



**Glasgow  
Children's  
Hospital  
Charity**

Continuing the care of  
Yorkhill Children's Charity



**LOTTERY FUNDED**



**Healthier  
Scotland**  
Scottish  
Government



**Edinburgh  
Children's  
Hospital Charity**  
Continuing to support the Sick Kids

**THE HUGH FRASER  
FOUNDATION**

# CLAPA Regional Coordinators Project: Scotland Interim Report End of Year Three May 2018

## **Contributors:**

### Centre for Appearance Research (CAR):

Miss Ella Guest (Research Associate), and Dr Nicola M. Stock (Research Fellow)

### Cleft Lip and Palate Association (CLAPA):

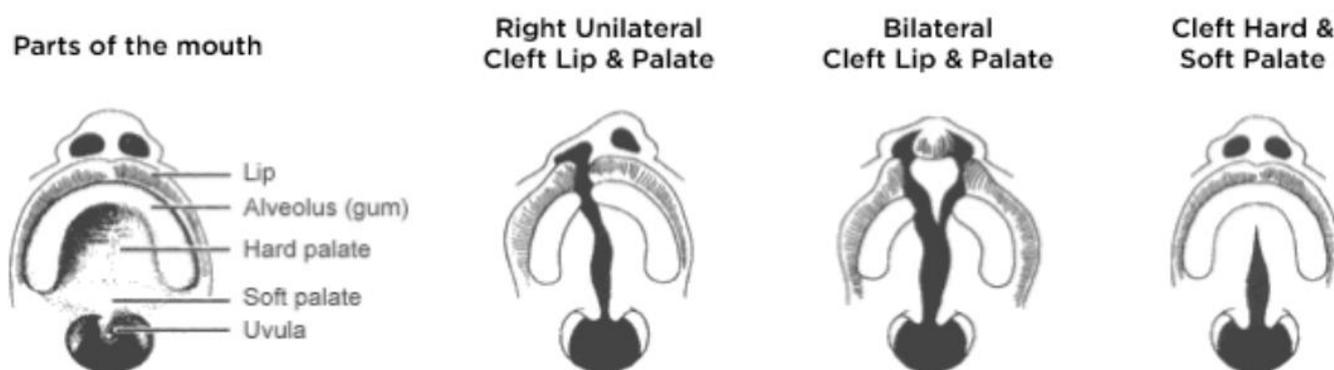
Ms Gillian McCarthy (Senior Scotland Regional Coordinator), Ms Melanie Skinner (Scotland Support Officer), Ms Rebecca McDonald (Scotland Support Officer), and Ms Claire Cunniffe (Deputy Chief Executive).

## Report Contents

<b>Glossary of Terms</b>	page 3
<b>Lay Summary</b>	page 6
<b>Introduction</b>	page 9
<b>Impact on Children and Young People</b>	page 12
<b>Impact on Adults</b>	page 17
<b>Impact on Parents</b>	page 19
<b>Additional Activities</b>	page 24
<b>Evaluation Report Summary</b>	page 27

## 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](http://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 Regional Coordinators 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, The Sick Kids Friends Foundation, Glasgow Children's Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust) to run a similar project in Scotland.
- The funding enabled CLAPA to employ one Senior Scotland Regional Coordinator (SRC) and one part-time Scotland Support Officer, with the aim of improving local service provision for children, young people, and adults affected by CL/P and their families from June 2015 to May 2018.



## Evaluation Findings in Year Three

- During Year Three, the SRC has continued to act as a key contact for people affected by CL/P and their families in the Scotland region.
- Over 18 events have been run during Year Three, with 7 further events planned before the end of the project.
- Over 300 individuals have attended events during Year Three.
- The events are aimed at families and young people, in addition to a number of awareness-raising activities and training sessions.
- Recommendations have been made for an increase in services for adults born with CL/P.
- There have also been recommendations for more activities aimed more specifically at increasing individuals' knowledge of CL/P and their ability to cope with any related challenges (e.g. with teachers, health professionals and school children).

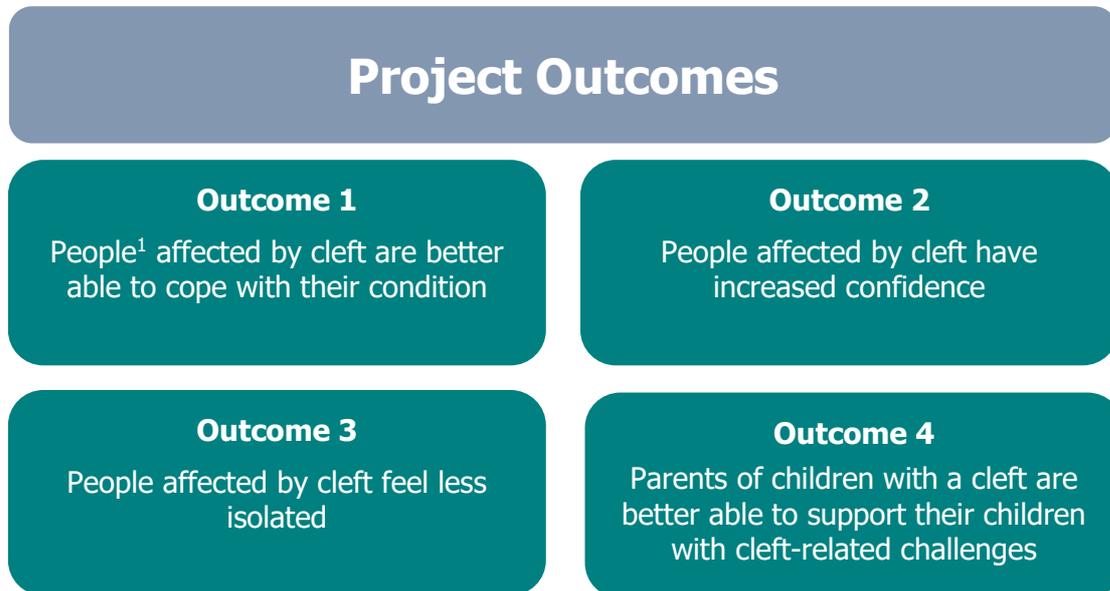
**Over 300 individuals have attended events**

**80% of children and young people have increased confidence**

**73% of parents feel more confident in supporting their child**

**Over 90% of parents feel part of a cleft community**

The project has four main outcomes:



<sup>1</sup>People includes children, young people and adults affected by cleft

## End of Year Three Evaluation

- The SRC Project is underpinned by a three year evaluation, carried out independently by the Centre for Appearance Research (CAR), based at the University of the West of England (UWE) in Bristol, UK.
- This allows service users to provide regular feedback, and supplies evidence to current and future funders to support the continuation of existing services and the development of new services and activities in Scotland.
- The End of Year Three report outlines evidence collected during the third year of the SRC project.

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

*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](mailto:Claire.Cunniffe@clapa.com).*

# Introduction

## Background and project rationale

A cleft in the 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 for most individuals the treatment pathway ends 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 Regional Coordinator 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, The Sick Kids Friends Foundation, Glasgow Children's Hospital Charity, the Scottish Government Social Care Directorate, the Hugh Fraser Foundation and the Tay Charitable Trust, to employ one Senior Scotland Regional Coordinator (SRC) and one

Scotland Support Officer. A second Scotland Support Officer was also employed, part-time, from September 2017. Year One of this project ran from June 2015 to May 2016, Year Two from June 2016 to May 2017, and Year Three from June 2017 to May 2018, with events being run until August 2018.

## Project outcomes

The CLAPA Regional Coordinators 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'.

### Project Outcomes

#### Outcome 1

People<sup>1</sup> 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

<sup>1</sup>People includes children, young people and adults affected by cleft

The CLAPA Regional Coordinators Project in Scotland is currently funded by eight different organisations. As a result, the outcomes above have been produced by CLAPA to cover the criteria of all eight organisations combined.

All evidence obtained during this project will be evaluated against these outcomes and presented in the following report.

## This report

This report describes the findings obtained from the evaluation during Year Three. A similar report has been produced for Year One and Two. Supplementary reports, and an End of Project Report, have also been provided throughout the duration of the project.

Data was predominantly collected using the feedback forms provided by CAR, as well as through other methods where appropriate. Copies of these forms can be provided upon request. Data are presented in relation to the patient group upon which activities were intended to have an impact. This is followed by a summary concerning progress in relation to the relevant project outcome(s) detailed above, as well as future recommendations.

In some cases, there was missing data within the feedback forms. For this reason, totals are given for individual questions, and percentages were calculated on a question-to-question basis. This will be presented as ' $n=x/x$ '.

## 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 since 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 in all three years of the project.

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

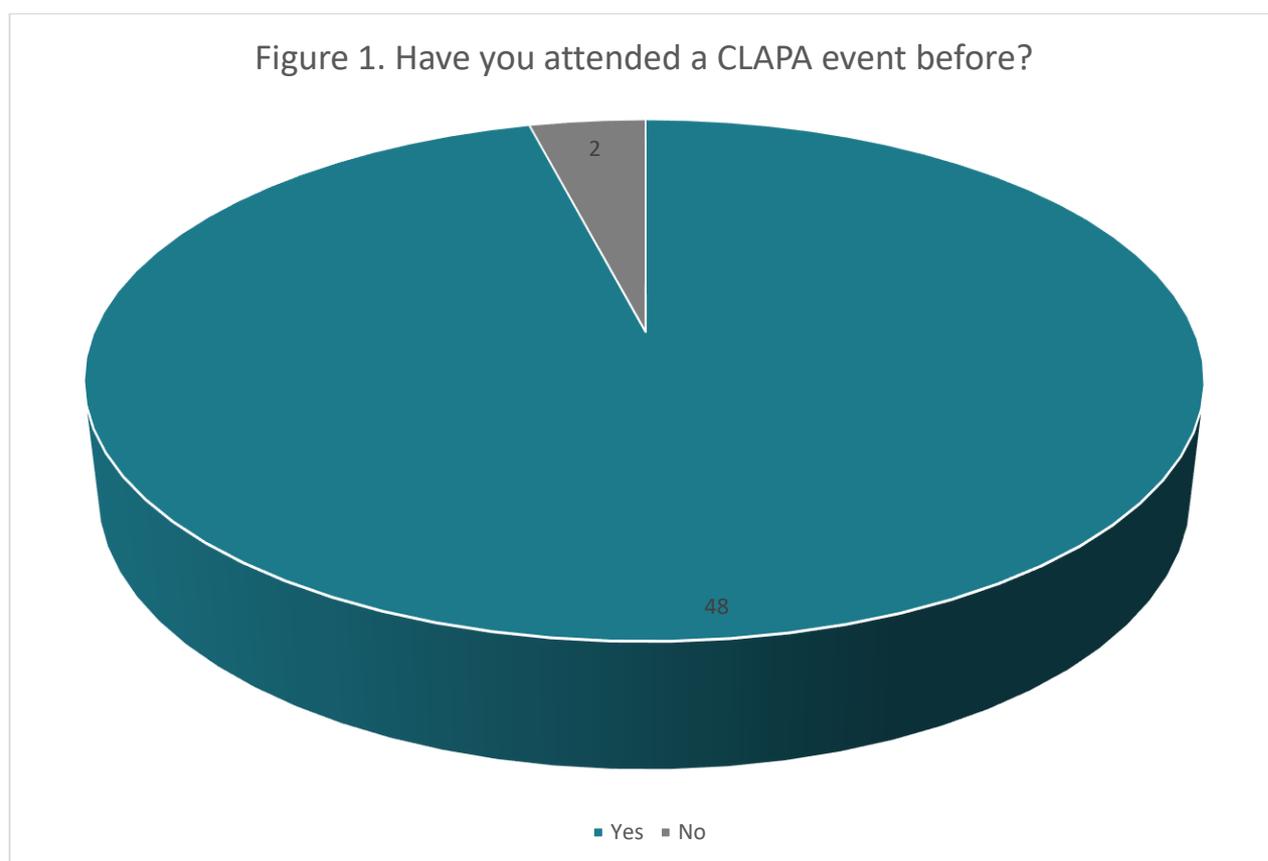
## Scotland Region

### Impact on children and young people

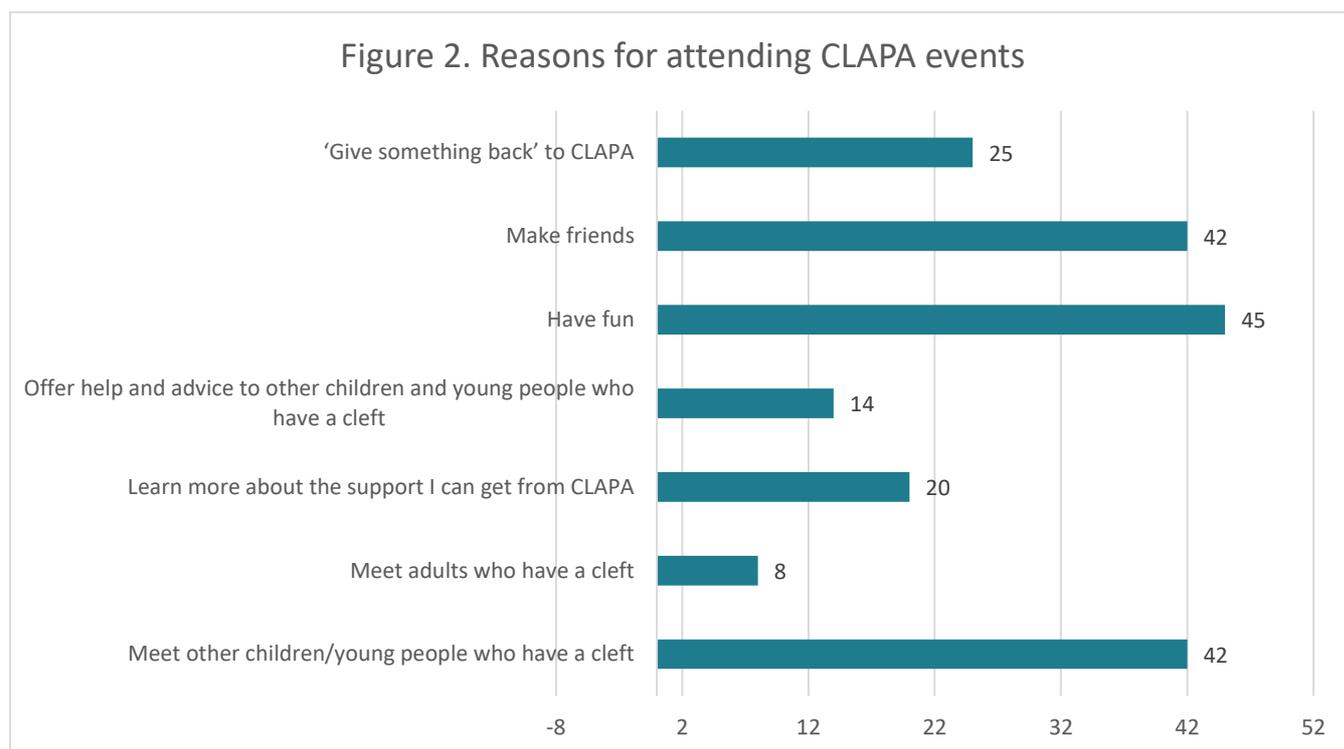
During Year Three of the SCR project, 88 children/young people attended events, and 52 feedback forms were collected from 11 events (from 41 children aged 11 or under, and 10 young people aged 12-17). These events included 4 Happy Faces events, 3 Family Days, 2 Christmas parties, 2 Older Children's Activities, and a Children and Young People's Council meeting.

Further to this, 7 more events have been organised, which will take place in summer 2018.

As can be seen in Figure 1, the vast majority (96%) of children and young people ( $n= 48/50$ ) had attended CLAPA events before. This suggests that children and young people enjoy the events and continue to attend them.



Children and young people were asked to indicate their reason(s) for attending these local events. In response, 88% of children and young people reported that they had attended to 'have fun', 81% to 'make friends' and 81% to 'meet other children and young people who have a cleft'. These findings are in line with those from Year Two, indicating that the high standard of services has been maintained. Additional information regarding reasons for attending events is detailed below in Figure 2.



A number of children and young people commented that that they most enjoyed being able to socialise with others at the events.

***"Meeting others with cleft lips"***

***"Meeting new friends"***

Additionally, parents frequently commented on the benefits that attending events had on their children:

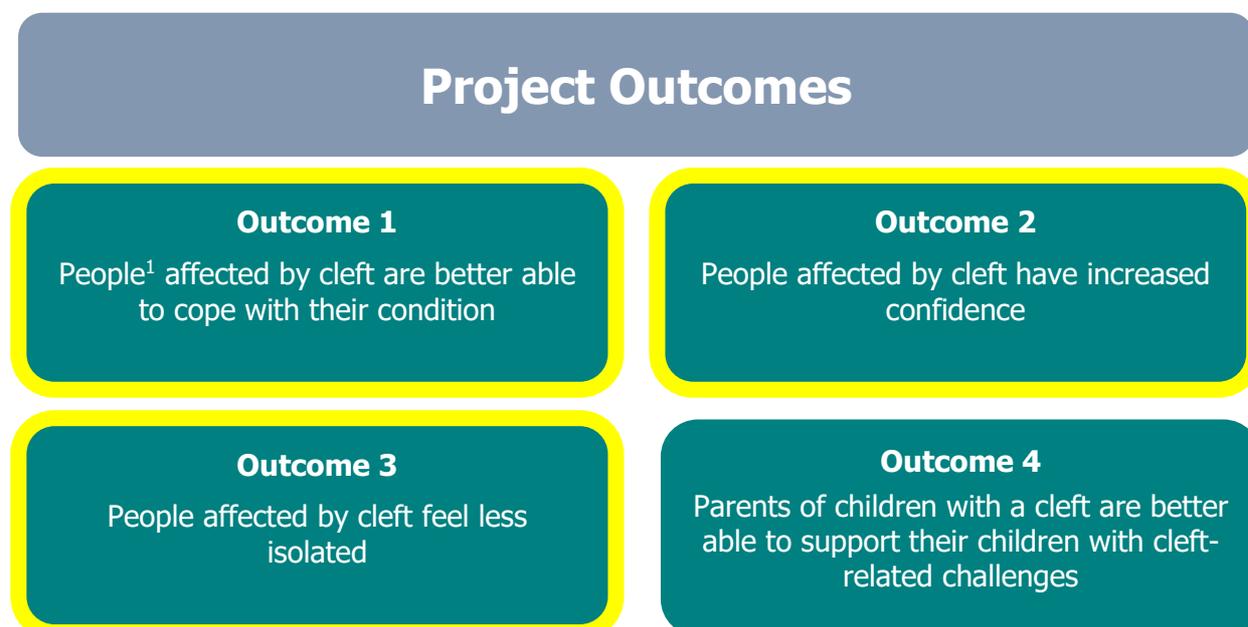
*"The children are now all good friends"*

*"Watching the kids interact and make friends"*

*"[It gives them the] ability to meet other children with cleft"*

At a slight increase from Year Two, 98% ( $n=123/125$ ) of parents reported that their son or daughter enjoyed the event(s) they had attended. Moreover, 92% ( $n=46/50$ ) of children and young people agreed that they would like to attend similar events in the future. Again, this finding is similar to that of Year Two, suggesting that these high standards have been maintained.

Outcomes 1, 2, and 3 are relevant to children and young people with CL/P:



<sup>1</sup>People includes children, young people and adults affected by cleft

**Outcome 1** – 66% ( $n=33/50$ ) of children and young people reported that they had learned new ways of coping with their condition as a result of the events. While this is a significant improvement from Year One, it is slightly lower than Year Two (70%). With 28% ( $n=14/50$ ) responding neutrally, and a small number (6%;  $n=3/50$ ) reporting that the events did not teach them new ways of coping. This increase in neutral responses may suggest that many children and young people have already learnt effective coping skills from previous events, and that this positive impact may have, therefore, plateaued. Nonetheless, the overall findings suggest that children and young people are learning coping and problem solving skills from attending events. The development of additional events, which are specifically aimed at promoting positive coping skills, may be worthy of consideration in order to better meet this outcome in future.

Positively, 74% ( $n=37/50$ ) of children and young people agreed that they could offer help to other children and young people as a result of the events, while 24% ( $n=12/50$ ) responded neutrally and 2% ( $n=1/50$ ) slightly disagreed. These findings suggest that the events continue to give children and young people the information and confidence they need to effectively support others affected by CL/P.

**Outcome 2** – Almost 80% ( $n=41/52$ ) of children and young people felt that attending the local events had increased their confidence. However, 19% ( $n=10/52$ ) responded neutrally to this question, and one person disagreed. This evidence is marginally lower than findings from Year Two (90%). Nonetheless, the findings suggest that the events are still helping the majority of children and young people to feel more confident in themselves. Again, a slight increase in neutral responses may reflect that the confidence some individuals gained from attending previous events has plateaued.

**Outcome 3** – In line with Years One and Two, most of the children and young people reported that they had made new friends who they were able to talk to about having CL/P, as a result of attending events (77%;  $n=40/52$ ). Furthermore, parents commented that the events had allowed their children to meet others with cleft and form friendships with them. This feedback is consistent with the data collected during the rest of the project, and suggests that children and young people, as a whole, feel less isolated as a result of SRC Project. However, 15% ( $n=8/52$ ) responded neutrally, and 8% ( $n=4/52$ ) disagreed with this statement. For this reason, developing different types of events may be needed to reach these individuals.

## Impact on children and young people: Summary and recommendations

The overall findings from Year Three remain very positive. The evidence collected shows that most children and young people have increased confidence and have friends that they can talk to about CL/P as a result of the events. In addition to this, most children also reported that they would be able to offer support to other children and young people with CL/P. Additionally, 66% reported that the events had helped them to learn new ways of coping with their condition. While this shows that the events are helping over half of the children and young people to learn new ways to cope, there are still a significant number who are not benefitting in this way. Incorporating coping and problem-solving skills into events for children and young people should be a key consideration going forward. This may include training the SRC in basic peer-support, counselling, or active listening skills, and collaborating with psychologists who specialise in CL/P.

Although some of the findings from Year Three are marginally lower than Year Two, with more reporting neutrally to questions in some cases, one important consideration is that as the vast majority of these children and young people have attended events before. Therefore, they may have already made new friends, increased in confidence, and developed CL/P-related coping strategies from attending previous events, which could explain the increase in neutral responses. However, consideration should be given to the individuals who are currently not accessing the services which are available.

Going forward, the SRC should continue to organise events for children and young people, and collect feedback from as many attendees as possible in order to document the impact of the events.

Additionally, the SRC could:

- Continue to organise activities which encourage children and young people to attend who have not attended a CLAPA event previously; with a particular focus on those living in more isolated areas of Scotland.
- Continue to facilitate peer support networks between children and young people born with CL/P.
- Consider how to incorporate activities to help children and young people develop coping and problem-solving skills. This might involve collaboration with cleft specialist psychologists.
- Consider engaging in training in relation to active listening skills, counselling, or peer support training, as well as gaining an awareness of how to refer children/young people who may be struggling to other support services.

- Identify opportunities to collect more varied types of feedback, such as case studies/testimonials, in order to better document the longer-term impact of the SRC Project on children and young people

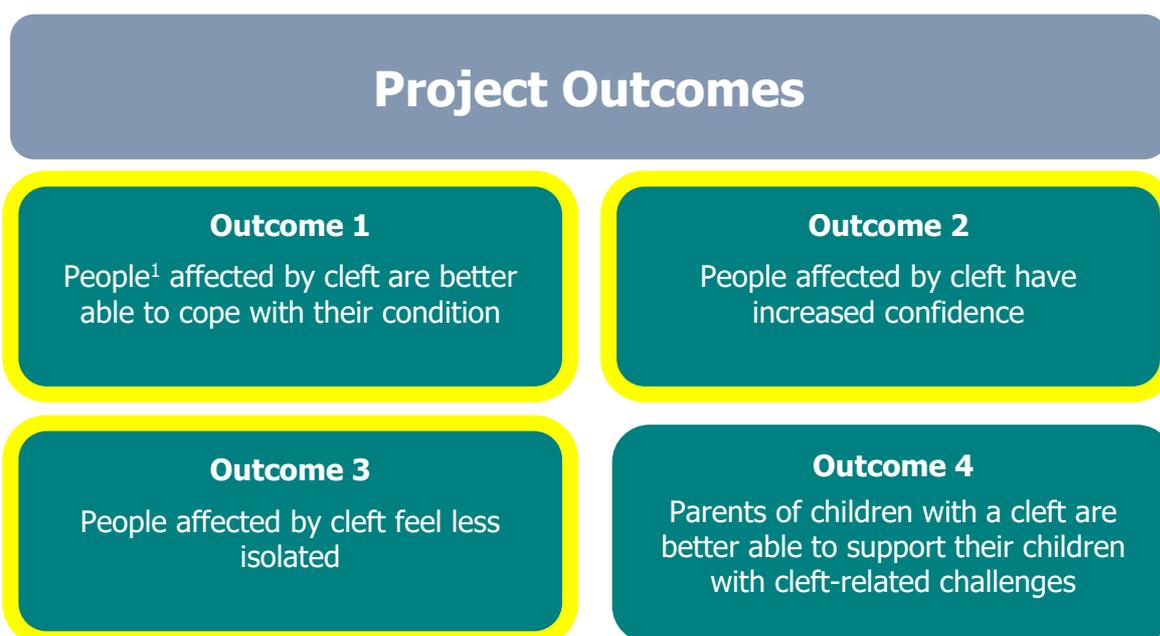
## Impact on adults born with CL/P

Evidence gathered on the impact of the SRC Project on adults who were born with CL/P continues to be limited in comparison to that of children, young people and parents. While a small number of adults have attended events, this is often because they are also the parent of a child with CL/P.

On a positive note, however, feedback was collected from one volunteer who attended a Family Day. This adult reported that they felt more confident connecting with others for support with cleft-related challenges as a result of the event. Additionally, they felt that the event had helped them to gain new knowledge and information relating to CL/P, and that they knew more people affected by CL/P. They also reported that they would like to attend similar events in the future.

There was also interest in holding volunteer-led Adult Meet-Ups in Aberdeen, Edinburgh and Glasgow, however these events had not gone ahead at the time of the project evaluation.

Outcomes 1, 2, and 3 are relevant to adults who were born with a cleft:



<sup>1</sup>People includes children, young people and adults affected by cleft

While there is not enough data to draw firm conclusions, CLAPA has now taken a major step to improve and expand the services they offer to adults affected by cleft, and to increase adult participation in events. CLAPA has enrolled a full-time Adult Services Coordinator (ASC) over the next three years, who has been liaising with the SRC to develop strategies to increase adult engagement with the project in Scotland and to plan further Adult Meet-Ups.

## **Adults born with CL/P: Summary and recommendations**

Little evidence has been gathered on the impact of the SRC project on adults affected by CL/P to date, making it difficult to summarise progress against the relevant outcomes. However, as most of CLAPA's services are aimed at new parents and young children, this is not unexpected. Additionally, while uptake for adults is slightly higher in the England RC project, engagement remains low in all areas. For this reason, developing events and support services which are suitable and accessible for adults born with CL/P remains an important priority for CLAPA.

Recommendations are as follows:

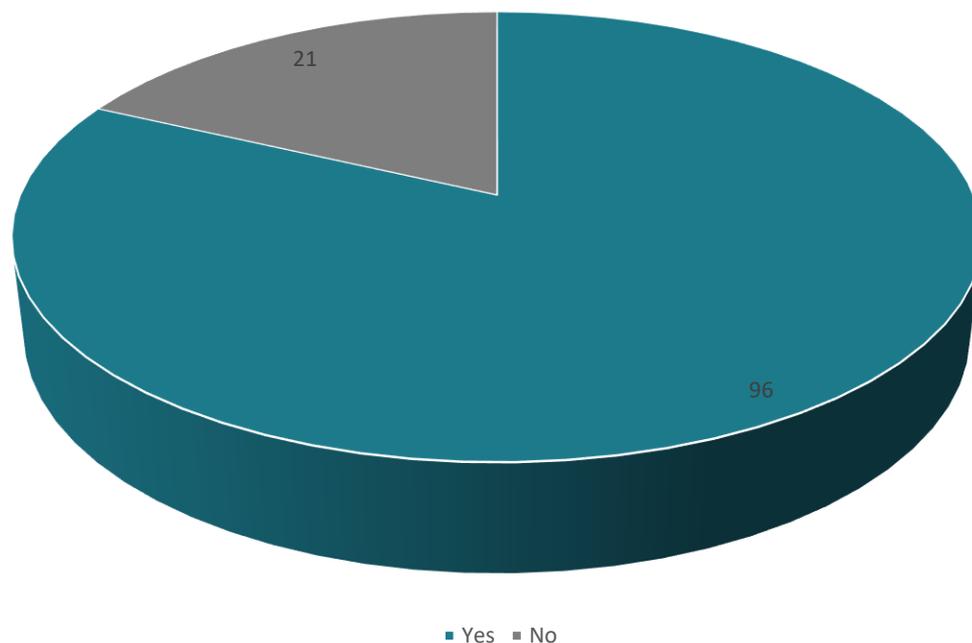
- Continue to work with the new Adult Services Coordinator (ASC) in order to increase adult engagement and to ensure that the type, format, and timing of events are suitable for adults with CL/P.
- Continue to work closely with volunteers in order to organise and run Adult Meet-Up events at different locations in Scotland.
- Identify opportunities to collect more varied types of feedback, such as case studies/testimonials, in order to better document the longer-term impact of the SRC Project on adults

## Impact on parents of children with CL/P

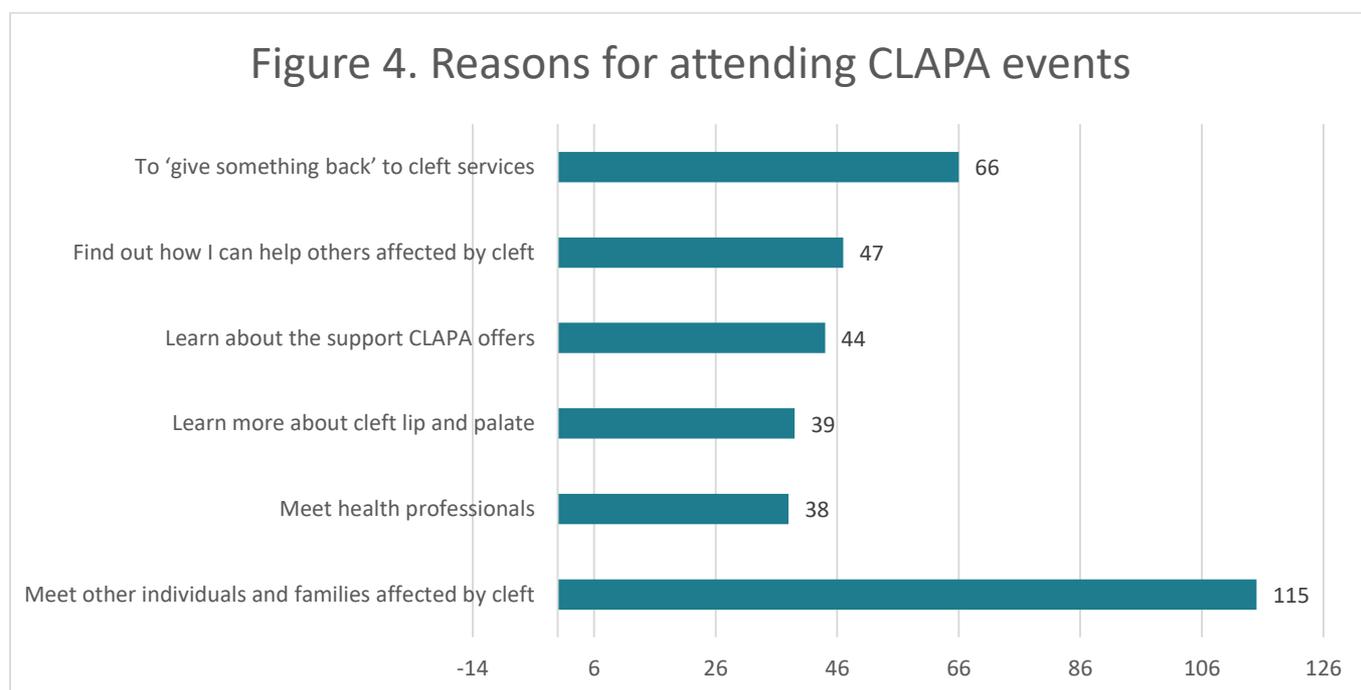
The SRC has continued to support the organisation of events for parents, and has also been involved with recruiting and training parents to be involved with running these group events. During Year Three, 124 individual parents have attended events, with over 160 recorded attendances in total. Feedback forms have been collected from 10 events. These include 3 Family Days, 5 Happy Faces events and 2 Christmas Parties. Overall, 125 feedback forms have been collected from parents who attended these events.

As can be seen in Figure 3, 82% of parents had attended one or more previous CLAPA events. This is a significant increase from 56% in Year Two, suggesting that parents are finding events beneficial, and therefore continuing to attend them.

Figure 3. Have you attended a CLAPA event before?



Parents reported attending local events for a variety of reasons. The most common reason, as reported by 91% of parents, was to 'meet other individuals and families affected by cleft'. In addition, just over half of parents (52%) attended events in order 'to give something back to cleft services'. These findings are consistent with Year Two, suggesting that the reasons for parents attending events has remained the same. More information regarding parents' reasons for attending local events is detailed below, in Figure 4.



Similarly to findings from Year Two, parents reported that they enjoyed events because they allowed them to meet, and form friendships with, other families affected by CL/P.

***"Meeting parents and kids with shared experiences"***

***"Great family fun with new friends made through CLAPA"***

***"Meeting other families affected by cleft"***

Parents also commented on other aspects of the events that they enjoyed:

***"Seeing my daughter happy"***

***"Learning more about CLAPA"***

Further to this, a small number of parents had suggestions for future events:

***"Things for babies- baby mats/toys etc."***

***"An alternative if the weather is bad"***

Encouragingly, 97% ( $n=118/125$ ) of parents reported that they would like to attend similar events in future.

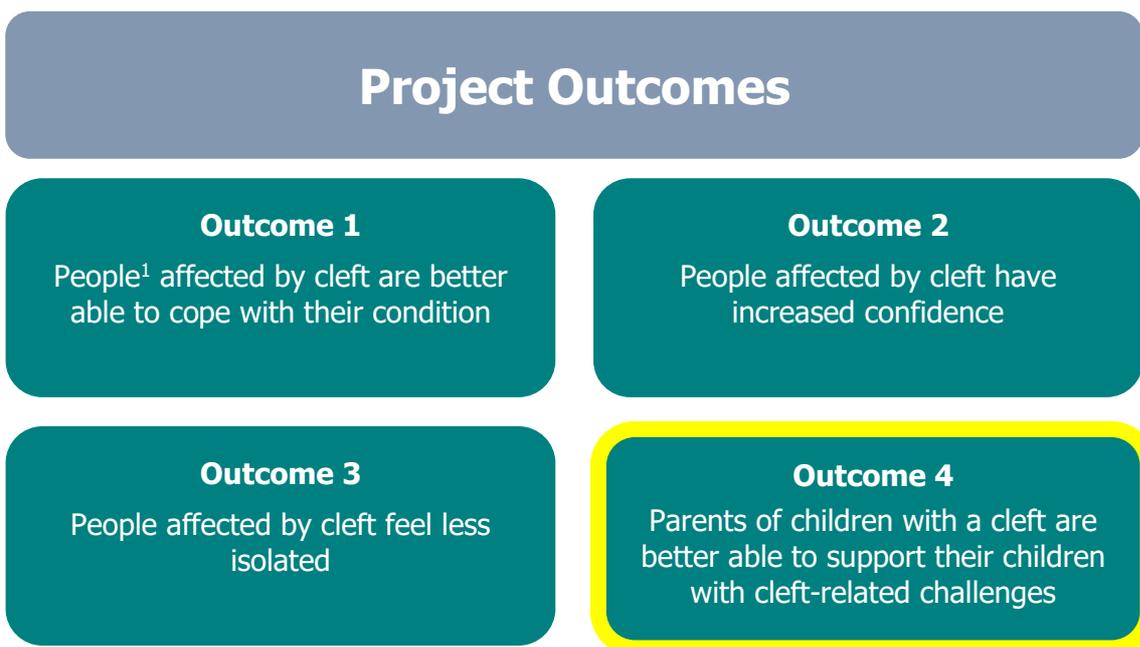
In addition to this, 82% ( $n=103/125$ ) of parents felt that they had access to a local support network as a result of the events, with 14% ( $n=18/125$ ) reporting that the events made no difference to this and a small number, 2% ( $n=3/125$ ), did not feel that the events had given them access to a support network. In line with this, the vast majority, 88% ( $n=110/125$ ), reported that they knew more people affected by cleft as a result of the events. However, 10% ( $n=12/125$ ) felt that the events made no difference to this, and only 2% disagreed ( $n=3/125$ ). Since most parents had attended events before, it is possible that some felt that they had already established a support network.

Another positive finding was that 79% ( $n=99/125$ ) believed that the events had made them feel more confident in connecting with other people for support with cleft-related challenges, however just under 20% (19.2%;  $n=24/125$ ) felt that the events had made no difference to their confidence in connecting with others for support, and 2% ( $n=2/125$ ) disagreed. Again, this may be a plateau effect because parents have already gained confidence from attending previous events. However, in future, it would be useful to consider ways of helping parents who have not yet benefitted to increase their confidence.

One very promising finding was that over 90% ( $n=113/125$ ) of parents felt part of a community of people affected by cleft as a result of the events, with only 9% ( $n=11/125$ ) reporting no difference, and under 1% ( $n=1/125$ ) slightly disagreeing. Finally, 82% ( $n=102/125$ ) felt more able to support other families and individuals affected by cleft as a result of the events. Conversely, 17% ( $n=21/125$ ) reported

that the events had not made a difference to how able they were to support other families and individuals, and 2% ( $n=3/125$ ) did not feel more able as a result of the events. Again, an explanation for this may either be that parents have already developed skills from previous events which help them to support other families. Alternatively, it may be that the current events do not specifically target these skills.

Outcome 4 relates to the impact of the SRC Project on parents of children with CL/P.



<sup>1</sup>People includes children, young people and adults affected by cleft

**Outcome 4** – The evidence collected during Year Three demonstrates that the majority of parents (73%;  $n= 91/125$ ) have increased confidence in supporting their child who was born with CL/P as a result of attending the events. While this finding is very positive, 25% ( $n=31/125$ ) reported no difference as a result of the events, and 2% ( $n=3/125$ ) did not feel the events had made them more confident in supporting their child. Furthermore, 64% ( $n=79/124$ ) reported that the events had allowed them to gather new knowledge and information which would help them to cope with CL/P-related issues in a positive way, with 32% ( $n= 40/124$ ) reporting no difference and 4% ( $n=5/124$ ) reporting that the events had not increased their knowledge or allowed them to cope with cleft-related issues in a positive way. These findings are encouraging, however more could be done to make CL/P-related knowledge and information more readily available to parents, and to look at ways of improving the confidence of all parents who attend events. It may be that parents are reporting no difference because events have already helped them to gain a sound knowledge of CL/P-related information, however it is also possible that the events do not target this. Therefore, this is something which should be considered in future.

## Parents of children with CL/P: Summary and recommendations

The evidence gathered from parents during Year Three is promising with regard to the project outcomes. The project has continued to facilitate a support network between parents and families affected by CL/P, in order to create a supportive community. Additionally, the events have helped many parents feel more confident in accessing CL/P-related support. Overall, most parents feel more confident in supporting their child with CL/P-related challenges in a positive way, however there are still a significant number of parents who did not report this. Therefore, it is important to consider ways to support these parents whose needs are not being met with the current events. While there are currently some information-based events (e.g. Bumps and Babies) run by nurses and psychologists, it could be of added benefit to have psychologists and other health professionals at other, peer support-focussed, events (e.g. Happy Faces, Family Days) in order to help more parents increase their confidence, and access more specialist support and information.

In future, the SRC could:

- Continue to organise events for parents and collect data from as many parents as possible.
- Continue to tailor events to help parents gain CL/P-related knowledge and support their children with CL/P-related challenges in a positive way.
- Identify opportunities to collect more varied types of feedback, such as case studies/testimonials, in order to better document the longer-term impact of the SRC Project on parents.

## Additional Activities

In addition to the data presented above, which relate directly to the four main outcomes measured by the evaluation, it is important to note a number of other activities in which the SRC has been involved during the course of Year Three.

### 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 members of the general public and non-cleft specialist health professionals. The aim of these sessions is to indirectly improve families' experiences in healthcare and community settings.

Awareness-raising sessions first began during Year One, and specific Awareness Raising Event Feedback forms have since been developed 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 members of the community, such as school pupils, teachers, and health professionals, in order to better evaluate the broader impact of awareness-raising activities.

Over Years Two and 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 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 dentists. Positively, 92% ( $n=12/13$ ) reported having an 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. The dentists 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 impact of CLP and how my role as a dentist can help with diagnosis and importance of support etc. I can use my time to do a quick palate exam in babies to maybe impact a child's life by diagnosing"***

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

Finally, sessions were also run with 46 individuals from three community groups. Feedback, which was collected from 38 individuals, revealed that 90% ( $n=34/38$ ) of attendees felt that they had an 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 awareness and knowledge of CL/P and they enjoyed the content and format of the sessions:

***"The talk was very interesting and informative"***

***"Information given in an easy to understand way"***

***"Better informed of how cleft affects children and parents"***

## **Volunteer training sessions**

During Year Three, the SRC has carried out one-to-one induction sessions with a number of new volunteers. Additionally, a volunteer development training day, attended by one new volunteer and two existing volunteers, was held in November 2017. As a result of the training, all of the volunteers felt more confident in their role, and better able to support families and individuals affected by CL/P. Furthermore, two felt that they had gained useful and transferable skills as a result of the training. Volunteers commented that it was especially useful to learn phrases for communication and to develop their listening skills.

## **Cleft Awareness Week**

The SRC has been involved in Cleft Awareness Week (<https://www.clapa.com/about-us/what-we-do/awareness-week/>) which takes place in May. This aims to raise funds and awareness of CL/P in the local community and across the UK. The SRC also encouraged CLAPA members to sign up to the Glasgow Kilt Walk in order to raise money for CLAPA. A newspaper article about the CLAPA's involvement in the Kilt Walk can be found here: <https://www.dailyrecord.co.uk/news/local-news/irvine-schoolgirl-walks-23-miles-12479527>.

## Facebook page

During Year One, the SRC established a Scotland-specific CLAPA Facebook page, which provides a forum for people affected by CL/P and their families to connect and share details of upcoming events. During Year Three, the Facebook page has been regularly used to advertise local SRC events and share photographs from the events with its members. Encouragingly, the number of followers has risen, with 78 in Year One, 545 in Year Two, and 915 at the end of Year Three. This suggests that many individuals are interested in the region-specific work of CLAPA, and that social media is a useful tool for relaying information and advertising events.

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 the Cleft Lip and Palate Association. The study identified common topics of concern among adults born with cleft and parents of children born with cleft, 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 (in press, 2018). #CleftProud: A content analysis and online survey of two cleft lip and palate Facebook groups. The Cleft Palate-Craniofacial Journal, in press.*

## Grandparents study

Focus groups carried out by CAR in 2015 as part of the SRC project 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 explore this further, 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 an insight into the experiences and support needs of grandparents, and were used to make a number of recommendations to CLAPA. Firstly, to increase grandparents' access to information about CL/P and its treatment (using both online and paper formats). Secondly, to provide access to practical and emotional support; for example practical information (e.g. feeding using CL/P-specific bottles), advertising existing peer support networks to grandparents, giving grandparents the opportunity to fundraise and share their personal experiences for the benefit of others, and considering how grandparents who live in remote areas of Scotland might access this support. More information can be found in the full report: *Guest, E., Costa, B. Stock, N. M., McCarthy, G., Skinner, M., & McDonald, R. (2018).*

*CLAPA Regional Coordinators Project: Scotland. Report: The Psychosocial Impact of Cleft Lip and/or Palate on Grandparents. March 2018.* The findings of this study are also being written up for publication in an academic journal.

## Evaluation report summary

The findings documented in the Year Three Report demonstrate that the SRC project has continued to provide many opportunities for individuals and families affected by CL/P to meet with each other, and has created an important local support network for many people in Scotland. Further to this, the events have facilitated parents, children and young people in gaining CL/P-related support and to cope with CL/P-related challenges in a positive way. The third year has also brought about more opportunities for adults born with CL/P to meet locally. Finally, a number of additional activities have been implemented which have a broader impact on health professionals, community groups, schools and volunteers. Nonetheless, opportunities for improvement have also been identified. A full summary of the findings of this evaluation from Year Three is provided in Table 1.

The recommendations detailed within this report identify specific patient groups and outcomes which it may be beneficial for the SRC to focus on in future. Additional feedback from other key partners, such as related charities/organisations and NHS cleft teams, may also be beneficial.

During the final year of the evaluation, CAR has continued to manage and assess event feedback data, which has been collected from a significant number of individuals who have attended events. Further to this, data has continued to be collected from Awareness Raising Sessions and a supplementary report has been written, detailing the experiences and support needs of grandparents, living in Scotland, who are supporting a child affected by CL/P.

The quantity of data collected has increased during both Years Two and Three. This has enabled a more clear evaluation of the project in relation to its outcomes. However, data collected from adults born with CL/P remains sparse. Positively, however, opportunities to develop and expand services for adults are now available in the form of the Adult Services Coordinator (ASC).

### Additional points for Year Three

Year Three has highlighted various recommendations for the project.

Where possible, CLAPA could:

- Continue to collect event feedback from a representative sample of adults, children and young people, and parents who attend events.
- Continue to collect information about the date, location and number of attendees at events.

- Collect data regarding where attendees have travelled from in order to see whether individuals and families from specific areas of Scotland are less able to attend events.
- Work closely with the Adult Services Coordinator (ASC) to develop events for adults born with CL/P.
- Consider how activities can further build the confidence 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.
- Collect varied types of data in order to enrich the quality of the evidence and better understand the long-term impact of the project. This may include collecting data to look at the 'journeys' of individuals, rather than just assessing the outcomes on an event-to-event basis. Recommendations to this effect have been outlined in previous reports connected to the evaluation of CLAPA's regional services in England and Scotland.

<b>Table 1. Quantity of children and young people, adults, and parents/carers who reported meeting the key indicators of the evaluation during Year Three</b>			
<b>Outcomes</b>	<b>Beneficiary Group</b>	<b>Indicators</b>	<b>Evaluation Figures</b>
<b>1. People affected by cleft are better able to cope with their condition</b>	Children/ Young People	Children/ young people have learned new ways of coping with cleft-related issues in a positive way	33
		Children/ young people can offer help to other children and young people with a cleft	37
	Adults	Adults have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way	1
<b>2. People affected by cleft have increased confidence</b>	Children/ Young People	Children/ young people have increased confidence	41
	Adults	Adults feel more confident in connecting with other people for support with cleft-related challenges	1
<b>3. People affected by cleft feel less isolated</b>	Children/ Young People	Children/ young people have made friends who they can talk to about having a cleft	40
	Adults	Adults feel they are part of a community of people affected by cleft	1
		Adults have access to a local support network	1
		Adults know more people who have been affected by cleft	1
<b>4. Parents/carers of children with a cleft are better able to support their children with cleft-related challenges</b>	Parents	Parents/carers have increased confidence in supporting their child who was born with a cleft	91
		Parents/carers have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way	79
		Parents/carers feel more confident in connecting with other people for support with cleft-related challenges	99
		Parents/carers have access to a local support network	103
		Parents/carers know more people who have been affected by cleft	110
		Parents/carers feel they are part of a community of people affected by cleft	113



**Glasgow  
Children's  
Hospital  
Charity**

Continuing the care of  
Yorkhill Children's Charity



**LOTTERY FUNDED**



**Healthier  
Scotland**  
Scottish  
Government



**THE HUGH FRASER  
FOUNDATION**