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CLAPA Regional Coordinators Project: Scotland

Evaluation Interim Report

End of Year One

May 2016

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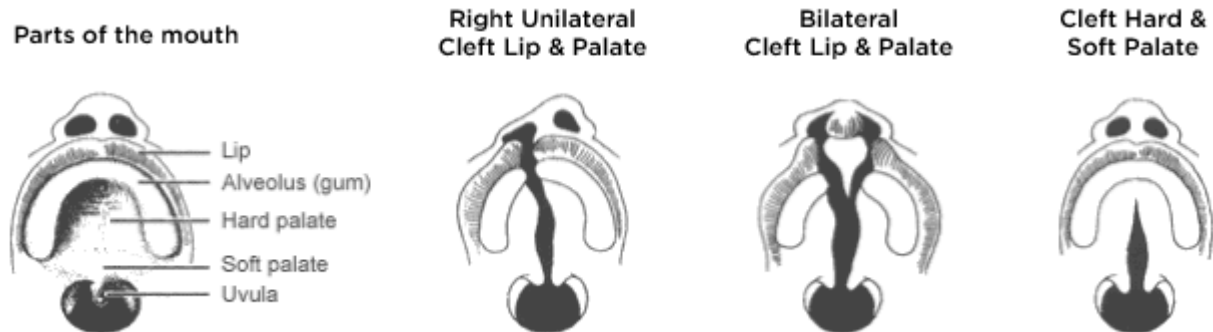
All those who contributed to the Regional Coordinators Project evaluation, including feedback respondents and focus group participants.

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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 (VTCT) – VTCT 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.

CLAPA Parent Contacts – trained volunteers who can offer personal knowledge of the difficulties that can be faced by new parents of babies born with CL/P. Contact details for Parent Contacts are provided on the CLAPA website. Parents can get in touch directly, or can ask CLAPA to approach a Parent Contact on their behalf.

CLAPA Peer Contacts – Peer Contacts are trained volunteers who were born with a cleft themselves. This is a new initiative by CLAPA but will follow similar protocols as Parent Contacts.

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.”

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). Patient representatives play an active role in shaping the services the benefit from.

CLAPA Awareness raising sessions/presentations – sessions/presentations to Health Professionals, 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.

CLAPA Regional Coordinators Project: Scotland Evaluation Interim Report (End of Year One, May 2016)

Lay summary

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. Following the success of the Regional Coordinators Project in England, the Cleft Lip and Palate Association (CLAPA) obtained 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, with the aim of improving local service provision for children, young people and adults affected by CL/P and their families. The main outcomes for this project are as follows:

Outcome 1: People¹ 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

The Centre for Appearance Research (CAR), based at the University of the West of England in Bristol, was commissioned to conduct an independent evaluation of the project. This evaluation 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.

During Year One, the SRC has established herself 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 several awareness-raising activities. Recommendations have been made for an increase in services for adults born with CL/P, as well as for activities aimed more specifically at increasing individuals' knowledge of CL/P and their ability to cope with any related challenges. The SRC has also been closely involved with the Cleft Surgical Review in Scotland and Cleft Awareness Week (7th-14th May 2016).

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 Matthew.Ridley@uwe.ac.uk, Nicola2.Stock@uwe.ac.uk or Claire.Cunniffe@clapa.com.

¹ People includes children, young people and adults affected by cleft

Introduction

Background and project rationale

A cleft in the lip and/or palate (CL/P) is the most common congenital craniofacial condition, affecting approximately one in 700 live births per year in the UK. For most parents, the 'diagnostic event' is an emotionally demanding experience, and families often express a number of concerns. Complex multidisciplinary care continues throughout the child's lifespan, 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 functioning. Although for most individuals the treatment pathway ends when they reach the age of 18 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 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 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 is already provided by CLAPA's network of local branches, significant gaps and limitations in this service has been observed. In addition, the amount of branches across the UK is decreasing, due to insufficient numbers of volunteers. As a result, some regions only have one branch, and other regions are no longer provided for.

In 2010, CLAPA obtained funding from the Vocational Training Charitable Trust (VTCT) to pilot a full-time Regional Coordinator in the East of England for one year. This project was piloted in 2011-2012 in the East of England and was evaluated by the Centre for Appearance Research (CAR) 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 runs from June 2015 to May 2016.

Project Outcomes

The CLAPA Regional Coordinators Project in Scotland has four key outcomes which CAR is independently evaluating:

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

The CLAPA Regional Coordinators Project in Scotland is funded by six different organisations. As a result, the outcomes above have been produced by CLAPA to cover the criteria of all six 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 One. A similar report will be produced for Years Two and Three. Supplementary reports may also be provided throughout the duration of the project.

Data was predominantly collected using the measures provided by CAR, as well as through other methods where appropriate. Copies of these measures 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.

An additional interim report is included as an attachment to this report, entitled 'Inverness Focus Group Study Report'.

Review of cleft surgical services in Scotland

It is important to note that during the course of the project's first year, an official review of cleft surgical services in Scotland by the National Services Division (NSD) has been ongoing. As a result of this review, a proposal has been made for a significant change in these services. Specifically, surgical activity will be reduced from two sites (Glasgow and Edinburgh) to one site (Glasgow) in the near future. A public consultation phase is currently coming to a close before these recommendations are finalised. 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, spending a considerable amount of time 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.

Scotland region

The Regional Coordinators Project intends to cover the whole of Scotland². Gillian McCarthy has been in post as the SRC since 1st September 2015 and is supported by Melanie Skinner (Scotland Support Officer) on a part-time basis. Data collected during Year One are presented below.

Impact on children and young people

The SRC held four events aimed specifically at young people (aged 10-17) over the course of Year One. Feedback was collected from two of these events. Seven young people attended the activity in Glasgow, while four attended the other in Aberdeen. Most of the young people attending said that they had attended CLAPA events before. When asked why they attended, the majority of young people responded with 'to meet other children/young people who have a cleft' and 'to make friends'. Similarly, when asked what they most enjoyed about this event, the following responses emerged as the most common:

- "Meeting new friends"
- "Socialising with other children"

The majority of respondents said they felt they could talk with these new friends about having a cleft and associated issues. When asked whether they felt that they could offer help to other children and young people with cleft as a result of the event, most responded positively. Some, however, did respond neutrally to this question. The response was more mixed when young people were asked whether they had learned new ways of coping with problems in a more positive way - as many young people responded by disagreeing, or by stating that they were not sure, as did agreed. However, the majority of children that attended this event described feeling more confident about themselves as a result.

The SRC also collected feedback from thirteen children/young people at a Pantomime in Glasgow. Similar to the above, when asked why they attended this event the majority of young people responded 'to meet other children/young people who have a cleft', 'to make friends' and 'to learn more about the support I can get from CLAPA'. Similarly, 'meeting up with friends who have a cleft' was a common response to the question, 'what did you enjoy most about this event?' Furthermore, the majority of children stated that they had made friends that felt they could talk to about having a cleft. When asked whether they felt that they would be able to offer help to other children and young people with a cleft after going to this event, the responses were split between 'agree a lot/agree a little' and 'not sure'. The response was similar when asked whether they had learned new ways of coping with problems in a positive way at this event. However, the majority of young people did state that they felt more confident after attending this event.

Two Christmas parties were held during Year One; one in Aberdeen and one in Edinburgh. The SRC gathered feedback from 37 children and young people who attended these parties. The most common reasons children/young people gave for attending included:

² Note that some organisations have contributed funding for use in specific regions of Scotland only, while others have contributed funding intended for use across the whole of Scotland.

- 'To meet other children/young people who have a cleft'
- 'To make friends'

Similarly, when asked what they enjoyed the most about the event, most responded that the best thing was meeting other people affected by CL/P. The majority stated that they had made friends at this event that they could talk about having a cleft with. In addition, most stated that they felt more capable of offering help to other young people with cleft after attending this event. The response was more mixed when asked whether they had learned new ways of coping with cleft-related problems in a positive way at the event, with as many feeling that they had as were unsure. The response was similar when asked whether the event had improved the confidence of the children, although, many (n = 11) did state feeling more confident as a result.

All parents responded positively when asked about any positive or negative effects the event had on their child, including (for example):

- "Socialising with other kids"
- "Mixing with other children of all ages"
- "It has helped my child to develop her self-confidence"
- "Seeing others who have had a similar pathway"
- "Sense of normality in case they thought they were different to others"
- "Very good for daughter to meet others affected by cleft"

During Year One, CLAPA held an official launch party for the Scotland RC Project. Parents who attended this event provided feedback regarding the impact the event had on their child(ren). Responses included the following:

- "My son is due an operation in a week's time and speaking to others that have gone through this already helped build confidence"
- "Always important for my son to have the opportunity to meet other cleft affected children in a fun/upbeat environment"
- "Brings people together to share experiences"
- "Great for [my son] to be with other children without having to explain his cleft"

Summary – impact on children and young people (relevant outcomes)

Overall, feedback was generally positive in terms of the impact which the SRC project is having on the children and young people that are involved. In particular, the opportunities the project is providing for young people with cleft to socialise, to meet others affected by cleft, and to have fun "without having to explain" their cleft consistently emerged.

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

Responses were mixed when asking young people whether they had learned new ways of coping with cleft-related problems in a positive way. This could suggest that problem-solving and coping skills are not a direct aim of the events held this year, that this is a difficult question for young people to answer, and/or

that increases in young people's ability to cope are not seen until later. Since this is a key part of Outcome 1, CAR and CLAPA should think about other possible ways of capturing this.

Outcome 2 – People affected by cleft have increased confidence

Predominantly, children and young people who attended one of these events described feeling more confident as a result. Parent feedback was also supportive of this outcome having been achieved.

Outcome 3 – People affected by cleft feel less isolated

Overall, children and young people reported that CLAPA's regional activities had allowed them to meet new people, to make new friends, and to share stories and experiences of having CL/P. This suggests that children and young people feel less isolated as a result of these activities, and demonstrates the potential of such events to facilitate social support networks.

Recommendations – children and young people

The SRC has arranged a high number of events aimed at children and young people over the course of the first year, and has collected a considerable amount of evidence over a relatively short period of time. The recommendation is therefore to continue to arrange similar events that provide the opportunity for children and young people affected by cleft to get together, socialise and support each other.

In addition, the SRC could:

- Consider organising activities that might provide more direct opportunities for learning (i.e., new ways of coping with cleft-related challenges) and/or:
- Acquire more varied types of feedback. For example, case studies may provide richer and more personal data in relation to the longer-term impact upon children and young people.
- Continue to support activities which cover all age groups, particularly in the more isolated regions.
- Collect as high a volume of feedback as is possible.

Impact on parents

The SRC has supported the organisation of existing Happy Faces groups, and has recruited, trained and supported parents to establish new groups in several areas of Scotland, including Edinburgh, Fife, Glasgow and Aberdeen. A group in Skye is also being set up currently. Although Happy Faces group meetings had taken place in some of these areas prior to the commencement of the RC project, these meetings had been sporadic and unmonitored. The SRC has gathered feedback from two Happy Faces group meetings (both in Glasgow) from eleven parents of children with CL/P. When asked why they attended the meetings, the majority of parents responded with 'to meet other individuals and families affected by cleft'. Other common responses included 'to learn more about the support CLAPA offers' and 'to give something back to cleft services'. All parents that attended reported feeling they have access to a local support network, and that they now know more people affected by cleft as a result of the Happy Faces meetings. The majority (n = 9) of the parents that attended these Happy Faces group meeting(s) felt they were part of a cleft community as a result. In addition, most (n = 10) felt more confident in connecting with other people for support with cleft-related challenges, and most (n = 7) had greater confidence in supporting their child. The response of the parents was more mixed when asked whether they gained new knowledge and information

that will help them to cope with cleft-related issues in a positive way, with half (n = 6) stating that they had, and the other half (n = 6) reporting no difference.

The SRC also collected feedback data from one Bumps and Babies group. Comments from parents on what they enjoyed most about the event included the following:

- "The unity of families"
- "Chatting with other parents and kids with cleft"
- "Loved talking to other parents"
- "Meeting other families and peers"

All (n = 5) of the parents that attended the Bumps and Babies group reported that as a result of the group, they now have access to a local support network, know more people affected by cleft, feel part of a community affected by cleft, and are more confident in connecting with other people for support with cleft related challenges. In addition, the majority of parents that attended felt more confident in supporting their child, were more able to support other families and individuals affected by cleft, and felt they had gathered new knowledge and information that would help them to cope with cleft-related issues in a positive way.

The SRC also collected parent feedback (n = 18) from the CLAPA Scotland launch event. When asked what they enjoyed the most about this event, responses included:

- "It was great meeting other families affected by clefts"
- "Finding out plans for Scotland"
- "Parents telling their stories and experiences"
- "Speaking to other cleft Mums"

Fifteen of the parents that attended reported feeling they now have access to a local support network, and are more able to support other families and individuals affected by cleft. Eleven parents felt they had increased confidence in supporting their child, and seventeen report having gathered knowledge and information that will help them to cope with cleft related issues in a positive way.

Data from parents was also gathered from two Christmas parties, one held in Edinburgh and the other in Aberdeen. When asked why they attended, the most common responses included:

- 'To meet other individuals and families affected by cleft'
- 'To learn about the support CLAPA offers'

When asked what aspects of the event they enjoyed the most, responses included:

- "Opportunity for kids to meet other kids affected by cleft"
- "Meeting other families/parents"
- "Children integrating with other children who share different or similar experiences in life"
- "Community spirit"

The majority of parents reported feeling that they have access to a local support network as a result of attending one of these events (26/38), although, the rest reported no difference. Findings were similar in relation to whether parents felt more able to support others affected by cleft from attending the event,

with many responding that they do (25/38), while others reported no difference. Responses from parents were more mixed when asked whether the event allowed them to gather information that will help them address cleft related issues in a positive way, with nearly as many (n = 14) responding with no difference as did that stated they had (n = 20). Neutral responses appeared to be due in part to parents' involvement with CLAPA prior to these events.

The SRC collected feedback from 11 parents following a pantomime visit in Glasgow. When asked why they attended this event, the majority stated this was to meet other families affected by cleft. Several parents reported no difference (n = 7) in response to the question of whether they feel they have access to a local support network, with a minority feeling more connected as a direct result of this event (n = 4). Similarly, when asked whether they felt more able to support others affected by cleft, just over half of parents responded with 'no difference' (n = 6). In addition, when asked whether they have gathered more information that will help them to address cleft-related issues in a positive way, most parents reported no difference (n = 7), with one parent disagreeing, and 3 parents feeling that they had gathered such information.

The following feedback was gathered from one parent that attended one of the activities aimed at young people, alongside their child (in the form of an email):

"Just want to take this opportunity to say thank you to [the SRC], CLAPA and anyone else who had an input into making today happen. My daughter and I really enjoyed meeting everyone. Speaking from a parent's perspective I found the experience very positive. Being able to talk with other parents who all have a deep understanding of our kids' journey was a learning experience".

Summary – impact on parents (relevant outcomes)

Predominantly, feedback has been positive in terms of the opportunities which the RC project is providing for parents to connect with other parents of children affected by cleft. However, feedback is more mixed in terms of the events providing information and/or strategies that help them to address cleft-related challenges, as well as to support others affected by cleft. This may be related to the type of events held so far, in that some of these activities (e.g. attending social events such as a pantomime) are unlikely to directly provide such opportunities for learning.

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

As yet, it is difficult to conclude with certainty whether parents of children with cleft are better able to support their children with cleft related challenges as a result of the RC project. As mentioned, parent responses have been predominantly mixed as to the opportunities the events are providing for learning new information and/or strategies to help support their child. Nonetheless, these types of events clearly provide the opportunity for parents of children with cleft to get together and share experiences, from which some may be able to learn from others.

Recommendations

In order to work towards this outcome the SRC could look to:

- Organise activities that might provide opportunities for parents to learn new information and/or strategies to support their child, as well as:
- Acquiring more varied types of feedback. For example, case studies may provide richer data in relation to the longer-term impact upon parents.
- Continue to support the development of new and existing Happy Faces groups.
- Continue to support the Bumps and Babies groups.

Impact on adults born with CL/P

To date, evidence gathered on the impact of the SRC Project on adults who were born with a cleft is limited. A small number of adults have attended some of the events, but this has tended to be because they are also parents of children with a cleft. No events have been organised to specifically target this patient group to date.

Of the small amount of feedback collected from adults at these events, the most common reason for their attendance was 'to meet other individuals and families affected by cleft'. When asked whether they feel they have access to a local support network as a result of the events, responses were positive. Most reported feeling more confident in connecting with other people for support with cleft-related challenges, and feeling part of a community. In addition, most felt more able to support other individuals and families affected by cleft. The response was more mixed when asked whether they had gathered new knowledge and information to help them to cope with cleft-related challenges in a positive way, with some reporting no difference.

Summary – impact on adults born with CL/P (relevant outcomes)

Little evidence has been gathered on the impact of the RC project on adults affected by cleft, making it difficult to summarize against the relevant outcomes. Nonetheless, this is not unexpected and is in line with progress toward developing adult services in other regions of the UK. The majority of CLAPA's services have historically been aimed toward new parents and young children; hence services for adults is a comparatively young endeavour.

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

From the small amount of data retrieved, at this point it is difficult to state whether or not this outcome is being met. More evidence is required.

Outcome 2 – People affected by cleft have increased confidence

From the small amount of data retrieved it is difficult to state whether or not this outcome is being met. However, the early signs are that confidence is being improved through bringing together individuals with cleft and providing them with the opportunity to share experiences.

Outcome 3 – People affected by cleft feel less isolated

From the small amount of data retrieved it is difficult to state whether or not this outcome is being met. Similarly, the early signs are positive in that adults that attended events/groups reported feeling part of a community, and therefore potential is there for helping adults affected by cleft to feel less isolated.

Recommendations

The SRC's work in the Scotland region has thus far focused on children, young people and parents in relation to events, support groups and evidence gathering. Going forward, the SRC could look to target adults affected by cleft as well, and to collect associated evidence of impact. Recommendations are as follows:

- Increase efforts to arrange events/groups for adults affected by cleft.
- Consider how to begin incorporating existing adult services (currently being developed and trialled in England) into Scotland (e.g. Peer Contacts).
- CAR to work with the SRC on how to best capture evidence in relation to adults affected by cleft.

Additional activities

In addition to those data presented above which relate directly to the outcomes measured by the evaluation, it is important to note a number of other activities in which the SRC has been involved. The SRC has supported the delivery of a number of awareness raising sessions/presentations aimed at increasing awareness of CLAPA in the local community. For example, talks have been given by CLAPA volunteers to various community groups, a group of cleft nurses (Glasgow), and a group of student health visitors (based at The University of the West of Scotland).

Although not directly linked to the outcomes of this project, such work targeting Health Professionals (HPs) is important. At the time of diagnosis and for some time afterwards, families are likely to come into contact with sonographers, midwives, paediatricians, health visitors, General Practitioners and other HPs who are unlikely to be cleft specialists. Later on, families affected by cleft often see a variety of health professionals, particularly if complications should arise and in relation to a range of cleft-related issues, such as feeding, breathing, speech, hearing and dental difficulties. Therefore, awareness raising sessions may be useful in improving the knowledge of non-specialist HPs, and in turn improving families' experiences and ability to cope throughout their journey.

The SRC collected data from student health visitors who attended an awareness raising talk at the University of the West of Scotland (n = 39). All of the student health visitors reported feeling more able to support families and individuals affected by cleft as a result of this event.

In the future, CAR may work with CLAPA to better evaluate the impact of additional activities, such as these awareness raising sessions.

The SRC was also involved in Cleft Awareness Week (7th-14th May 2016) which aims to raise funds and awareness of CL/P in the local community and across the UK.

Finally, the SRC has established a Scotland-specific Facebook page, which provides a forum for people affected by CL/P and their families to connect and share details of upcoming events. There are currently 78 members.

Evaluation report summary

This evaluation report has outlined the considerable progress made towards the outcomes of the RC Project during Year One. This is in spite of the SRC being new to the role, the project being in its infancy, and the impact of the Cleft Surgical Review. As could be expected, more progress has been made within specific patient groups compared to others. The recommendations detailed throughout this report identify particular patient groups and outcomes which the SRC could focus more attention on going forward into Year Two. Additional feedback from other key partners, such as related charities/organisations and NHS cleft teams may also be beneficial.

In terms of the evaluation itself, CAR spent much of the first year providing training and support to the SRC in relation to the collection of evidence, as well as on redesigning data collection tools in line with the various outcomes across the RC Project as a whole. Another large aspect of this year's evaluation was to conduct focus groups in the Scotland region. Since the SRC had already carried out two focus groups (with CAR's input) prior to the submission of funding applications, only one further focus group study was deemed necessary to collect a suitable amount of data. Further, although the SRC did not start in post until September, the financial year began in June. As a result, the evaluation for Year One is underspent. Discussions as to how this underspend could be utilised with be carried out with CLAPA and the various funding organisations.

A report of the focus group study carried out by CAR in Inverness is provided as an attachment to this main evaluation report. Additional recommendations provided by this report should be considered when planning future activities. Details of the original two focus groups may be obtained from CLAPA upon request.

Additional points for Year Two

The first year of the Scotland RC project has highlighted a number of key learning points, which CAR and CLAPA would like to take forward into Year Two.

Where possible, CLAPA will:

- Provide CAR with figures in relation to the number of attendees at each event.
- Provide CAR with information about which location the event took place in (and thus which funder(s) the data relate to).
- Support CAR in understanding where attendees have travelled from.

Including a cover sheet (see version previously provided by CAR) when sending data by post may be a helpful way to achieve these aims.

Where possible, CAR will:

- Organise monthly phone calls with the Scotland SRC which are separate from those carried out with the RCs working in England.
- Introduce more structure to these monthly phone calls.

