

## FIVE YEARS ON – SURVEY REPORT

2010 – 607 completed survey, inc. 177 paper surveys

2015 – 735 completed survey inc. 112 paper surveys

### ABOUT YOU

#### CONNECTION TO CLAPA

	2010 Survey	2015 Survey	Change
Adult with a cleft (18+)	16.3%	15.60%	-0.7%
YP with a cleft	5.5%	2.6%	-2.9%
Parent of child 0-4 yrs	23.4%	29.69%	+6.29%
<b>Parent of child 5-17 yrs</b>	<b>35.6%</b>	<b>34.06%</b>	<b>+6.94%</b>
<b>Parent of child 18+</b>		<b>8.48%</b>	
Cleft Health/Research Prof	15.9%	3.69%	-12.21%
Other Health/Research Prof	5.9%	1.92%	-3.98%
Other friend/family member	4.8%	7.39%	+5.4%
OTHER		1.78%	

#### GENDER

	2010 Survey	2015 Survey	Change
Male	15.6%	17.08%	+1.48%
<b>Female</b>	<b>84.4%</b>	<b>82.1%</b>	<b>-2.3%</b>
Other	-	0.82%	-

#### ETHNICITY

	2010 Survey	2015 Survey	Change
<b>White British</b>	<b>87.2%</b>	<b>89.3%</b>	<b>+2.1%</b>
White Other	6.5%	5.62%	-0.88%
Black or Black British	1%	0.55%	-0.45%
Asian or Asian British	1.7%	1.78%	+0.08%
Mixed	1%	0.82%	-0.18%
Other Ethnic Group	0.5%	0.69%	+0.19%
Rather Not Say	2.2%	1.23%	-0.97%

#### AGE RANGE

	2010 Survey	2015 Survey	Change
Under 18	2.2%	4.64%	+2.44%
18-25	11.1%	6.69%	-4.41%
26-30	9.5%	10.4%	+0.9%
<b>31-40</b>	<b>34.4%</b>	<b>29.23%</b>	<b>-5.17%</b>
<b>41-50</b>	<b>25.8%</b>	<b>28.96%</b>	<b>+3.16%</b>
51-60	12%	12.84%	+0.84%
61-70	3.5%	4.1%	+0.6%

71+	1.4%	2.05%	+0.65%
Rather not say		1.09%	-

#### APPROXIMATE ANNUAL INCOME (excl. benefits or government assistance)

	2010 Survey	2015 Survey	Change
Below £15,000		13.4%	
£15,000 - 24,999		14.52%	
<b>£25,000 - £34,999</b>		<b>14.66%</b>	
£35,000 - £49,999		15.21%	
£50,000 - £70,000		13.69%	
Above £70,000		12.31%	
Don't know / rather not say		16.46%	

#### UK REGION

	2010 Survey	2015 Survey	Change
Central England		13.7%	
East of England		9.32%	
North East England		8.49%	
North West England		10.96%	
Northern Ireland		1.64%	
Scotland		9.59%	
<b>South East England</b>		<b>27.12%</b>	
South West England		9.73%	
Wales		4.25%	
None – ROI		0.27%	
None – outside of UK & Ireland		1.23%	
Don't Know		3.70%	

### CLAPA LOCAL

#### ARE YOU INVOLVED WITH YOUR LOCAL BRANCH?

	2010 Survey	2015 Survey	Change
YES – I volunteer with my Branch	5.9%	8.03%	+2.13%
YES – I have attended Branch events	12.9%	11.68%	-1.22%
NO – Would consider it	15.5%	23.21%	+7.71%
NO – Would like to, no local Branch	9%	11.24%	+2.24%
NO – Was involved, Branch inactive	-	3.50%	-
NO – Not interested	3.9%	7.59%	+3.69%
NO – Not relevant to me	5.5%	4.23%	-1.27%
NO – Didn't know about Branches	21.7%	16.2%	-5.5%
NO – Other reason	10.5%	14.31%	+3.81%
Don't know (if I'm a 'Branch member')	12.1%	-	-

**DO YOU ATTEND A HAPPY FACES GROUP?**

	2010 Survey	2015 Survey	Change
YES – regularly		0.88%	
YES – not regularly		3.08%	
NO – would consider it		14.81%	
NO – not relevant to me		14.96%	
NO – not close enough		11.44%	
<b>NO – didn't know about these</b>		<b>35.04%</b>	
NO – not interested		8.5%	
NO – other reason		11.29%	

**DO YOU KNOW WHO YOUR REGIONAL COORDINATOR IS?**

	ALL RESPONSES	REGIONS WITH RCs
YES	20.71%	25.49%
NO – Have one, not sure who	16.57%	17.16%
<b>NO – Not sure if we have one</b>	<b>60.21%</b>	<b>56.13%</b>
N/A – We don't have one	2.51%	1.23%

**DO YOU THINK CLAPA's MOVE TOWARDS MORE REGIONAL SUPPORT HAS BEEN SUCCESSFUL?**

	ALL RESPONSES	REGIONS WITH RCs
YES	20.18%	20.05%
YES, but not in my area	10.16%	8.31%
Somewhat successful	11.63%	13.2%
No	7.36%	6.85%
<b>Not Sure</b>	<b>50.66%</b>	<b>51.59%</b>

**DO YOU THINK IT'S IMPORTANT FOR CLAPA TO HAVE A LOCAL PRESENCE?**

	2010 Survey	2015 - ALL	Change	2015 - RCs
<b>YES</b>	<b>88.8%</b>	<b>91.16%</b>	<b>+2.36%</b>	<b>91.22%</b>
NO	1.8%	1.33%	-0.47%	1.22%
DON'T KNOW	9.3%	7.51%	-1.79%	7.56%

**CLAPA NATIONAL**

**ARE YOU A MEMBER OF CLAPA NATIONAL (2010) / DO YOU CONSIDER YOURSELF TO BE PART OF THE CLAPA COMMUNITY (2015)?**

	2010 Survey	2015 - ALL	Change	2015 - RCs
<b>YES</b>	<b>47.8%</b>	<b>50.3%</b>	<b>+2.5%</b>	<b>52.12%</b>
NO	27.7%	27.66%	-0.04%	27.76%
NOT SURE	24.5%	22.04%	-2.8%	22.11%

### DO YOU RECEIVE REGULAR CONTACT FROM CLAPA?

	2010 Survey	2015 Survey	Change
<b>Yes – regular e-newsletters</b>		<b>46.61%</b>	
Yes – local e-mailings		23.45%	
<b>Yes – CLAPA News</b>		<b>46.31%</b>	
Yes – from CLAPA Staff Member		6.49%	
Yes – social media		27.29%	
Not sure		3.39%	
No		12.68%	

### WHY JOIN CLAPA?

	2010 Survey	2015 Survey		Change
		Priority	Score	
To be kept up to date about the latest developments in cleft lip and palate	1	1	249	
To get support from others affected by cleft	-	2	222	
Support CLAPA as an organisation	2	3	218	
To get information about NATIONAL events & activities	5	4	214	
To receive CLAPA News and/or e-newsletters	2	5	210	
To be a part of a cleft community	-	6	204	
To get information about LOCAL activities and events	5	7	194	

### WHY NOT JOIN CLAPA?

	2010 Survey	2015 Survey	Change
Didn't know I could join CLAPA	63.7	47.95%	-13.75%
Not interested	6.5%	8.19%	+1.69%
Doesn't seem relevant to me	21%	14.62%	-6.38%
Don't want to receive e-mails or magazines	12.1%	1.17%	-10.93%
Other		28.07%	

### ARE THERE ANY OTHER CLAPA COMMUNITY BENEFITS YOU THINK WE SHOULD PROVIDE MEMBERS?

	2010 Survey	2015 Survey	Change
No		16.4	-
Not Sure		72.99	-
Yes		10.61	-

## RESPONSES

- More information/resources
- More activities/resources/involvement for adult/older children
- More information/resources for speech therapy

### WOULD IT AFFECT YOU PROFESSIONALLY/PERSONALLY IF CLAPA CEASED TO EXIST?

	2010 Survey	2015 Survey	Change
Yes	58%	42.81%	+12.73%
A Little		27.92%	
No	22%	17.94%	-4.06%
Don't Know	20%	11.34%	-8.66%

### WOULD YOU CONSIDER PAYING AN ANNUAL SUBSCRIPTION FEE FOR CLAPA NEWS?

	2010 Survey	2015 Survey	Change
Yes - £5		15.3%	-
Yes - £10		4.57%	-
Yes - £15		0.63%	-
Yes - £20		1.89%	-
Yes – but voluntary		36.44%	-
No – shouldn't be a fee		25.24%	-
No- not interested in CLAPA news		5.52%	-
No – should be sent to anyone making a regular donation		5.52%	-
Don't know about CLAPA News		4.89%	-

### RANK CLAPA'S ACTIVITIES IN TERMS OF HOW IMPORTANT THEY ARE TO YOU (1 most, 7 least)

	2010 Survey	2015 Survey	2015 ONLINE
Promoting parent & patient involvement with cleft research	7	6	7
Raising awareness of cleft	3	3	3
Emotional support (parent/peer contacts)	4	1	2
Providing information	5	4	4
Campaigning to improve NHS services	2	5	5
Practical support services (e.g. feeding)	1	1	1
Activities & events for people affected by cleft	6	7	6

## 2015 - WHAT DOES CLAPA DO WELL? WHAT SHOULD CLAPA IMPROVE?

	DOES WELL	SHOULD IMPROVE
<b>Communication with the public (raising awareness of cleft and CLAPA)</b>	<b>43.19%</b>	<b>55.36%</b>
Communication with our community/membership	38.89%	21.46%
Representing people affected by cleft	60.57%	21.24%
Acting on feedback from our community	17.56%	17.6%
Supporting mothers	55.91%	22.10%
Supporting fathers	38.71%	21.46%
Supporting adults with cleft	29.93%	22.32%
Supporting children & young people	49.28%	28.11%
Supporting other friends & family members	20.43%	20.60%
Information about cleft	69.35%	21.67%
Feeding service (bottles & teats)	71.68%	18.45%
National Events (e.g. conference)	31.00%	11.8%
Regional & local events (e.g. sponsored walks, parties)	27.24%	27.9%
Fundraising support	33.51%	18.24%
Volunteer Support	20.79%	18.67%

## 2010 - WHAT SHOULD CLAPA PROVIDE IN THE FUTURE?

- Info about treatment options
- Cleft-related products to buy, wider range of bottles
- Advice on benefits and financial aid
- DVDs and video info
- Offer support directly to parents who get starter packs – keep in touch
- Advice/helpline
- Half day seminars with experts

## 2010 – WHAT SHOULD CLAPA IMPROVE?

- Greater public awareness
- More local events
- Publicise our plans more
- Emotional support
- Narrowing activities down to be more focused
- Better activities for children

## WHICH CLAPA SERVICES HAVE YOU (OR YOUR CHILD) EVER USED OR ACCESSED?

	2010 Survey	2015 Survey	Change
Buying Feeding Equipment	58%	59.79%	+0.79%
Free Welcome Pack for new parents	42.8%	46.44%	+3.66%
Information leaflets (printed)	74.2%	58.01%	-16.19%
Website	85%	71.35%	-13.35%
CLAPA News magazine	73.7%	58.54%	-15.16%
CYP Residential Weekends/ day activities	15%	4.27%	-10.73%
CLAPA Conference	12.8%	10.14%	-2.66%

Family activity days	24.8%	16.19%	+16.12%
Local social or fundraising events by CLAPA		24.73%	
Training from CLAPA	-	10.14%	-
Local, face-to-face support	27.8%	11.03%	-16.5%
Remote support (Parent/Peer Contacts)	23.6%	8.9%	-14.7%
Adult-specific support	15%	3.74%	-11.26%

## THE NHS

### HAVE YOU HAD ANY PROBLEMS ACCESSING ANY ASPECT OF CLEFT CARE OVER PAST 5 YEARS?

	No Problems		Some Problems			Didn't Know		Didn't Need	
	2010	2015	2010	2015 Minor	2015 Major	2010	2015	2010	2015
Surgery	79.6	71.27	4	8.66	2.39	0.9	0.37	8.3	17.31
<b>Speech &amp; Language Therapy</b>	<b>64</b>	<b>58.94</b>	<b>8.5</b>	<b>11.13</b>	<b>4.74</b>	<b>1.3</b>	<b>0.91</b>	<b>18.3</b>	<b>24.27</b>
<b>Orthodontics</b>	<b>64.4</b>	<b>60.26</b>	<b>3.8</b>	<b>8.69</b>	<b>2.03</b>	<b>2</b>	<b>2.22</b>	<b>21.3</b>	<b>26.8</b>
<b>Psychology</b>	<b>33.3</b>	<b>40.72</b>	<b>3.6</b>	<b>6.06</b>	<b>1.89</b>	<b>15.7</b>	<b>11.17</b>	<b>36.5</b>	<b>40.15</b>
<b>Audiology</b>	<b>68.2</b>	<b>59.66</b>	<b>3.6</b>	<b>8.82</b>	<b>3.00</b>	<b>4</b>	<b>3.56</b>	<b>15.2</b>	<b>24.95</b>
<b>Genetic Counselling</b>	<b>34.7</b>	<b>36.58</b>	<b>5.6</b>	<b>5.45</b>	<b>1.95</b>	<b>20.8</b>	<b>14.79</b>	<b>29</b>	<b>41.25</b>
Dental Care	70	61.83	5.1	10.83	4.04	4	1.83	13.9	21.47
Paediatrician	62	53.17	2.2	3.84	0.96	4.5	4.8	21.3	37.24
Referral to Cleft Service	70.9	68.03	3.6	5.2	2.6	5.3	2.42	12.3	21.75
Cleft Nurse Specialist	68.4	63.97	3.8	5.51	2.39	8	3.86	13.4	24.26
Diagnosis of Cleft Palate	59.7	54.91	9.6	6.42	6.23	3.3	1.13	17	31.32
Returning to Treatment as an Adult	14.3	20.31	3.8	5.08	2.34	6.7	4.69	60	67.58
Accessing information about the treatment pathway	64.9	51.53	3.8	8.78	4.39	11.6	9.16	9.8	26.15