



# CLAPA Regional Coordinators Project: Scotland Interim Report End of Year Two May 2017

## **Contributors:**

### Centre for Appearance Research (CAR):

Miss Ella Guest (Research Associate), Dr Nicola M. Stock (Research Fellow), Mr Matt Ridley (Research Associate), and Professor Nichola Rumsey (Centre Co-Director).

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

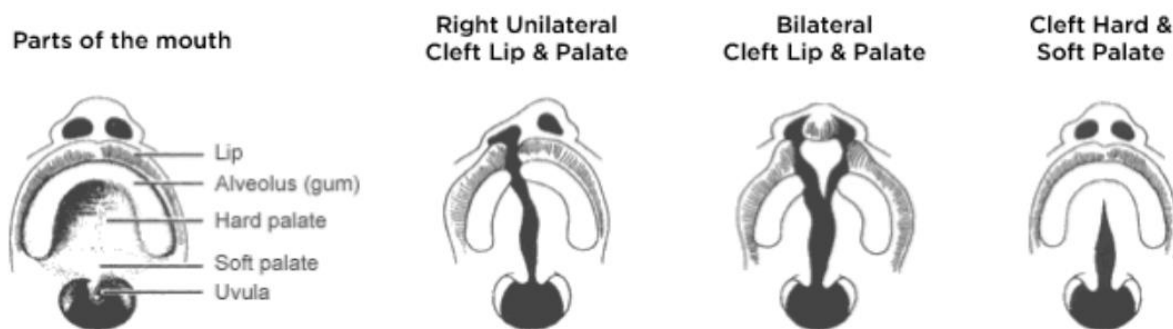
Ms Gillian McCarthy (Senior Scotland Regional Coordinator), Ms Melanie Skinner (Scotland Support Officer), Ms Rebecca McDonald (Scotland Support Officer), and Ms Claire Cunniffe (Deputy Chief Executive).

## Table of Contents

Glossary of Terms .....	2
Lay summary .....	4
Introduction.....	7
Scotland Region .....	10
Impact on children and young people .....	10
Impact on adults born with CL/P.....	14
Impact on parents of children with CL/P.....	16
Additional Activities .....	19
Evaluation report summary .....	21
Outcomes Overview Table.....	23

## 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. VTCTF 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 (or devolved country) and is responsible for increasing the diversity and frequency of local activity within that region/country.

**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.

**CLAPA Parent Supporters** – trained volunteers who can offer personal knowledge of the difficulties that can be faced by new and prospective parents of babies born with CL/P. The process for contacting a Parent Supporter can be found on the CLAPA website.

**CLAPA Peer Supporters** – Peer Supporters are trained volunteers who were born with a cleft themselves. The protocol for this service is the same as for Parent Supporters.

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

**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.

**Patient and Public Involvement (PPI)** - 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 the benefit from.

**CLAPA Awareness raising sessions/presentations** – 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 Lip and Palate 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

**Adult Meet-Up** - a new type of event, designed to give adults born with CL/P the opportunity to meet other adults born with CL/P.

## 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 (SRC) 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 Edinburgh Children's Hospital Charity, Glasgow Children's Hospital Charity, the Scottish Government Social Care Directorate 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 Scotland Support Officer, with the aim of improving local service provision for children, young people, and adults affected by CL/P and their families.





## Evaluation Findings in Year Two

- During Year Two, the SRC has continued to act as a key contact for people affected by CL/P and their families in the Scotland region.
- A large number of events aimed at families and young people have been held, 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 recommendation 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).

74 children / young people reported having increased confidence

153 parents learned how to cope better with cleft-related challenges

211 parents gained access to a local support network



Crieff Hydro, September 2016



Loch Lomond Shores, October 2016



Galloway, June 2016



Galloway, June 2016



Galloway, June 2016

The project has four main outcomes:

## 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

## End of Year Two 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, helps CLAPA to improve their services and develop evaluation methods over time, 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 Two report outlines evidence collected during the second year of the SRC project.

***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. Year One of this project ran from June 2015 to May 2016, and Year Two from June 2016 to May 2017.



## 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 funded by five different organisations. As a result, the outcomes above have been produced by CLAPA to cover the criteria of all five 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 Two. A similar report has been produced for Year One, and will be produced at the end of Year Three. Supplementary reports may also be 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 is currently being 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 both Year One and Year Two 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 supported part-time by Rebecca McDonald (Scotland Support Officer) while Melanie Skinner is on maternity leave.

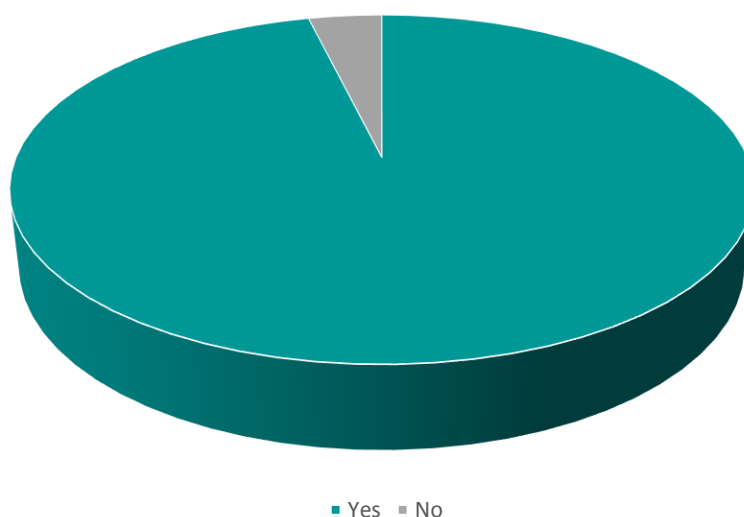
## Scotland Region

### Impact on children and young people

During Year Two of the SCR project, 114 children/young people attended events, and feedback was collected from a total of 84 of these children/young people (with 60 children reporting to be aged 11 or under, and 23 young people aged 12-17). Event feedback from children and young people was collected at nine events during Year Two. This included one Happy Faces event, two Scotland Children and Young People's Councils, three Older Kids Activities, one pantomime trip, and two Branch Christmas parties (held in Glasgow and Edinburgh).

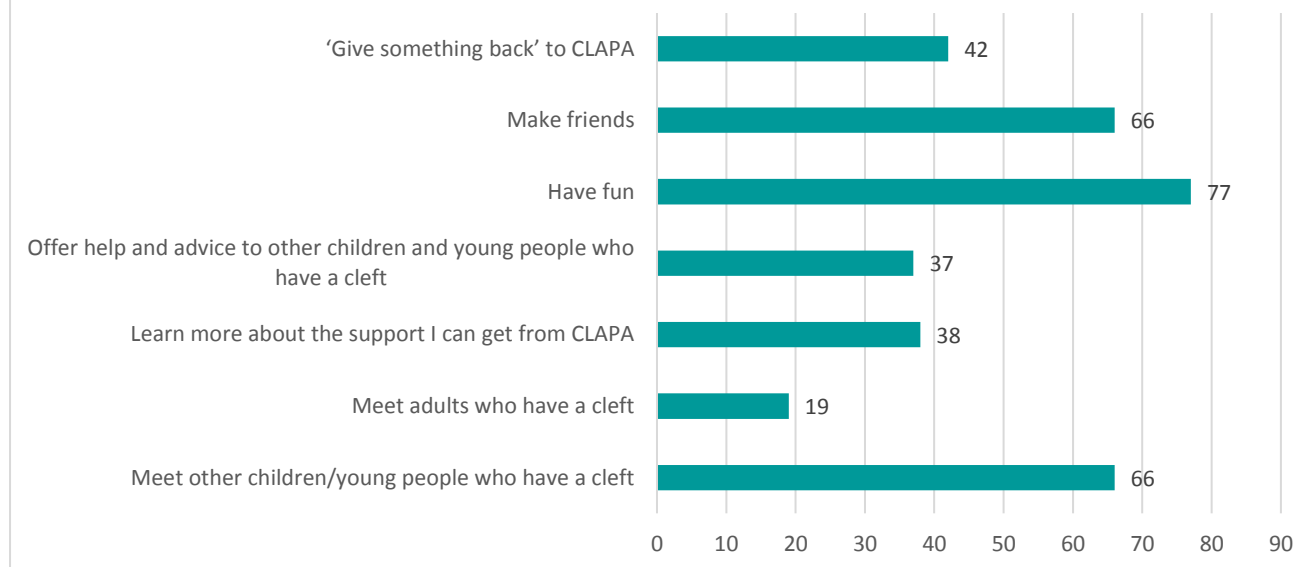
As can be seen in Figure 1, the vast majority (96.2%) of children and young people ( $n=76/79$ ) had attended CLAPA events before.

Figure 1. Have you attended a CLAPA Event before?



Children and young people were asked to indicate their reason(s) for attending these local events. In response, 91.6% of children and young people ( $n=77/84$ ) reported that they had attended to 'have fun', 78.6% ( $n=66/84$ ) to 'make friends' and 78.6% ( $n=66/84$ ) to 'meet other children and young people who have a cleft'. Additional information about reasons for attending events is detailed below, in Figure 2.

Figure 2. Reasons for attending CLAPA events



Children and young people listed a number of things which they enjoyed about attending events. Many mentioned that they most enjoyed being able to socialise, make friends and have fun at the events:

***"I enjoyed meeting new friends"***

***"Having fun with everyone"***

***"Playing and having fun"***

A number of children and young people also commented that they enjoyed the peer support they gain from attending events:

***"Being able to speak to other children with cleft lip and palate"***

***"The way in which I could relate to other children's experiences. Also, being able to voice my opinion"***

***"Meeting friends, getting support"***

Additionally, parents frequently commented that they enjoyed seeing their children having fun and making friends at the events:

***"Seeing children with cleft so happy"***

***"My daughter making new friends"***

***"My son loves all of the parties and met new friends who all have been through it as well"***

Parents also commented that the events made their children feel like they were part of a community:

***"Knowing she [daughter] is not alone"***

***"It's great for him [son] to see other kids with clefts and other differences so he doesn't feel alone"***

Ninety-five percent of parents ( $n=205/215$ ) reported that their son or daughter enjoyed the event they had attended. Moreover, 94% ( $n=78/83$ ) of children and young people agreed that they would like to attend similar events in the future.

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

## 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



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

The majority of children and young people (70.4%;  $n=57/81$ ) reported that they had learned new ways of coping with their condition as a result of the events, demonstrating a significant improvement from Year One. This evidence is promising, and suggests that the events are helping children and young people to develop their problem-solving and coping skills. However, 23.5% ( $n=19/81$ ) of children and young people response neutrally, and a small number (6.2%;  $n=5/81$ ) did not feel that they had learned new ways of coping. Additionally, 76.5% ( $n=62/81$ ) agreed that they could offer help to other children and young people as a result of the events, while 18.5% ( $n=15/81$ ) responded neutrally and 4.9% ( $n=4/81$ ) disagreed.

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

Almost 91.4% ( $n=74/81$ ) of children and young people felt that attending the local events had increased their confidence. Just over ten percent (8.6%,  $n=7/81$ ) responded neutrally to this question, and nobody disagreed. This evidence is in line with the Year One report, and suggests that the events are continuing to help many children and young people to feel more confident in themselves.

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

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 (81.5%;  $n=66/81$ ). Moreover, many parents commented that the events had enabled their children to make new friends who they could relate to. This feedback is consistent with the data collected during Year One, and suggests that children and young people as a whole feel less isolated as a result of SRC Project. However, 9.9% ( $n=8/81$ ) responded neutrally, and 8.6% ( $n=7/81$ ) disagreed with this statement, indicating that some opportunities may be being missed, or that case studies are required to demonstrate the longer-term impact.

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

Overall, the evidence collected from children and young people in regard to the SRC project has been extremely positive. Feedback has revealed the project to be especially helpful for children and young people to socialise, make new friends, and gain peer-support from other children and young people who are also affected by CL/P. A further key outcome of the events has been an increase in confidence among children and young people affected by CL/P.

During Year Three, the SRC should continue to organise events for children and young people, and collect feedback from as many attendees as possible.

Additionally, the SRC could:

- Organise activities which encourage children and young people to attend who have not attended a CLAPA event previously, particularly in more isolated areas of Scotland
- Organise activities for, and collect feedback from children and young people of all ages, and at all stages of the treatment pathway
- Consider additional ways of encouraging children and young people to engage with others affected by CL/P, and to form lasting friendships
- Consider how to tailor events in order to better target coping skills in children and young people
- 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

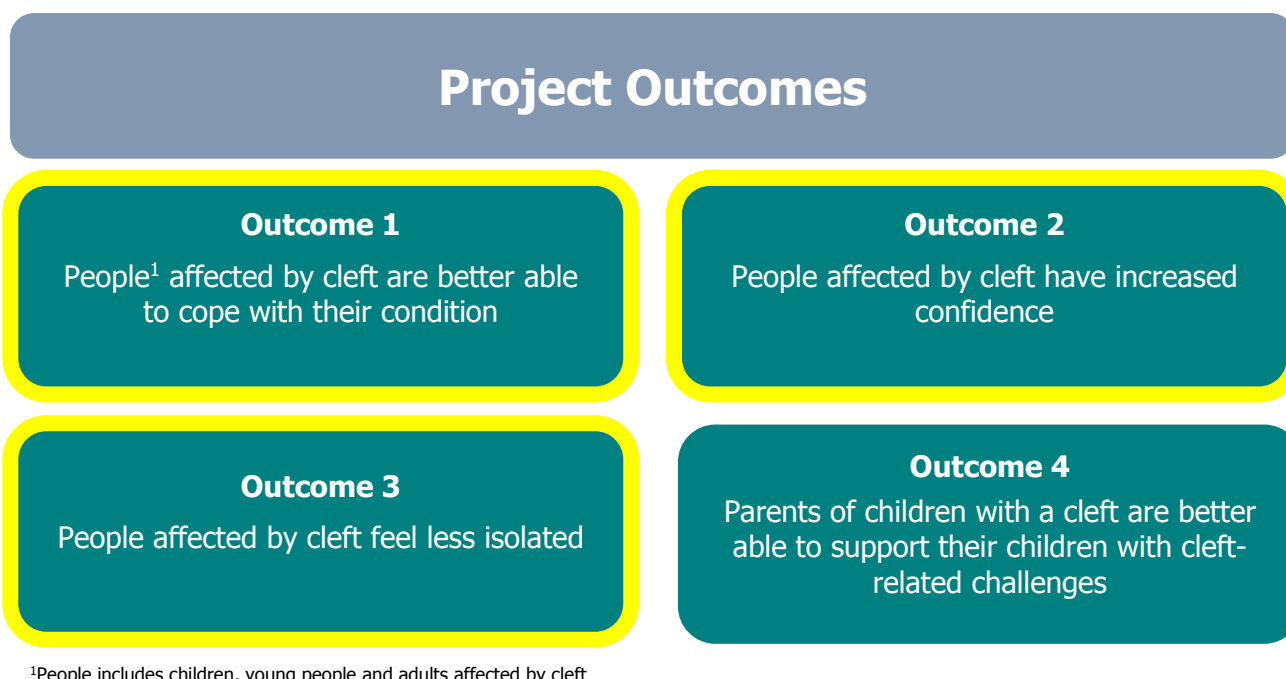
## Impact on adults born with CL/P

During year two an Adult Meet-Up was piloted in Aberdeen. The aim of this new initiative is to give adults who were born with CL/P the opportunity to meet other adults born with CL/P. These events will involve a group activity, followed by a social get-together. These events will be facilitated by CLAPA or a CLAPA volunteer.

At present, evidence gathered on the impact of the SRC Project on adults who were born with CL/P is sparse. Although a small number of adults have attended some of the events, this has often been because they are also parents of children with CL/P. During Year Two, only one adult with CL/P completed a feedback form (Adult Meet-up in Aberdeen).

This adult gave 'meeting other individuals and families affected by CL/P' as their reason for attending the event; commenting that it was "just to chat". Additionally, when asked whether they felt that they had more access to a local support network following the event, they reported 'no difference'. Moreover, they also purported 'no difference' when asked whether they felt part of a community of people affected by cleft following the event, and whether they had gathered new knowledge and information which helped them cope with cleft-related challenges in a positive way. However, they agreed that they would like to attend similar events in future. As this is a developing service, it is possible that longer-term effects will be seen, and therefore other forms of evidence, such as case studies, may be required to demonstrate this.

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



The feedback collected suggests that adults may not be gaining knowledge and skills to help them become more confident and cope with cleft-related issues in a positive way from attending events. However, it is not possible to draw firm conclusions, or state whether the outcomes are being met, from the very small amount of evidence collected.

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

Very little evidence has been gathered on the impact of the SRC project on adults affected by CL/P, making it difficult to summarise progress against the relevant outcomes. This is not unexpected, since the majority of CLAPA's services have historically been aimed toward new parents and young children, rendering services for adults as a comparatively young endeavour. Nonetheless, and although uptake for adults with CL/P is slightly higher for the RC Project in England, participation from adults born with CL/P remains low across the board. Events and support services specifically tailored to adults with CL/P should remain a broad priority for CLAPA.

Recommendations for Year Three are as follows:

- Organise further Adult Meet-Ups in order to engage adults who were born with CL/P.
- Consider whether type, format, and timing of events are suitable for adults with CL/P
- Increase efforts to arrange suitable events/groups for this patient group
- Continue to incorporate existing adult services (currently being developed and trialled in England) into Scotland (e.g. the Peer Supporters Service).

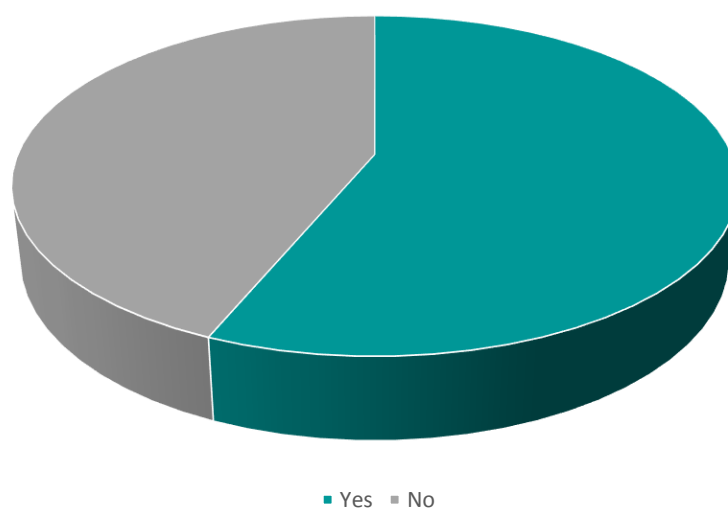
- Identify opportunities to collect more varied types of feedback, such as case studies/testimonials, in order to better document the longer-term impact of the SRC Project on children and young people

## Impact on 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 Two, six types of events have been held. These include Happy Faces groups (held in Edinburgh, Glasgow and Aberdeen;  $n=9$ ); Branch Christmas Parties (held in Edinburgh and Glasgow;  $n=2$ ); a Glasgow branch pantomime trip; an Edinburgh Branch Picnic; an Older Kids Activity; and five Family Days. A total of 308 parents attended 20 events as part of the SRC project during Year Two. Overall, 229 feedback forms have been collected from parents who attended these events.

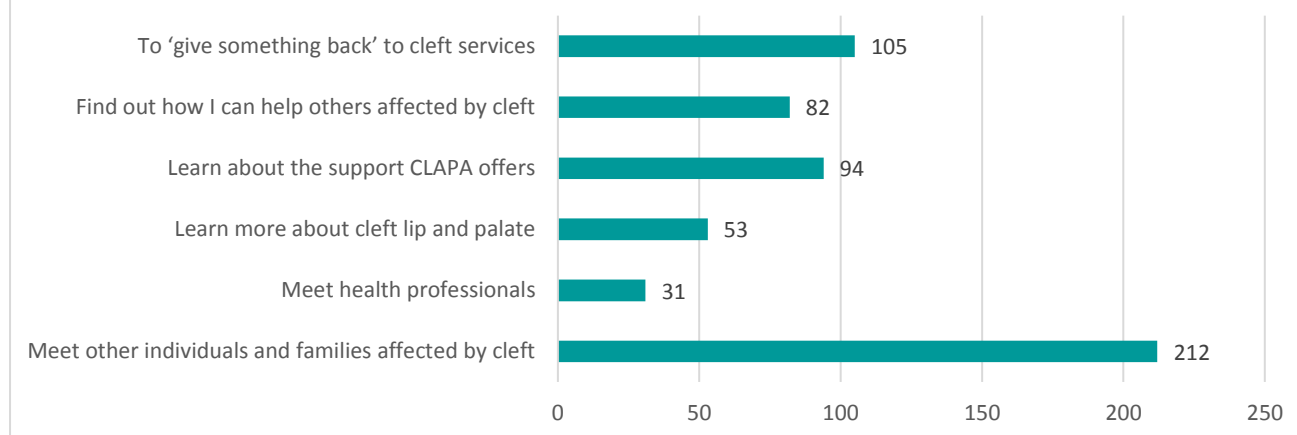
As can be seen in Figure 3, just over half of these parents (56.3%) had attended one or more previous CLAPA events ( $n=125/ 222$ ).

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 92.6% of parents, was to 'meet other individuals and families affected by cleft' ( $n=212/229$ ). In addition, almost half of parents (45.9%) attended events in order 'to give something back to cleft services' ( $n=105/229$ ) and 41% of parents attended in order to 'learn about the support CLAPA offers' ( $n=94/229$ ). More information regarding parents' reasons for attending local events is detailed below, in Figure 4.

Figure 4. Reasons for attending CLAPA events



Parents commented on several aspects of the events that they had particularly enjoyed. One common theme was being able to speak to other families affected by CL/P:

***"Speaking with the other parents and hearing their experiences"***

***"Chatting informally with other parents"***

***"Getting to socialise and meet others in a similar situation"***

***"Meeting CLAPA staff and parents"***

Other positive comments related to the organisation and content of the event itself:

***"Fantastic awareness raising"***

***"Catered for all ages"***

***"Well organised event"***

When asked how the events could be improved in future, a small number of parents had suggestions:



***"Keep changing event locations"***

***"Make events more regular"***

***"More advertising"***

Almost 98.7% of parents ( $n=221/224$ ) agreed that they would like to attend similar events again in future.

When asked whether they felt that they had more access to a local support network as a result of these events, 91.3% of the parents ( $n=211/231$ ) reported that this was the case, with 8.7% reporting no difference ( $n=20/231$ ). Similarly, 94.2% of parents ( $n=194/206$ ) felt that they knew more people who have been affected by CL/P as a result of the events, with only 5.8% ( $n=12/206$ ) reporting that the events had not made a difference. Eighty-nine percent of parents ( $n=185/208$ ) agreed that the events had made them feel more confident in connecting with other people for support with cleft-related challenges, with only 11.1% ( $n=23/208$ ) reporting 'no difference'.

Ninety-five percent of parents ( $n=190/201$ ) agreed that they now felt part of a community of people affected by cleft, with only 5.5% ( $n=11/201$ ) reporting 'no difference'. Finally, 87.2% of parents ( $n=198/227$ ) agreed that the events had made them feel more able to offer support to other families and individuals affected by CL/P. Nonetheless, 11.9% ( $n=27/227$ ) felt that the events had made no difference, and 0.9% ( $n=2/227$ ) felt that the events had not helped them in this regard.

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

## 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

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

The evidence collected during Year Two demonstrates that most parents (78.1%;  $n=160/205$ ) have increased confidence in supporting their child who was born with CL/P as a result of attending the events. This finding is very encouraging; however, 21.5% ( $n=44/205$ ) reported that the events had made no difference to their ability to support their child with cleft-related issues, and 0.5% ( $n=1/205$ ) disagreed. Similarly, 68% ( $n=153/225$ ) of parents reported that they had gained knowledge about CL/P which would help them cope with cleft-related challenges in a more positive way. Yet, 31.6% of parents ( $n=71/225$ ) felt that the events had made no difference to this outcome, and a small number of parents (1.8%;  $n=4/225$ ) reported that the events had not helped in this area.

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

Overall, the feedback from parents collected during Year Two has been positive. The SRC project has continued to facilitate connections between parents of children affected by CL/P. As a result, many parents have reported feeling that they have better access to local support, are more confident in connecting with others for support, and feel that they are part of a supportive community.

On the whole, parents also believed that the SRC Project had increased their confidence in supporting their child with CL/P and their ability to deal more effectively with any cleft-related issues. However, a considerable proportion of parents indicated that this was not always the case, suggesting that Outcome 4 has not been fully met during Year Two.

During Year Three, the SRC could:

- Consider ways of meeting Outcome 4 more effectively
- Continue to organise, and collect data from events targeted at parents throughout the year
- 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 Two.

## Awareness raising sessions

During Year One and Two, the SRC has continued to organise awareness-raising sessions/presentations. While not directly related to the project outcomes, these sessions are designed to increase general knowledge of CL/P and related issues. The aim of these sessions is to improve families' experiences, increase their support network, and enhance their ability to cope with cleft-related challenges.

Awareness-raising sessions first began during Year One, and specific Awareness Raising Event Feedback forms have been developed and trialled during Year Two; 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 members of the community, in order to better evaluate the broader impact of awareness-raising activities. Data is currently being collected using these forms, and the evidence gathered will be presented in an interim report specifically focused on awareness-raising activities during Year Three.

## Volunteer training sessions

The SRC has also supported two training sessions for nineteen CLAPA volunteers during Year Two. Half of the attendees had attended CLAPA training previously. The main reasons for attending the training events were to 'find out how I can help others affected by cleft' (77.8%), 'to give something back to cleft services' (72.2%), and to 'learn about the support CLAPA offers' (66.6%). All attendees ( $n=19/19$ ) reported feeling more confident as a volunteer following the sessions, and 94.7% ( $n=18/19$ ) agreed that they had gained useful and transferable new skills. Additionally, 89.5% ( $n=17/19$ ) felt more able to support other families and individuals affected by cleft as a result of the sessions.

## Cleft Lip and Palate Awareness Week

The SRC has been involved in Cleft Lip and Palate Awareness Week (6th-14th May 2017), which aims to raise funds and awareness of CL/P in the local community and across the UK.

## 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 Two, 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 from 78 during Year One, to 545 at the end of Year Two; suggesting that many individuals are interested in the work of CLAPA, and that it is a useful media for relaying information.

Further to this, there are also Facebook pages for North East Scotland, Edinburgh, Glasgow, and the Happy Faces events.

## 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.

To address this, CAR is currently carrying out a qualitative study with grandparents, as part of the SCR project, to explore the impact of having a grandchild with CL/P, and to investigate the kind of support services which may be beneficial for grandparents. This study has been reviewed and approved by the Regional Coordinators Advisory Panel. The findings of this study will help to improve provisions to provide support for grandparents in Scotland, and may form the basis of similar research in the rest of the UK.

## Evaluation report summary

This evaluation report, documenting Year Two of the SRC project, has demonstrated significant progress toward the project outcomes. A number of benefits for parents, children and young people, as well as a broader impact from the project's additional activities, is evident. Nonetheless, some opportunities for improvement have been identified. A full summary of the findings of this evaluation from Year Two is provided in Table 1.

The recommendations detailed within this report identify specific patient groups and outcomes which the SRC may want to focus on during Year Three of the project. Additional feedback from other key partners, such as related charities/organisations and NHS cleft teams may also be beneficial.

During Year Two of the evaluation, CAR has continued to manage and assess event feedback data, which has been collected from a much greater proportion of events this year. In addition to this, CAR has created Awareness Raising feedback forms to be used within the SRC project, and is currently undertaking a qualitative study to look at the support needs of grandparents who are supporting a child affected by CL/P.

Although the quantity of data collected has increased during Year Two, data from adults affected by CL/P remains sparse. Across the board, CLAPA may wish to give particular consideration to the type, format and timing of events for adults born with CL/P.

## Additional points for Year Three

The second year of the SRC project has highlighted a number of key learning points, which CAR and CLAPA would like to take forward into Year Three.

Where possible, CLAPA could:

- Continue to collect feedback from as many events as possible during Year Three

- Send event feedback to CAR as soon as it is collected
- Continue to provide CAR with information about the date, location, and number of attendees at each event
- Support CAR in understanding where attendees have travelled from
- Collect testimonials and case studies, which will enrich the quality of data and provide an understanding of the longer-term impacts
- Meet with CAR to discuss the optimal plan for data collection during the final year of the SRC Project

Where possible, CAR will:

- Continue to hold monthly phone meeting with the Scotland RC
- Input feedback from events onto a database in a timely manner, and ensure that the RC has the most up-to-date version of the database



## Outcomes Overview Table

**Table 1. Quantity of children and young people, adults, and parents/carers who reported meeting the key indicators of the evaluation**

Outcomes	Beneficiary Group	Indicators	Evaluation Figures	Percentage achieved
<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	57	70.4%
		Children/ young people can offer help to other children and young people with a cleft	62	76.5%
	Adults	Adults have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way	0	0%
<b>2. People affected by cleft have increased confidence</b>	Children/ Young People	Children/ young people have increased confidence	74	91.4%
	Adults	Adults feel more confident in connecting with other people for support with cleft-related challenges	0	0%
<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	66	81.5%
	Adults	Adults feel they are part of a community of people affected by cleft	0	0%
		Adults have access to a local support network	0	0%
		Adults know more people who have been affected by cleft	0	0%
<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	160	78.1%
		Parents/carers have gathered new knowledge and information which will help them to cope with cleft-related issues in a positive way	153	68%
		Parents/carers feel more confident in connecting with other people for support with cleft-related challenges	185	88.9%
		Parents/ carers feel more able to offer support to other families and individuals affected by CL/P.	198	87.2%
		Parents/carers have access to a local support network	211	91.3%
		Parents/carers know more people who have been affected by cleft	194	94.2%
		Parents/carers feel they are part of a community of people affected by cleft	190	94.5%

