

Stronger together: Collective endeavours of a cleft and research organisation to promote the role of young people affected by a cleft in research



S.Tierney¹, N. Stock², R. Preston³, C. Cunniffe³

¹ University of Warwick (formerly at the Cleft Collective) ² Cleft Collective (<http://cleftcollective.org.uk/>) ³ Cleft Lip and Palate Association (<http://www.clapa.com/>)

Introduction

About 1 in 700 babies are affected by a cleft lip and/or palate (CL/P), which can result in the need for surgery, dental treatment, speech therapy and help with hearing.

The Cleft Collective is the world's largest cleft lip and palate research programme, with teams in Bristol and Manchester.

Since its inception in 2012, the Cleft Collective has had close links with the Cleft Lip and Palate Association (CLAPA).

CLAPA is a national charity that provides support and information to people with a CL/P and their relatives/friends.

For researchers, working with CLAPA has the advantage of reaching over 4500 members who are part of the charity.

CLAPA has several groups that meet face-to-face on a regular basis, including a Children and Young People's Council (CYPC).

The CYPC is composed of approximately a dozen members aged 9-18 from across the UK; all have personal experience of a CL/P.

It holds meetings every 3 months.

The Cleft Collective has consulted with this group on several occasions and received valuable feedback that has been used to shape its research.

Objectives

To consider how best to involve young people with a CL/P in designing, developing, delivering and disseminating research through Patient and Public Involvement (PPI).

Method

At a CYPC meeting in May 2014 we talked to the group about issues relating to involving young people in research.

Written notes were taken of what was said during a 1 hour discussion.



The CYPC hard at work on tasks to help them talk about involving young people in shaping research on cleft lip and/or palate

Results

Several activities were carried out on the topic of involving young people in shaping research. Four key areas were discussed during the meeting:

1. What does research mean to you?

Members tended to mention negative terms in relation to research:

- Costly
- Boring
- Science
- Independent study assignments

2. What are the barriers and potential solutions to involving young people with a CL/P in research?

The group was invited to list potential obstacles to engaging young people in PPI activities.

They were also asked to note potential solutions.

Both are listed in Figure 1.

Barriers	Solutions
People might be embarrassed about sharing information	Skype / internet based / social media – less formal
Location of meetings	Central England (in the middle) London (good transport links) Relaxed environment – where you feel at home University – mature, professional feel
Time (e.g. clashing with exams)	August is a good time
Young people may not understand the technical language	“Dumb it down” / layspeak Training – jargon buster (glossary of terms) Written information should not exceed 2 sides of A4 and include pictures and bullet points

FIGURE 1: Barriers and solutions to PPI for young people

3. What might young people want to get out of being involved in shaping a study?

Predefined gains were listed on squares by one of the authors and taken to the meeting.

Members of the CYPC were also given the opportunity to list their own gains – they added ‘fun time’.

They then ordered the ‘gains’ they would expect from PPI activities, which are listed in Figure 2.

Better research on the topic of cleft was placed as the top gain and knowledge of what research involves came at the bottom.

The group disagreed about the importance of payment; some members said this was imperative, whilst others said knowing they were helping make research better was enough.

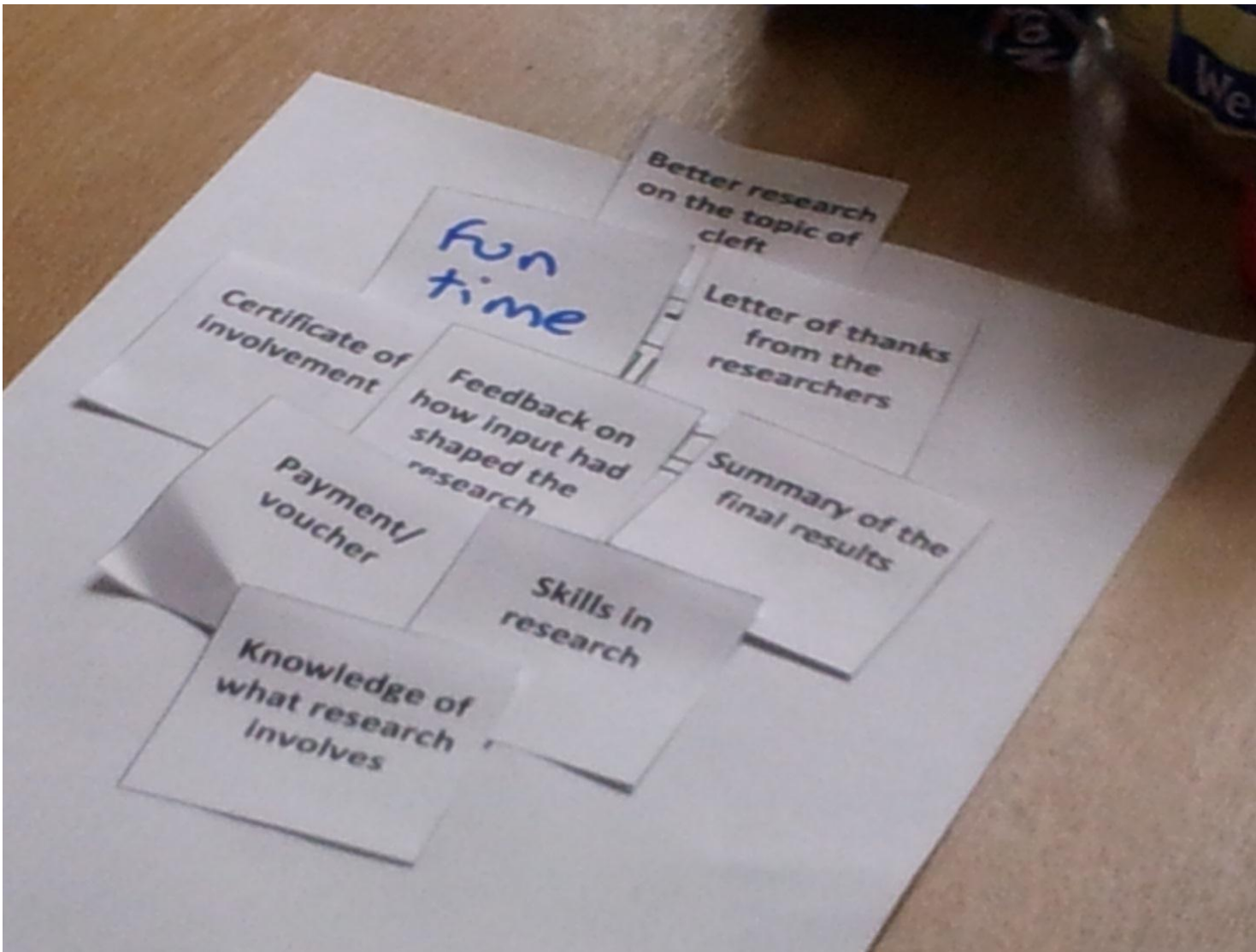


FIGURE 2: Gains in order of importance for the young people

4. What skills do young people bring to research projects?

Young people were asked to list skills they had that could be used to help researchers shape a project.

They were also asked what skills they would need to develop to be effective PPI partners.

Existing skills that were mentioned included: questionnaire design using Survey Monkey, interviewing for media projects, use of PowerPoint and Prezzi at school, interpreting graphs/charts and personal experience.

Skills they said they might need to be develop included: overcoming nerves when engaged in public speaking and research vocabulary.

Conclusions

- Recognition for their input was important for group members, although this need not be monetary.
- Technology was listed as a skill that young people brought to research.
- It was suggested that good ways to communicate with young people included Skype, Face Time and Google Chat.
- Perceptions of what research is and what it involves could be a barrier to involving young people in PPI work.
- They could also be put off if too much research jargon is used in communication about PPI activities.

We would like to thank the young people who helped us with developing the content for this poster