of highly-valued National services. As part of their strategic review, CLAPA conducted a National survey open to anyone with an interest in CL/P ('CLAPA 2010 Survey'). A key finding of this survey was the clear need for more support at a local level. Although local support was already provided by CLAPA’s network of local branches, significant gaps and limitations in this service had been observed. In addition, the number of branches across the UK was decreasing, due to insufficient numbers of volunteers. As a result, some regions only had one branch, and other regions were no longer provided for.

In 2010, CLAPA obtained funding from the Vocational Training Charitable Trust Foundation (VTCTF) to pilot a full-time RC in the East of England for one year. This project was piloted in 2011-2012 and was independently evaluated by the Centre for Appearance Research (CAR), based at the University of the West of England (UWE). With the support of this evaluation report, and the progress made over the last three years of the project in England, CLAPA was able to gain further funding from the Big Lottery Fund, The Robertson Trust, Edinburgh Children’s Hospital Charity, Glasgow Children’s Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust, Rathbones Trust, to employ one Senior SRC and one Scotland Support Officer. In Year Three, the project had sufficient funds to employ a second Scotland Support Officer. Year One of the project evaluation
ran from June 2015 to May 2016, Year Two from June 2016 to May 2017, and Year Three from June 2017 to May 2018.

**Project outcomes**

The CLAPA RC Project in Scotland has four key outcomes, which CAR is independently evaluating. These outcomes relate to children, young people, parents, and adults affected by CL/P; collectively known as ‘people’.

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**Project Outcomes**

<table>
<thead>
<tr>
<th>Outcome 1</th>
<th>Outcome 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>People¹ affected by cleft are better able to cope with their condition</td>
<td>People affected by cleft have increased confidence</td>
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<table>
<thead>
<tr>
<th>Outcome 3</th>
<th>Outcome 4</th>
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<tbody>
<tr>
<td>People affected by cleft feel less isolated</td>
<td>Parents of children with a cleft are better able to support their children with cleft-related challenges</td>
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</tbody>
</table>

¹People includes children, young people and adults affected by CL/P

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**This report**

This report aims to evaluate the overall success of the CLAPA SRC Project in relation to the four key project outcomes. The report reviews evidence collected over the duration of the three-year project evaluation, which ran from June 2015 to May 2018. The report contains findings gathered from previous evaluation reports (further information is listed in Appendix 5), as well as qualitative data collected from an online survey, data collected from the Children and Young People’s Council, a reflection from the Regional Coordinator, and evidence of support for the project collected from clinical specialists working in NHS cleft services. Supplementary information, including case studies from parents and young people who have accessed CLAPA’s services are also included in the appendices.
Review of cleft surgical services in Scotland

It is important to note that during the course of the project’s first year, there was an official review of cleft surgical services in Scotland by the National Services Division (NSD). As a result of this review, surgical activity has been reduced from two sites (Glasgow and Edinburgh) to one site (Glasgow). This review is part of the NHS in Scotland, and is separate to CLAPA. Nonetheless, the SRC has been actively involved in this review since her appointment, ensuring the views of affected families and individuals are communicated to the NSD. Although the SRC’s involvement in this review process has been crucial, at times the review has impacted upon CLAPA’s ability to deliver other services within the Scotland region during all three years of the project.

The SRC Project aims to cover the whole of Scotland. Gillian McCarthy has been in post as the Senior SRC since 1st September 2015 and is supported part-time by Support Officers Melanie Skinner and Rebecca McDonald.

Evaluation of evidence collected throughout the project

All event outcome data collected during the three years, and reported in the corresponding ‘End of Year’ reports, has been combined and presented in relation to the project outcomes in this section of the report. Additionally, a number of events took place following the publication of each ‘End of Year’ report. Data was collected at these events, but not presented in the End of Year reports. Where possible, this additional data has been included in the calculations in this report to give a more comprehensive representation of data collected during the project.

Project Outcomes

<table>
<thead>
<tr>
<th>Outcome 1</th>
<th>Outcome 2</th>
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<tbody>
<tr>
<td>People(^1) affected by cleft are better able to cope with their condition</td>
<td>People affected by cleft have increased confidence</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outcome 3</th>
<th>Outcome 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>People affected by cleft feel less isolated</td>
<td>Parents of children with a cleft are better able to support their children with cleft-related challenges</td>
</tr>
</tbody>
</table>

\(^1\)People includes children, young people and adults affected by CL/P


Outcome 1: People affected by cleft are better able to cope with their condition

During the project, over 150 feedback forms were collected from children and young people, and two from adults with CL/P in relation to Outcome 1. Evaluation figures for the number of people who reported having achieved the indicators for Outcome 1 are presented in the tables below.

Children and Young People

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children/young people have learned new ways of coping with cleft-related issues in a positive way</td>
<td>102/153</td>
</tr>
<tr>
<td>Children/young people can offer help to other children and young people with a cleft</td>
<td>117/153</td>
</tr>
</tbody>
</table>

Overall, the evidence shows that many children and young people feel better able to cope with their condition as a result of the project. Indeed, 67% reported that they have learned new ways to cope with CL/P-related issues in a positive way as a result of the events, and 76.5% feel able to offer help to other children and young people. These findings show that the events have gone some way in achieving this project outcome. In future, it may be beneficial to consider how activities which specifically target the promotion of coping skills may be incorporated into some events for children and young people.

Adults

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way</td>
<td>1/2</td>
</tr>
</tbody>
</table>
The evidence from adults is limited in relation to Outcome 1. This is due to only a small number of adults engaging during the course of the project. Although one adult did report that the events helped them to gather information which could help them deal with CL/P-related issues, consideration needs to be given in relation to methods of increasing adult attendance, and the format(s) of events in which adults are most likely to engage with and gain information and new skills from.

**Outcome 2: People affected by cleft have increased confidence**

Over the course of the project, feedback was gathered from over 150 children and young people, and one adult, regarding Outcome 2. Evaluation figures for the number of people who reported having achieved the indicators for Outcome 2 are presented in the tables below.

### Children and Young People

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children/ young people have increased confidence</td>
<td>134/156</td>
</tr>
</tbody>
</table>

As can be seen from the table, the vast majority of children and young people (86%) felt that they had gained confidence as a result of attending events. This finding suggests that excellent steps have been made towards Outcome 2, and that most children feel more confident as a result of the project. Going forward, consideration should be given regarding how increase the confidence of all children attending events.

### Adults

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults feel more confident in connecting with other people for support with cleft-related challenges</td>
<td>1/1</td>
</tr>
</tbody>
</table>

Data regarding Outcome 2 was only collected from one adult during the project. While this adult did report increased confidence in connecting with others for CL/P-related
support, there is not enough data to draw conclusions. Going forward, and as stated above, methods of engaging adults affected by CL/P need to be more thoroughly considered and trialled.

**Outcome 3: People affected by cleft feel less isolated**

During the project, over 150 feedback forms were collected from children and young people, and from two adults in relation to Outcome 3. Evaluation figures for the number of people who reported having achieved the indicators for Outcome 3 are presented in the tables below.

**Children and Young People**

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Children/ young people have made friends who they can talk to about having a cleft</td>
<td>124/156</td>
</tr>
</tbody>
</table>

Almost 80% (79.4%) of children and young people reported that they had gained new friends who they could talk to about having CL/P as a result of their engagement with the project. This strongly suggests that most children and young people are feeling less isolated as a consequence, and that the events are largely fulfilling Outcome 3. Additionally, qualitative data collected throughout the project also finds that many children and young people are reporting that the events have allowed them to make new friends who they are able to gain support from and feel that they can relate to.

In future, consideration could be given to helping the small number who are not currently reporting this increase in social support. However, it is important to appreciate that children may not make friends that they feel able to open up to about CL/P-related challenges after attending just one or two events. This outcome may be best achieved through continued attendance at events, since the development of trusting friendships is more likely to happen as children and young people advance further through their CL/P journey.
Adults

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adults feel they are part of a community of people affected by cleft</td>
<td>1/2</td>
</tr>
<tr>
<td>Adults have access to a local support network</td>
<td>1/2</td>
</tr>
<tr>
<td>Adults know more people who have been affected by cleft</td>
<td>1/1</td>
</tr>
</tbody>
</table>

Again, data regarding Outcome 3 in relation to adults with CL/P is sparse, with one adult reported feeling less isolated as a result of the project. In future, organising more events for adults may help to reduce isolation, and to form a community through which adults affected by CL/P can engage in peer support.

**Outcome 4: Parents of children with a cleft are better able to support their children with cleft-related challenges**

More than 300 feedback forms were collected from parents during the project. Evaluation figures for the number of parents who reported having achieved the indicators for Outcome 4 are presented in the table below.

<table>
<thead>
<tr>
<th>Indicators</th>
<th>Project Evaluation Figures</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents/carers have increased confidence in supporting their child who was born with a cleft</td>
<td>265/345</td>
</tr>
<tr>
<td>Parents/carers have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way</td>
<td>243/367</td>
</tr>
<tr>
<td>Parents/carers feel more confident in connecting with other people for support with cleft-related challenges</td>
<td>297/348</td>
</tr>
<tr>
<td>Parents/carers have access to a local support network</td>
<td>331/375</td>
</tr>
</tbody>
</table>
Parents/carers know more people who have been affected by cleft & Parents/carers feel they are part of a community of people affected by cleft

<table>
<thead>
<tr>
<th>Description</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents/carers know more people who have been affected by cleft</td>
<td>316/346</td>
</tr>
<tr>
<td>Parents/carers feel they are part of a community of people affected by cleft</td>
<td>317/341</td>
</tr>
</tbody>
</table>

Evidence collected from parents of children with CL/P over the course of the project is promising, and suggests that the events have helped parents to better support their children with CL/P-related challenges. As a result of the events held, 77% of parents felt more confident in supporting their child, 66% had gathered knowledge and information to help them support their child in a positive way, and 85% reported feeling more confident in connecting with others for support. Furthermore, 93% of parents reported that the events made them feel part of a community. In conjunction with this, qualitative data collected during the project reflects these findings, with parents commonly reporting that events have helped them to meet other families affected by CL/P who they feel able to talk to and seek support from. These findings are very promising with regard to Outcome 3. In future, it may be beneficial to consider how to further incorporate CL/P-related information and the specific development of coping skills for parents into events, in order to increase these figures further.

**Online Survey for Project Beneficiaries**

In addition to collecting event feedback, an online survey was launched to explore the longer-term experiences of individuals who have accessed CLAPA’s services in Scotland during the duration of the Project. Data was collected between 03/08/2017 and 23/03/2018, and the survey was completed by 54 individuals who had engaged with the SRC Project. The respondents’ ages ranged from 26-69, with a mean age of 40. Of these respondents, 29 were female and 3 were male (22 did not disclose gender). The sample consisted of 1 grandparent, 1 adult with cleft (who was also a volunteer), 1 health professional, 26 parent/carers, and 3 parent/carers who were also volunteers (22 did not disclose role). The vast majority of individuals reported that they had become involved with CLAPA because a close family member (often their own child) had been diagnosed with CL/P. Additionally, 37% (20/54) of those surveyed had not been involved with CLAPA before coming into contact with the SRC.

Most individuals stated that they had become involved with the project in order to meet and gain support from other families who were also affected by CL/P. Other reasons included being able to offer support to others in a similar situation, wanting to give something back to the cleft community, and for their child to be able to make new friends.

"My son was born with a cleft palate and I wanted him to meet other children born with cleft lip and/or palate. It also helped me find support and make friends“
"I wanted to help raise awareness about cleft"

Most of the sample felt that their involvement with CLAPA had changed for the better since the SRC came into post. Moreover, they cited a number of positive changes which had occurred as a result of the SRC position:

"The Regional Coordinator is great at keeping you up-to-date with events which are taking place, and opportunities to support CLAPA locally"

"I have been more involved with CLAPA since the Regional Coordinator Project began. I have attended more events, my child has joined the Scotland Children and Young People’s Council, we have been kept better informed about CLAPA and its events etc. and it has been a lot more organised.”

"The Regional Coordinator has helped to get CLAPA in the public eye and also helped me find the confidence become more involved - initially by attending events and I now help with fundraising activities too”

"[The Regional Coordinator] keeps everyone in the know of what is going on with cleft health services in Scotland”

Further to this, some participants voiced that having a SRC has helped to develop a community of people affected by CL/P and has, in turn, contributed to confidence-building among its members:

"When my daughter was first diagnosed I thought that CLAPA was just a website with information. Now I feel more like it’s a family there to support one another and help our children lead happy, confident lives. The Regional Coordinator has done a wonderful job of making the service accessible to all children and families affected by cleft lip and/or palate”.

"We have taken part in different activities that have taken us out our comfort zone and made us grow as individuals”

On the other hand, a very small number of respondents felt that some aspects of their engagement with CLAPA had been less positive since the project commenced:

"Our relationship with CLAPA changed as many policies, protocols and procedures were introduced”
Nonetheless, those who completed the survey mentioned a number of benefits of having an RC based in Scotland. These related to having a representative who understands the needs of families, and having someone to organise and manage events, who families also trust and can seek advice from.

"A better understanding of the issues that arise locally"

"The Regional Coordinator knows what patients and families need at a regional level and is able to represent their views"

"[The Regional Coordinator is] always aware of what is happening. Events are in good locations which allows more families to attend without having to travel too far"

"Children and families have built up a good rapport with the Coordinator, and they know who to approach for information and advice..."

Furthermore, it was noted that many more events had been implemented since the SRC came into post.

"There have been lots more activities and events available since the Regional Coordinator started compared to what there ever was before, therefore giving the children the chance to participate in events like kayaking, rock climbing, skiing, sky park, laser tag, zoo & safari trips"

Interestingly, a considerable number of respondents were unable to comment on how services had changed with the introduction of the SRC Project because they had not been involved with CLAPA before the SRC came into post. This illustrates that the SRC Project has been pivotal in encouraging new individuals and families to become involved with CLAPA.

Among survey respondents, there was overwhelming support for the continuation of the RC post in Scotland. Furthermore, many had concerns regarding support in Scotland if the funding for the post did not continue. This included less opportunities and support for individuals and families and poorer organisation of events.

"The Regional Coordinator inspires not just the children but also the family with her friendly helpful approach. It’s important to really
know the person who is working with your children and don’t feel the group would be so successful without a regional presence”

"I believe the Regional Coordinator plays a key part within CLAPA in Scotland. Without this post in Scotland I feel the children would lose out on their activities that they gain so much from in their journey”

"[Without the post] there would be a lack of coordination and events may not be initiated at all or not run to their best advantage”

"Volunteers would need to be managed by the London office. More volunteers would need to be recruited to replace the post. Existing events and activities may not exist. No local support. No visible presence in the Scotland”

"[Without the SRC] few families would have these opportunities that arise from the organised activities and could feel quite isolated”

Positively, the vast majority of respondents felt that their expectations of the SRC’s role had been met.

"[The SRC] gives a great presence in Scotland and always keeps CLAPA at the forefront when it comes to charities”

"I feel [my expectations] have been met and also exceeded. Everything has been much better organised and arranged since the coordinator started and more events have taken place”

However, a small number voiced that their expectations had not been met because smaller, local community branches have declined during the past few years:

"Everything from services and CLAPA has been heavily weighted to the west. Families in the East have gone from having a branch and a cleft team to nothing”

"There isn't really anything at the moment in the East for older children”

Interestingly, the same number of activities are offered by the SRC to both the East and West regions. However, these findings suggest that some members from the East of Scotland feel that there is less support available to them. This may be associated
with the outcome of the review of cleft surgical services in Scotland, where surgical activity in Scotland was reduced from two sites (Glasgow and Edinburgh) to one (Glasgow). Going forward, the SRC should consider how to re-develop relationships and support smaller branches, particularly in the context of the Scotland Surgical Review and the recent reduction in healthcare services delivered in Edinburgh.

Many individuals felt that the project had benefitted them and the rest of their family in positive ways. Encouragingly, these comments were in line with the project outcomes;

Increasing confidence:

"[I am] more confident to talk about my daughter’s cleft and look forward to meeting more new families at every event”

"I can see a difference in my daughter since she started going, she has grown so much more confident”

Being part of a community of people affected by CL/P:

"I have been able to access a community which will hopefully remain for my family. It will be a source of support for all of us”

"My son will have access to a community of other young people born with cleft allowing him to share experiences. It will be invaluable”

Helping them to cope with CL/P-related challenges:

"It has helped my child develop and helped me as a parent to cope better”

While the project is clearly benefitting many families, it is nonetheless important to consider areas of Scotland which are currently lacking in some services, and how to ensure the needs of those who are interested in volunteering are better met. This is particularly important for those living in remote areas of Scotland.
Respondents also mentioned that the project benefits various other beneficiaries, such as wider family members, schools, and health professionals:

"Local schools. Cleft Team at hospital"

"Wider family...grandparents meeting other grandparents and sharing their stories"

"Wider family members can benefit from being involved in things like Christmas parties"

Although most respondents did not feel that there were any particular barriers to accessing support in their area, some individuals mentioned things that might make it difficult for some people to access CLAPA’s services:

"[Advertisements are] mainly done via social media, so you would be at a disadvantage if you could not access this"

"The area I live in is big and I don't drive so getting to activities is very difficult"

In conjunction with this, some respondents provided suggestions as to how existing services could be improved:

"More help for adults"

"Communication program for all cleft affected families that don't have or regularly check Facebook or email"

"Give local branches ridged, structured and helpful support"

"Longer notice [for events] would be great as I need to book time off work"

Additionally, whilst most were happy with CLAPA’s current services, there were some suggestions of how they might be expanded in future:

"Awareness sessions for new parents and parents-to-be"

"More awareness in schools"
"Local networks throughout the country"

"More opportunities for young people to meet regularly"

"Adults may find comfort in speaking to others who are affected by a cleft"

"CLAPA needs to be a voice for everyone in Scotland. Families in the East are not being communicated with over current services. CLAPA should be central to this"

Finally, it was felt that CLAPA is able to provide individuals born with cleft and their families with support, information, and skills which are not provided anywhere else. For example:

"It's a place to trade advice and support one another. It's so much more than just a website or leaflets that explain what has caused your child to have a cleft or what to expect in the next few years. It's much more practical one to one advice from one parent to another. I know as a parent I can take advice better from someone who has lived my situation rather than a doctor or nurse who I don't have that emotional connection with"

"Support network for people who have already, or are about to, have similar experiences/operations. The cleft nurses are fantastic but it's really important to be able to relate to families who are going through the same as you"

"Understanding of the condition and raising awareness of the challenges that people can face"

Overall, these findings strongly indicate the positive impact that the SRC Project has had on individuals and families affected by CL/P in Scotland. The role and support provided from the SRC is clearly valued and makes a real difference to the lives of individuals and families affected by CL/P. Additionally, the services are considered to offer support for individuals and families affected by CL/P that is complimentary to the support already provided by the NHS cleft teams. Further to this, survey respondents provided a number of useful suggestions of how CLAPA could expand their regional services to benefit even more people as the project continues to develop over the coming years.
Additional supporting evidence

Regional Coordinators Project Advisory Group (RCPAG)
The Regional Coordinators Project Advisory Group (RCPAG) is made up of members of CLAPA, members of the Centre for Appearance Research (CAR), patient and parent representatives, and representatives from other charitable organisations. The group meets twice a year and provides crucial feedback and guidance to the project as a whole. Meeting documents from the duration of the SRC Project are available from CLAPA upon request.

Support from NHS Cleft Teams
Feedback about the project was collected from three Health Professionals (HPs) who work within NHS cleft services in Scotland. Two of the HPs felt that they knew a great deal about the SRC Project and the services which CLAPA offers in their area, while one reported knowing about this only to some extent. Nonetheless, all three of the HPs reported having referred their patients to CLAPA’s services in Scotland.

The HPs also commented on the difference that the SRC has made to services for people with CL/P in their areas:

"The Scotland Coordinator has engaged with families across Scotland, and family activities and Christmas Parties are happening in areas where families don’t have too far to travel. There is also better joint working with cleft teams for events and teaching”

"[There is a] more coordinated service, improved links with CLAPA, and between all health professionals working within cleft services. Day events [have been organised] for children and families with increased support for all involved”

Further to this, letters of support for the SRC Project were provided by the NHS cleft team based in Glasgow, and by colleagues in Ayrshire and Arran. These can be found in Appendix 1.

Scotland Regional Coordinator’s Personal Reflection
The SRC was asked to provide a personal reflection on her thoughts on the project to date, and why she believes that the SRC role is an important aspect of CLAPA’s services. This personal reflection can be found in Appendix 2.
Parent and Peer Supporters
Parent and Peer Supporters are trained volunteers who can offer personal experience of the difficulties that can be faced by those affected by CL/P. Parents, adults with CL/P, and other beneficiaries can access this service by contacting CLAPA, who then match them to an appropriate volunteer.

In order to improve access and peer matching, this service was reviewed and re-launched in November 2016. There are currently 33 volunteer Parent and Peer Supporters. During this time, 37 adults and 92 parents have accessed this service across the UK. A broad range of enquiries have been made, including information about treatment, emotional support, becoming a new parent, bullying, appearance concerns, and general information and support enquiries. As well as demonstrating that this service is regularly accessed and highly valued, these data give an indication of the areas of information and support which are most frequently requested.

Awareness-Raising via Local Media
Over the course of the three year project, 21 articles documenting the work of CLAPA have been published in Scottish Newspapers. A list of these articles can be found in Appendix 3.

Scotland Facebook groups
The SRC Project has a Scotland-specific Facebook page where members can connect with each other, share stories and photographs from events, and learn about local events. The Facebook page has continued to grow over the course of the project, and has 915 followers and 927 likes at the time of writing. Additionally there are local CLAPA Facebook groups for different regions in Scotland (e.g. Glasgow, Edinburgh, Fife, Aberdeen & North East etc.).

A recent study carried out by CAR and CLAPA has examined survey data and real-time posts collected from two existing Facebook groups hosted by CLAPA. The study identified common topics of concern among adults born with CL/P and parents of children born with CL/P, as well as benefits and disadvantages of group participation. The findings suggest that social networking sites can be a helpful source of health-related information and peer support when appropriately managed. More detailed information can be found in the academic paper: Stock NM, Martindale A, Cunniffe C, and the VTCT Foundation Research Team at the Centre for Appearance Research (e-pub prior to print, 2018). #CleftProud: A content analysis and online survey of two cleft lip and palate Facebook groups. The Cleft Palate-Craniofacial Journal, https://doi.org/10.1177/1055665618764737.
Case studies
Detailed case studies were collected from two parents and one young person who had engaged with the SRC Project, which document their involvement with the project and how it has benefitted them over the course of the three years. These case studies can be found in Appendix 4. In future, the collection of additional case studies are recommended, in order to better document the journey of beneficiaries over a longer period of time.

Feedback from the Scotland Children and Young People’s Council
A Scotland Children and Young People’s Council (SCYPC) was formed as part of the SRC project. The SCYPC now meets 4 times a year and is made up of a group of 9-17 year olds who were born with CL/P. The members act as Scotland representatives for children and young people affected by CL/P and help to improve CLAPA’s services, raise money for CLAPA, and raise awareness of CL/P. Feedback about the project was collected from 6 members of the SCYPC (3 aged 9-11, 3 aged 12-17) toward the end of the project.

When asked why they joined the SCYPC, members answered that they wanted to meet others with CL/P and to find out more about the support CLAPA provides:

"I wanted to meet friends that had a cleft"

"To find out what support CLAPA could give me"

"To join into CLAPA more"

There were a number of very positive reasons that the children and young people enjoyed being a part of the council:

"I like getting involved and letting my voice be heard"

"Meeting others with clefts"

"I have a voice"

"[I] learn about how to support CLAPA"
In addition to this, a number of the children and young people reported that joining the council had helped them to become more confident and to feel part of a CL/P community:

"[It has] helped me really to be myself, and I'm not alone"

"[I am] more confident talking about my cleft"

**Awareness-Raising Sessions**

During all three years of the project, the SRC has organised awareness-raising sessions/presentations. While not directly related to the project outcomes, these sessions are designed to increase knowledge of CL/P and related issues among the general public. The indirect aims of these sessions are to improve families’ experiences, increase their support network, and enhance their ability to cope with CL/P-related challenges.

Awareness-raising sessions first began during Year One, and specific Awareness Raising Event Feedback forms have since been developed by CAR and trialled during Years Two and Three; a recommendation stated in the ‘End of Year One’ report. These forms have been designed to capture the views of school pupils, teachers, health professionals, and other members of the community in order to better evaluate the broader impact of these awareness-raising activities.

Over Years Two and Year Three of the project, awareness-raising sessions were carried out with 390 pupils (358 aged 8-11, 10 aged 12-17) from six schools in Scotland. Feedback forms were collected from 225 of these pupils. Feedback from the events was encouraging: 91% \((n=203/224)\) reported having an increased knowledge of CL/P as a result of the sessions, and 88% \((n=196/223)\) felt that they had a better understanding of what it is like to have CL/P. Pupils also commented that they enjoyed the interactive nature of the sessions, which included watching videos and doing an experiment with a straw to show how it feels to drink water when you have CL/P.

In addition to this, sessions were carried out with 13 health professionals, specifically community dentists. Positively, 92% \((n=12/13)\) reported increased knowledge of CL/P as a result of the sessions, as well as a better awareness of the challenges individuals and families affected by CL/P may experience. Furthermore, 85% \((n=11/13)\) felt more confident offering support to individuals and families affected by CL/P as a result of the session, and 92% \((n=12/13)\) felt that they would know where to get further CL/P-related information should they need it. Health professionals also commented that the session had given them more of an awareness of CL/P-related issues within their role:
"I am much more aware of the impact of CL/P and how my role can help with diagnosis, and the importance of support, etc."

"I feel more confident in providing information and support to patients/families affected by CL/P"

Finally, sessions were run with 46 individuals from three local community groups, including Parish Church Guilds. Feedback, which was collected from 38 individuals, revealed that 90% (n=34/38) of attendees felt that they had increased knowledge of CL/P and 95% (n=35/37) had gained a better awareness of the challenges individuals and families affected by CL/P experience.

Attendees commented that the session had increased their understanding of CL/P and that they enjoyed the content and format of the sessions:

"The talk was very interesting and informative"

"Information given in an easy to understand way"

"[I am] better informed of how cleft affects children and parents"

Volunteer Training Sessions
Over the course of the project, the SRC and other RCs have worked to update training materials/sessions for volunteers and to improve the recruitment and induction processes involved. This has enabled a core group of volunteers to be recruited and trained using a standardised process, and has helped to ensure that they feel confident in supporting families within their role. Additionally, the new model has also changed the volunteering structure from a ‘branch’ to a ‘group’ basis. This has allowed the RCs to identify specific areas/events which volunteers are interested in helping out with, thereby streamlining the process of event organisation.

Over the course of the project, the SRC has trained more than 20 new and existing CLAPA volunteers. As a result of this training, and according to the feedback received, all of the volunteers reported feeling more confident in their role. Additionally, most felt better able to support families and individuals affected by CL/P, and reported that they had gained useful and transferable skills as a result of the training.
Grandparents Report

Focus groups carried out by CAR in 2015 as part of the SRC project (see Appendix 1) identified that the majority of CL/P services are currently designed to address the support needs of parents and carers of children born with CL/P. However, a number of other family members, particularly grandparents, reported that they would also like to engage in support services.

In order to address this, CAR carried out semi-structured telephone interviews with 12 grandparents (1 male, 11 female) of children born with CL/P in Scotland. Thematic analysis was used to look for common themes within the data. The findings gave insight into the experiences and support needs of grandparents, and were used to make recommendations to CLAPA as follows. First, to increase access to information about CL/P and its treatment (using both online and paper formats). Second, to provide access to practical and emotional support. This included providing practical guidance (e.g. how to feed a baby with CL/P using specialist bottles), advertising existing peer support networks to grandparents, giving grandparents opportunities to fundraise and share their personal experiences for the benefit of others, and considering how grandparents who live in remote areas of Scotland might better access support. A copy of the full report is available via the CLAPA website and upon request (Nicola2.Stock@uwe.ac.uk). The study is also being written up for publication in an academic journal.

Summary of Key Achievements

Children and Young People:
- An increase in the number and variety of events for children and young people
- Development of a Children and Young People’s Council (SCYPC) in Scotland
- A notable increase in children and young people’s confidence
- The introduction of Residential Weekends in Scotland
- A large number of children and young people continuing to attend events throughout the duration of project

Adults:
- Adult Meet-Ups successfully trialled in some areas of Scotland
- Collaboration with the Adult Services Coordinator (ASC) during Year Three to plan new ways of engaging with and supporting adults in Scotland
Parents:
- Feedback collected from over 300 parents
- A large number and variety of events held for parents and families in Scotland
- A significant proportion of parents reporting that they feel less isolated and part of a broader CL/P community
- A large number of newly recruited parents, as well as existing parents who continued to engage and attend events throughout the duration of the project

Additional Achievements:
- Awareness raising sessions delivered to several community groups, schools, and health professionals
- Attendance of wider family members (such as grandparents and siblings) at family events
- Service recommendations collected from a study of the experiences and support needs of grandparents affected by CL/P
- Over 20 volunteers have been trained

Potential Areas for Development

Children, Young People and Adults:
- Consider how to specifically target coping and problem solving skills in order to better meet this project outcome. This could involve collaboration with cleft-specialist clinical psychologists and other members of NHS cleft teams.
- Organise activities which give children and young people the chance to meet up more regularly.
- Consider how to engage with children, young people and adults who are not currently accessing services; especially those living in more remote parts of Scotland.
- Work with volunteers to increase number of adult meet-ups arranged across Scotland.
- Work with the Adult Services Coordinator in order to increase adult engagement and ensure that type, format and timing of events are suitable for adults with CL/P.
Parents:
- Consider how to tailor events so that they enable parents to gain more information which will help them support their child with CL/P-related challenges in a positive way.
- Look to secure further funding to run events for parents living in more remote areas of Scotland, and for those who rely on public transport.

Additional Areas for Development:
- Consider how activities can further improve the wellbeing of individuals and families when dealing with CL/P-related challenges. This might involve staff members undergoing training for active listening skills, counselling skills, or peer support training, introducing activities which target coping skills, collaborating with psychologists who specialise in CL/P, and clearly sign-posting families and individuals to existing support services when necessary.
- Consider methods of delivering materials containing information about CL/P and its treatment to the wider family.
- Advertise activities to wider family members, such as grandparents; including practical guidance, peer support, and opportunities to volunteer and fundraise for CLAPA.
- Standardise the delivery and measure the outcomes of awareness-raising sessions, which appear to have potential for wide-ranging appeal and positive impact.

Final summary
Throughout the duration of the SRC Project, a large number of activities have been run for children, young people and families affected by CL/P. Further to this, the quantity of feedback has continued to grow throughout the three years, allowing for a relatively comprehensive evaluation of the project against its outcomes. Events during the project have been well attended by parents and children and, overall, feedback has been extremely positive; indicating that events are beneficial to and valued by individuals and families affected by CL/P. Evidence gathered indicates that the majority of children and young people have increased confidence and feel less isolated as a result of the events. Additionally, the majority of parents reported being better able to support their children with CL/P-related challenges in a positive way. Over half of children and young people reported being better able to cope with CL/P-related challenges as a result of the events; however, it may be beneficial to consider how to incorporate the development of coping skills into future events in order to address this outcome more fully. Additionally, it is also important to consider how to engage those who are not currently benefitting from events; with a particular focus on those in more isolated areas of Scotland.
A small number of adults have attended events during the project, with feedback gathered suggesting that the events were beneficial. However, there was not enough data to draw any firm conclusions in relation to the project outcomes for adults with CL/P. CLAPA has now appointed an Adult Services Coordinator, which should provide opportunities to further develop and expand services for adults in Scotland and increase adult engagement.

Feedback gained from parents and young people in the form of case studies and the online survey have documented a clear picture of the longer-term positive impacts of engagement with the SRC Project. These data offer additional support for the finding that events increase children and young people’s confidence and create a valuable support network of people affected by CL/P, from which both parents and children are able to gain peer-support. Additionally, the data show that this support is beneficial at all stages of the treatment pathway and illustrate the potential isolation that families may experience if the regional services did not exist.

Additional findings from the online survey were also overwhelmingly positive. Many individuals commented on the impact that the project had on their, or their child’s confidence, and they stressed the importance of being able to meet other families who are also affected by CL/P. The findings also highlighted the key role that the SRC plays in keeping all regions of Scotland up-to-date with service-related information, and acting as a voice for families. Moreover, many reported that the SRC Project has helped to feel part of a CL/P community, which is able to provide invaluable support which is not available in any other context.

Letters of support and feedback forms from Health Professionals working within NHS cleft services in Scotland also highlight the benefits of the SRC Project to individuals and families in Scotland, as well as an increase in collaborative working between the NHS and CLAPA. Benefits included allowing families to meet others who they could relate to, subsequently reducing isolation felt by families affected by cleft. Moreover, HPs reported that they often referred families to CLAPA’s services in order for families to access peer-support and other services which are complementary to the services provided by the NHS cleft teams.

In addition to this, SRC has made great steps towards raising awareness of CL/P and related challenges by holding a number of Awareness Raising sessions. These have been carried out with local community groups, a large number of school children, and health professionals. The feedback suggests that the sessions have been very well received, and that attendees have gained a better understanding of CL/P as a result.

The SRC has also developed a network of volunteers, who successfully run a variety of events throughout Scotland and provide vital support and first-hand advice to those who attend. Work has been done to improve the recruitment, induction, and training of volunteers over the course of the project. This has ensured that volunteers are comfortable within their role and that the workload of each volunteer is appropriate
to the time that they are able to give. Volunteers are a key part of the project, both in running events and in providing vital peer-support to families affected by CL/P.

In conclusion, the SRC Project has continued to grow and provide support to an increasing number of individuals and families affected by CL/P over the course of the three-year project, as well as developing a volunteer network and raising awareness of CL/P within a number of community groups. Furthermore, it is clear from qualitative feedback collected during Year Three that the SRC Project offers crucial peer-support, which is not otherwise available to families through their engagement with the NHS cleft service. The role of the SRC is valued very highly by those who use CLAPA’s services in Scotland and many have highlighted how much more challenging it would be for families to gain support if the SRC Project did not exist, or was not based locally. Overall, the project has been very successful and has gone a long way towards achieving the project outcomes. There are, however, some considerations which could help to further improve CLAPA’s services in Scotland and allow for a greater number of people, especially in more remote areas of the country, to benefit from the services.
Appendices

1. Letters of support from NHS Cleft Teams

Dear Big Lottery Fund

I am writing in support of the Regional Coordinators Project proposal which is being submitted by the Cleft Lip & Palate Association (CLAPA) to the Big Lottery Fund.

I work in NHS Ayrshire & Arran and am the Lead for the Multi-disciplinary Cleft Lip & Palate Clinic in Ayrshire. We are linked into the Cleft Care Scotland Network but being slightly remote from the central belt of Scotland it is not always easy to keep in touch with what is going on towards the central hub.

Our local (Scottish) Regional Co-ordinator, Gillian McCarthy, has been really excellent in keeping me informed of social events that she has organised on a regional and more local basis. I have been able to spread the word to my patients about these social opportunities and they have been extremely well received. A couple of parents have commented that it had been the first time where their child with a cleft had had the opportunity to meet another child with a facial cleft, which they found incredibly beneficial. The events have also given the parents an opportunity to mix.

The Cleft Lip & Palate Association does truly excellent work in supporting parents especially through the early years of having a child with a cleft and subsequently the children themselves. However this can only be delivered very remotely from a central office unless Regional Coordinators are available to spread the work of the charity and I think this is especially important in Scotland with its widely dispersed population.

I therefore fully support the continued funding of the Regional CLAPA Coordinators Project because ultimately they are improving the lives of the people that really matter, the children who are born with cleft lip and palate.

With kind regards

Yours sincerely

Mr David Morrant
Consultant in Orthodontics, BDS, FDS (Orth), MDO, RCPS, M.Orth, RCS, MSc
Acute Services Division

Women and Children’s Directorate
West of Scotland Multidisciplinary Cleft Team

Mr Mark Devlin
Consultant Cleft & Maxillofacial Surgeon

Mr Craig Russell
Consultant Cleft & Plastic Surgeon

Mr David Wynne
Consultant Otorhinolaryngologist

Dr Margo Whiteford
Consultant Clinical Geneticist

Jenny Pettigrew
Shirley Wallace/Annie Crawford
Anne Maclean/Connie Macdonald
Cleft Nurse Specialists

Mr Toby Gillies
Consultant Cleft Orthodontist

Lisa Crampin/Linsey Campbell
Specialist Speech & Language Therapist

Dr Rebecca Crawford/Dr Jess Hare
Clinical Psychologist

Karen Britton/Sarah McDonald
Paediatric Dental Service

Erin Ward
Cleft Service Co-ordinator

Telephone 0141 451 6524
Cleft Nurses 0141 452 4905

To Whom it May Concern

We wanted to express our appreciation of the input and work of all local CLAPA branches in Scotland.

Ongoing benefits include greatly improved communication and renewed links between CLAPA and professionals involved in cleft care. Regular update meetings arranged by CLAPA Scotland allow engagement and discussion around care and support provision for our families. Regular activities arranged by the branch benefit families affected by cleft lip and palate, providing support and have gone a long way helping families feel less isolated. Examples of these are the children’s Christmas party, family outings and activity days.

Attendance at the Children’s Hospital especially during cleft awareness week helps to raise awareness of cleft lip and palate amongst professionals here at the hospital and the general public.

Having a regional coordinator and working with our CLAPA branch has improved the quality of care we provide and is an invaluable support to families and professionals involved in cleft care.

The National Cleft Surgical Service for Scotland fully supports the efforts of CLAPA as they seek funding to continue providing valuable non medical support to families affected by cleft lip and/or palate.

Yours Sincerely

Jenny Pettigrew
Shirley Wallace
Cleft Nurse Specialist
Cleft Nurse Specialist

05/04/2018
2. Regional Coordinator’s Personal Reflection

1) When did you first become involved with CLAPA and what inspired you to work for the charity?

I first became involved with CLAPA in October 2014. I started work as an Engagement Officer which was a part time post approximately 2 days a week for an initial 5 month period. The job has grown since then.

I was attracted to the Regional Coordinator Project and the Engagement Officer Post, partly because it was a part time post and I was looking for something new to do to complement my other job. The other role I had was funded for a set period of time, the funding was coming to an end and so I was keen to explore other interesting opportunities.

The main reason though that I was attracted to the project was linked to the fact it was working with cleft lip and palate. I am a qualified Speech and Language Therapist, and worked for several years in this role before moving to project work/business ownership. The variety that the Regional Coordinators role allows was of great interest along with the opportunity to build a CLAPA community in Scotland and to bring this community together.

2) Since you have been in post, what do you feel are your key achievements in the following areas?

- Volunteering

Our volunteers are vital to the growth of CLAPA and to ensure support for families can be offered in a variety of regions across Scotland. We are developing a group of core volunteers who are committed to running activity to support families. We have identified that volunteers felt that there was too much pressure/demands on their time and so a new model involving “groups” rather than “branches” has been established. This has identified volunteers who are keen to be “helpers” and “help” organise an event such as a Christmas Party without the burden of having to organise other events throughout the year.

- Supporting children, young people and adults with cleft

I feel we have been successful supporting children and young people with a cleft over the 3 years of the project. 3 Adventure Days a year aimed at children aged 8-17yrs, 3 meetings a year for the Scotland Children and Young Persons Council (SCYP) and a residential weekend each year along with our volunteer run activities including Happy Faces, Christmas Parties, Summer picnics etc has meant children and young people have had a chance to meet others affected by cleft and develop friendships.
We started to look at adult meet up groups and there was really positive feedback from the first group we ran. We now have an Adult Services Coordinator for the UK who will work with adults to identify what services they require and would like and this will help guide us further.

- Supporting parents and other family members

I feel I have built up great relationships with families who attend CLAPA events, with a group of people who regularly want to help with fundraising and also planning events such as the Christmas Party. We now run 3 Family Days a year for a big range of ages to bring everyone together, plus have Happy faces groups in Glasgow, Edinburgh, Aberdeen and Fife which specifically target parents of younger children born with a cleft. Parents and Grandparents attend these events and I have seen friendships develop over the 3 years I have been involved.

- Any additional activities

Adults born with a cleft, have been involved in shaping the new adult pathway for treatment in the NHS.

We have been delivering talks in schools, the community and with professional groups/students to raise awareness of cleft lip and/or palate.

3) What do you believe the Regional Coordinator role brings to CLAPA as an organisation? What would be lost if the role no longer existed?

I believe the Regional Coordinator Role brings various things to CLAPA as an organisation. It gives CLAPA a stronger presence in Scotland. Families feel CLAPA is supporting the Scottish families by having staff based in the Country. The RC has a stronger sense of what is going on locally in Scotland and a better understanding of the issues for people in Scotland. Scotland is a country and often people confuse it with a “region” in a National organisation, however it has a different set of laws, the funding picture is different and the population/geography is different. A Regional Coordinator can speak up about the local differences so that national staff can understand these.

A Regional Coordinator is important for connecting with families and for bringing in new families. Local volunteers are brilliant at connecting with people in their local area and it’s important that there is a Regional Coordinator to oversee this, supporting volunteers, but also to bring all the local people together into one big group and to give the local volunteers opportunities to join in activities as parents rather than always being the volunteer. Having a RC ensures local activity runs though out the year and allows things such as a residential weekend to run, which would not be within a volunteers role to organise.
Regional Coordinators can also help raise awareness in Scotland via our primary school talks and the partnerships we have built. The RC can also be more strategic in the planning and also can look at the bigger picture for fundraising. Trust and Grants are possibly more likely to fund activity when there is a local RC and local people are more willing to fundraise when there is a local contact rather than everything being managed from a National office based down South.

4) What is left to do?

We need to continue to offer activity for all ages across Scotland. It is difficult to get the numbers to engage with rural parts of Scotland so that is something we need to be mindful of and possibly develop stronger links with other small organisations where we can link together. The RC has started discussions around this type of work but progress is slow particularly if the aims do not meet other organisations priorities. Funding for this type of work would also be required. We need to engage with adults more and the adult services coordinator project will help develop this work, with roadshows already planned.

We need to ask families what they want to see next. There are key things that younger children are looking forward to, such as the adventure days for older children and the residential. It is good we have activities for families to move on to and that they are excited about them. I think we have to be careful not to oversaturate the activity. Good attendance at less activity is better than lots of activity with little attendance. We need to focus on what works and what people want.

It is important to get new people coming through the door even in areas where activity is established. I think that although we work well with the NHS teams we can certainly develop this area of our work. The difficulty is the time pressures on those members of staff but it’s something we are keen to develop. We are already planning a meet the team day and helping the Cleft Nurse Specialists with a venue so we can get a new Bumps and Babes group started.

I am keen that we continue to establish partnerships with other organisations and build ways of working together. I am excited that other organisations are keen to look at ways we can run collaborative training for our volunteers, sharing our knowledge and skills.

It is important that we continue to raise awareness of cleft and I am keen that we develop the work we have started in primary schools and with professionals, students and community groups. Not only does this inform more people about cleft but it can also open fundraising opportunities. It would be great to get some small projects established in Scotland but funding is a huge issue and so everything is done on a small scale.
### 3. Awareness-raising Via Local Media

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<thead>
<tr>
<th>Date</th>
<th>Publication</th>
<th>Subject of Article</th>
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<tbody>
<tr>
<td>15/05/2015</td>
<td>Stornoway Gazette</td>
<td>Local Mum Sets Up Event to Raise Awareness of Cleft Lip</td>
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<tr>
<td>10/06/2015</td>
<td>The Angus &amp; Mearns Courier (online)</td>
<td>Fergie tractors will plough on to complete John o’ Groats to Land’s End Charity Challenge</td>
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<td>15/06/2015</td>
<td>Inverclyde Now</td>
<td>Boys Brigade Notes - 3rd Gourock Charity Presentation</td>
</tr>
<tr>
<td>23/07/2015</td>
<td>Milngavie and Bearsden Herald</td>
<td>Fiddler's Album Raises Thousands for Charity</td>
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<td>30/09/2015</td>
<td>Herald Scotland</td>
<td>Plan to change surgical services to single site</td>
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<tr>
<td>28/09/2015</td>
<td>The Courier (Scotland)</td>
<td>Leaked paper suggests Scotland’s cleft surgery could be reduced to single Glasgow site</td>
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<td>01/10/2015</td>
<td>Scotland Herald</td>
<td>Centralisation of cleft palate services a small price to pay for excellence</td>
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<tr>
<td>21/12/2015</td>
<td>Dunfermline Press</td>
<td>Dumfermline mum joins fight to save cleft surgical service</td>
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<tr>
<td>16/03/2016</td>
<td>BBC News Online</td>
<td>Cleft lip surgery: Anger at proposal to close Edinburgh service</td>
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<tr>
<td>06/05/2016</td>
<td>Dunfermline Press</td>
<td>Petition to save cleft services reaches 5000</td>
</tr>
<tr>
<td>09/06/2016</td>
<td>Scotland 4 Kids</td>
<td>My Story - Yvonne Galbraith</td>
</tr>
<tr>
<td>19/07/2016</td>
<td>BBC News (Edinburgh Fife &amp; East Scotland)</td>
<td>NHS Accountant’s Twitter posts anger cleft lip campaigners</td>
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<td>Fife Today</td>
<td>Happy Days for New support Group (New Kirkcaldy/Fife Happy Faces Group)</td>
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<tr>
<td>14/09/2016</td>
<td>The Courier (Scotland)</td>
<td>Support for opponents of cleft palate surgery centralisation.</td>
</tr>
<tr>
<td>14/09/2016</td>
<td>Dunfermline Press</td>
<td>Rowley backs mum’s bid to keep cleft surgery in Edinburgh</td>
</tr>
<tr>
<td>16/09/2016</td>
<td>Border Telegraph</td>
<td>Lauder lad George takes on 5 marathons in 5 days across Florida</td>
</tr>
<tr>
<td>13/04/2017</td>
<td>The Gazette (Renfrewshire)</td>
<td>Olivia Galbraith, a pupil at Inchinnan Primary, organised a ‘wear your own clothes’ day for CLAPA</td>
</tr>
<tr>
<td>14-Jun</td>
<td>Lennox Herald</td>
<td>Sean and Liam Milligan - Awareness Week Fundraising</td>
</tr>
<tr>
<td>04/01/2018</td>
<td>Evening Express (Aberdeen)</td>
<td>Aberdeen Panto</td>
</tr>
<tr>
<td>08/04/2018</td>
<td>STV</td>
<td>Dad auctions off original-recipe irn-bru for charity (Yorkhill &amp; CLAPA)</td>
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<td>03/05/2018</td>
<td>Data missing</td>
<td>Beth’s Birthday Gift to Charity (Beth’s family at Kiltwalk &amp; awareness-raising for CLAPA, SCYP)</td>
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4. Case Studies

Interview with Shirley-Ann and Beth conducted and summarised by Jenny Toni Andrews (Cleft Lip and Palate Association) in April 2018

Like most parents, Shirley-Ann’s first concern when her baby was born was; “Is she healthy?”

Before meeting baby Beth, she and her husband Mitchell didn’t know anything about cleft lip and palate, and certainly didn’t know their daughter would be born with one. Beth had kept her face mostly hidden in scans during pregnancy, so her cleft came as a complete surprise.

Once the emergency C-section was over with and Shirley-Ann held her baby, she felt relieved. Whilst Beth may have looked different than her family had been expecting, she was healthy, and Shirley-Ann was delighted.

“I got over the shock quickly, but I think it would have been good to know more information about what cleft was so that I could have been more prepared,” Shirley-Ann explains.

A Cleft Team representative joined them afterwards to talk them through what was to follow. She and Mitchell learned all about cleft, and how it affects babies born with the condition in the UK as they grow up. Before this, they had never met anyone who had been born with a cleft or whose baby was affected.

With 1 in 700 babies born with a cleft in the UK each year, the condition is both more common than most people realise and rare enough that few people who have not been directly affected are aware of its existence. Later, as Shirley-Ann spoke with her mum, she learned it was more common than she’d known. Her mother had worked as a specialist care practitioner for a number of years, and her awareness and matter-of-factness about cleft helped a great deal. As a result of her own experience and understanding, Shirley-Ann’s mother was also able to explain the situation to Beth’s dad’s side, reassuring them as well.

As well as coming as a surprise to Shirley-Ann and her husband, a lack of public understanding of cleft could make her family’s situation difficult to explain to others. She remembers a couple of unpleasant incidents when strangers were rude, one instance in particular when a stranger in the street treated baby Beth like a “freak show” attraction for his children. Thankfully, she remembers most people being very accepting.

Shirley-Ann remembers that another difficulty in those early months was feeding. Beth could only feed in short bursts, so to make sure she was getting all the nutrients she needed, Shirley-Ann had to feed her much more often.
“It felt like every other hour until her operation,” she recalls.

The first of Beth’s operations, to close the gap in her lip by stitching together the tissue that hadn’t fused before she was born, took place that winter. Shirley-Ann explained how she found it difficult whilst holding Beth as she was put under anaesthetic, though the hardest part was Beth’s recovery.

“It would’ve been nice to have more preparation,” Shirley-Ann admits. “Her face was so swollen. We didn’t expect that at all.”

She remembers that as the worst of Beth’s operations.

“We were just thinking ‘What have we put her through?’ It was such a relief after a few hours when the swelling went down.”

Shirley-Ann goes on to describe what a strange feeling it was for all of the family to see Beth’s new smile for the first time. Beth has a brother who is a couple of years older than she is and Shirley-Ann remembers her son including Beth’s cleft in his childhood drawings. He had accepted his sister’s cleft very quickly. Soon the family got used to and loved Beth’s new smile, just as they had the smile she was born with. “It was a ‘good’ different,” Shirley-Ann remembers. “Just a change.”

The family first found out about CLAPA from the Glasgow Dental Hospital. Staff there put them in touch with Gillian McCarthy, CLAPA’s Senior Regional Coordinator in Scotland, when Beth was eight-years-old.

During the first years of hospital visits, Beth was still so small and, while it was a hard time for the rest of the family, Beth was too young to understand or remember her surgeries. By the time it came to her alveolar bone graft surgery to help her adult teeth grow properly, Beth was older and more aware of what was happening.

Her parents worried that this was frightening for her, but were grateful to have met other families through CLAPA so Beth knew other children in similar situations. This meant that Beth had someone to answer her questions, like what she would be able to eat after surgery and what to expect. Attending CLAPA events during the past few years helped Beth to make friends from all across Scotland who were also born with a cleft. Visiting from Glasgow and Aberdeen, these friends come to Beth’s home for sleepovers, often chat over the phone, and regularly write to each other as pen-friends.

Through this, Shirley-Ann has also made a group of new friends herself. She and these fellow parents share experiences and advice, passing time together around town while their children catch up at CLAPA events for young people nearby. Their support extends online as well and Shirley-Ann knows she can always pick up the phone when she needs someone to speak to.
Beth herself didn’t realise she had been born with any kind of visible difference until she was around five-years-old.

“When she saw a child on the TV with a cleft, she asked about it. I told her she had one too and she couldn’t believe it.” Shirley-Ann laughs at the memory. “I had to pull out old photos to show her and explain.”

As Beth has grown up she’s learned more and more about her cleft journey and now her and her mum can talk about everything.

Speaking to Beth, now ten-years-old, it’s clear that being born with a cleft has not held her back. She speaks cheerfully about school and is excited to tell her story.

“I’m fine to talk about it at school if people ask,” she explains. “I don’t worry about explaining everything. I just tell them ‘this is something I was born with’.”

As she gets older, Beth is keen to share the story behind her life so far. She wants to be able to show other children born with a cleft that things will be alright and to help them avoid worrying. She describes how she is in the early stages of putting together a scrapbook, full of notes, clippings, and photographs. She hopes this will help to teach other children more about what growing up with a cleft is like and will be a source of comfort and support to her peers. She is acting as a buddy to a young girl in nursery at the moment as well, who was also born with a cleft.

“All the children involved with CLAPA are very caring,” Shirley-Ann notes with admiration.

Meeting others born with a cleft has been very important to Beth.

“When I was younger I thought I was the only one and I’d think ‘Why have I got this?’” She explains. “Meeting other people like me makes me happy and feel not alone.”

Her favourite CLAPA activities are the Residential Weekends. On these trips she gets to take part in team building activities, make campfires, toast marshmallows, and spend time with her friends.

“They’re always a lot of fun!” Beth says.

She admits she wishes she’d known more about cleft earlier in her life, rather than finding out from the TV. When asked if she has any advice she would offer to other children affected by cleft, she is quick to reply.

“Stay positive, remember you’re not alone. Stay strong. ‘CLAPA strong’, I like to say!”
Its two years now since the family attended their first CLAPA event. They met other families affected by cleft and spent the day sledging and playing in the snow. Beth’s brother went with her too and it helped him understand what she was going through. “They’re really close,” Shirley-Ann says. “He gets very worried about her operations. This kind of support really does help the whole family.”

When asked if there was something she wishes she and Mitchell had been told back on that first day in the hospital, Shirley-Ann considers what advice she would offer other parents in their situation.

“I’d want to tell parents that cleft won’t hold their child back. People can be cruel and operations are hard but there is worse out there. I count my lucky stars.”

If you would like more information about this item, please contact CLAPA directly: jenny.andrews@clapa.com.
CLAPA Regional Coordinators Project Case Study Report Form

I am:
Parent/ carer

Q1. How were you first involved with CLAPA before you came into contact with the Regional Coordinator?
My son has cleft lip and palate

Q2. How did you first come into contact with the CLAPA Regional Coordinator?
I met at one of the Happy Faces events.

Q3. What local CLAPA activates have you been involved with since your first contact with the Regional Coordinator?
I have attended Wonderland several times, Christmas party (Glasgow central hotel), Briarlands Farm this summer

Q4. As a result of your involvement with CLAPA, in what ways do you feel connected to a local support network and wider cleft community?
When attending these events you don't feel so isolated, you meet parents and children in the same or similar situations to yourself and your child.

Q5. As a result of your involvement with CLAPA, in what ways do you feel able to support your child and other people affected by cleft? (if this does not apply to you, please leave blank).
I find it really beneficial attending these local events as I meet parents whose children have been through / are going through what my son has/still to have and this helps me in how I can support him. For instance, I had no idea that he would be able to suck or blow until I met with a father and his daughter who is a year older than my son and she was sucking through a straw and blowing a party whistle. It took a while but on holiday a few weeks ago he took a sip through a straw for the first time and he attended a birthday party yesterday and he blew a party whistle. I had no idea this was possible!

Q6. As a result of your involvement with CLAPA, in what ways do you feel your ability to cope with cleft-related challenges has improved? (if this does not apply to you, please leave blank)
It’s improved as I feel that I have more knowledge which I get from other parents at these events. I also feel more confident in how I deal with people who stare at him or make hurtful comments. I can talk to parents and parent mentors and ask how best I deal with situations.
Q7. How did your find your experience of working with the CALAP Regional Coordinator?
Professional, organised, helpful and happy – great with kids and always keen to make sure everyone has a great time at the planned events.

Q8. What do you feel are the benefits of having a CLAPA Regional Coordinator?
I think that having a regional coordinator is a very beneficial to us as I have spoken to parents who are travelling from Falkirk etc. previously. Our coordinator knows the parents, age groups of the kids and plans the events accordingly. There are never any issues with gaining entry, attending the events is easy by registering on Eventbrite. I feel that if there was no regional coordinator then events wouldn’t always be a short car ride away and also maybe not organised as frequently as what they are at present.

Q9. In what ways could CLAPA continue to improve their local services?
Having activities.
I am terrible for looking are social media and also emails so possibly texting out about local events etc. (I also don’t open my mail very often!) or possibly coffee morning if it suits when kids are at school/ nursery?

If you have any other comments you would like to make, please write them in the space below:
I think CLAPA provide an excellent service. My son was born in London and a representative called us and arrived at the hospital the day after he (and his twin sister) were born. I would not have been able to cope without this invaluable service.
5. **Table of evaluation reports produced during the project.**

<table>
<thead>
<tr>
<th>Date</th>
<th>Report Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>May 2016</td>
<td>Focus Group Studies in Scotland</td>
</tr>
<tr>
<td>May 2016</td>
<td>End of Year One Report</td>
</tr>
<tr>
<td>May 2017</td>
<td>End of Year Two Report</td>
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<tr>
<td>March 2018</td>
<td>The Psychosocial Impact of Cleft Lip and/ or Palate on Grandparents</td>
</tr>
<tr>
<td>May 2018</td>
<td>End of Year Three Report</td>
</tr>
<tr>
<td>May 2018</td>
<td>End of Project Report</td>
</tr>
</tbody>
</table>