

## Clubfoot in low and middle income countries: Snapshot 2011

### Background

One of the aims of Global Clubfoot Initiative is to collect and share information on the global picture of clubfoot, what services are available for children born with clubfoot and where.

Most reports estimate that between 160,000-200,000 children are born with clubfoot each year around the world, with 80% (128,000-160,000) of these in low and middle income countries (LMIC). To our best knowledge there is no other organisation that collects and shares information on services available for these children, although individual Ministries of Health may collect country level data.

Two previous pieces of work provided baseline data: a report on a 2007-2009 10 country collaborative initiative and a report on 20 countries in 2009.

In 2012, GCI decided to update this information with another round of data collection for 2011, and to update this regularly. The aims of collecting the data were:

- Capture and collate data in order to estimate how much of the need for services for children born with clubfoot is being met globally
- To map what services are available for children with clubfoot in LMIC and provided by whom
- To enable sharing of information between organisations and individuals involved in providing treatment for children with clubfoot

### Methods

For the purposes of this report the majority of data was collected from NGOs that were partner organisations of GCI, or from contacts provided by them. This was not meant to exclude those that were not part of GCI but reflected the capacity within GCI to carry out this survey and also the willingness and ability of other stakeholders to collect and share information.

The data were collected by survey using an 'Information Gathering Form'. This was emailed to all participants and they were asked to fill in as much information as possible and return it for collating. However, most organisations used their own data collection methods and many replied by submitting data in the format in which they had collected it. Thus it was not possible to consistently collect data on any but the most basic of parameters. These were organised by country:

- Organisations working to provide services for children with clubfoot
- Numbers of children enrolled for \*treatment in 2011

\*Treatment defined as: Ponseti method as treatment of first choice. It is not known how many children went on to receive surgical treatment.

Those who replied were a mixture of:

- International NGOs; many of whom were supporting national programmes for clubfoot in multiple countries
- Regional NGOs
- Country level NGOs
- Individual doctors or practitioners working on a regional or country level

A full list of respondents can be found in Appendix 1.

Where two or more organisations were working in the same country they were asked to clarify whether the data they provided was likely to overlap and any duplicated data was corrected.

## Results

Twenty two NGOs or individuals, known to be working in 56 countries were contacted asking them to provide data. Of these thirteen responded, giving data from 30 low and middle income countries.

### Number of children enrolled for treatment by country, 2011

Continent	Country	Number of children enrolled for treatment in 2011
Africa	Burundi	136
Africa	DRC	343
Africa	Eritrea	95
Africa	Ethiopia	753
Africa	Ghana	710
Africa	Kenya	680
Africa	Malawi	843
Africa	Niger	75
Africa	Rwanda	501
Africa	Sierra Leone	111
Africa	Togo	72
Africa	Uganda	718
Africa	Zambia	494
Africa	Zimbabwe	150
<b>Africa total</b>		<b>5681</b>
Asia	Afghanistan	653
Asia	Bangladesh	2631
Asia	Cambodia	124
Asia	India	2003
Asia	Laos	157

<b>Asia</b>	Nepal	321
<b>Asia</b>	Solomon Islands	33
<b>Asia</b>	Vietnam	110
<b>Asia total</b>		<b>6032</b>
<b>South America</b>	Brazil	90
<b>South America</b>	Dominican Republic	179
<b>South America</b>	El Salvador	47
<b>South America</b>	Guatemala	6
<b>South America</b>	Haiti	137
<b>South America</b>	Honduras	109
<b>South America</b>	Mexico	40
<b>South America</b>	Nicaragua	50
<b>South America total</b>		<b>658</b>
<b>Total</b>		<b>12,181</b>

A total of 12,181 children were enrolled for treatment in the 30 countries for which data were provided.

### Expected numbers of cases

For each country, the expected numbers of cases were calculated using the following formulae:

- $(\text{Total number of babies born}^*/1000) \times 1.2^{**} = \text{Expected number of babies with clubfoot}$

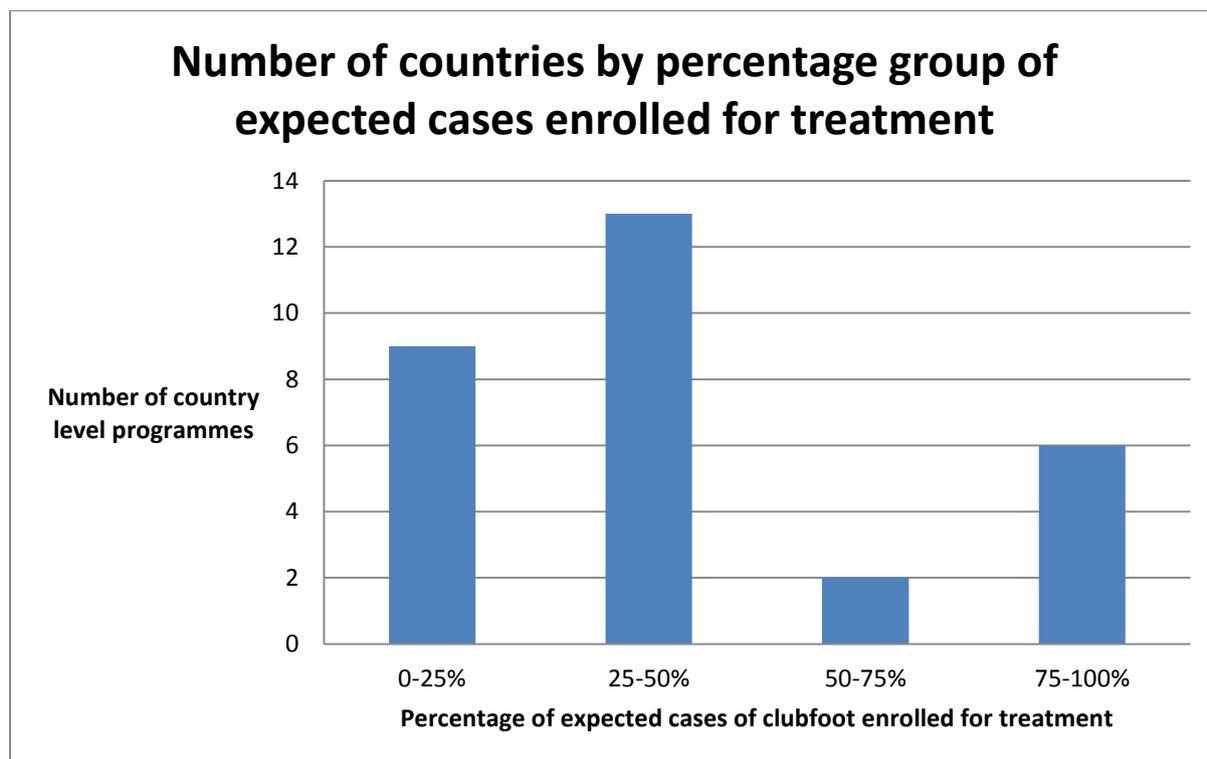
\*Total number of babies born calculated using CIA Factbook Data for 2011  
 \*\*1.2/1000 is the most widely accepted estimate of the incidence of clubfoot worldwide

The data for percentage of expected cases enrolled by country is included as Appendix 2.

Overall, across the thirty countries the percentage of expected cases enrolled was 19%. This reflected programmes at various stages of development, with some reaching up to 100% of expected cases and others only a small percentage of the population.

In order to measure the reach of the country-level programmes we broke the percentage of expected cases enrolled into treatment down into 4 groups: 0-25%, 25-50%, 50-75% and 75-100%.

Across all thirty programmes, the majority (13) enrolled between 25-50% of the expected number of cases for treatment in 2011. One fifth (6) of the country level programmes enrolled between 75-100% of expected cases of clubfoot into treatment.



**2011 data compared with 2009**

Data on numbers of children enrolled for treatment were also collected in 2009. The table below shows numbers of children treated in each of the countries surveyed where data were available for both 2009 and 2011.

Continent	Country	Number of children enrolled 2009	Number of children enrolled 2011
Africa	DRC	203	343
Africa	Ethiopia	616	753
Africa	Ghana	282	710
Africa	Kenya	691	680
Africa	Malawi	590	843
Africa	Niger	17	75
Africa	Rwanda	554	501
Africa	Uganda	733	718
Africa	Zambia	434	494
Asia	Afghanistan	78	653
Asia	Bangladesh	181	2631
Asia	Cambodia	203	124
Asia	India	203	2003
Asia	Laos	78	157
Asia	Nepal	469	321
South America	Dominican Republic	383	179

<b>South America</b>	Haiti	267	137
<b>South America</b>	Honduras	203	109
<b>Total</b>		<b>6185</b>	<b>11,431</b>

For the 18 countries where data on numbers of children enrolled were available for both 2009 and 2011 the total number enrolled for treatment increased by 5246 over the two years – an increase of nearly 85%. The greatest increases were seen in India and Bangladesh – both countries with rapidly expanding country level programmes for clubfoot.

## Discussion

In 2011, the 30 country-level programmes for which data were submitted enrolled more than 12,000 children, or approximately 8-10% of expected cases of clubfoot in all low and middle income countries for treatment. This represented 19% of expected cases across 30 countries. These data represent reported cases only and it is acknowledged that in many of the countries reported on there may be individual practitioners or programmes that were not included in the survey treating children with clubfoot. Thus, the true numbers of children enrolled for treatment both in the 30 countries and worldwide are likely to be substantially higher.

Comparisons with data collected in 2009, for the 18 countries where this was available showed that numbers of children enrolled for treatment had increased by nearly 85% over the two year period. The majority of this increase was seen in countries with rapidly expanding country level programmes such as India and Bangladesh. In some countries, numbers enrolled decreased over two years. This may reflect several factors:

- Reduction of an initial ‘backlog’ of cases presenting for treatment where new services are made available
- Reduction in effectiveness of country-level programme
- Other unexplained factors, such as natural disaster (possibly an explanation in Haiti)
- Data errors, incomplete data set for 2009

However, most country level programmes did not substantially decrease numbers enrolled indicating that across 2 years there was sustained provision of, and demand for, services.

The reach of programmes included was measured by grouping countries by percentage of expected cases enrolled. The majority (22) reached less than 50% of expected cases. This is likely to be due to 3 factors:

- New programmes, growing but not yet fully reached potential, particularly in countries with very large populations such as India
- NGOs supporting and reporting on a small number of individual practitioners rather than aiming to provide a country wide programme
- Full data set for country not collected

Programmes that reached more than 75% of expected cases made up 20% of the 30 countries surveyed. These tended to be countries with smaller populations that were known to have longer standing, more established national programmes for clubfoot in place.

Overall, the data gathered by this survey show that progress has been made in addressing the global burden of disease caused by clubfoot. Country level programmes with varying degrees of NGO support can be effective in providing treatment for clubfoot, and the number of children accessing these is increasing rapidly. However, the numbers of children in LMIC receiving the treatment they need remains low and therefore efforts must be sustained and increased on a global level in order to prevent large numbers of children becoming disabled by a potentially treatable condition.

According to our best estimates the vast majority of children born with clubfoot in LMIC in 2011 did not access Ponseti treatment. Large numbers will go on to develop neglected clubfoot. It is therefore essential that strategies for addressing clubfoot in individuals too old to be fully treated using the Ponseti method continue to be developed.

### Limitations

As already stated, one of the main limitations of this survey is that, despite our best efforts, data was collected from a relatively small group of respondents. Data was self-reported and it was not within the scope of this report to evaluate individual respondents' data collection methods so we are not able to guarantee its accuracy. It is therefore difficult to base any firm conclusions on the number of children accessing treatment for clubfoot globally on this data. It does, however, help provide a baseline estimate for the countries included and a picture of worldwide activity that can be built on in future surveys.

The data set collected was also very basic and was not able to show the exact treatment given or the outcomes of that treatment, although it was understood by all submitting data that 'treatment' would be defined as Ponseti method as the treatment of choice. In some cases, especially those of older children this may have been supplemented with surgical intervention. We were not able to collect data on numbers of children dropping out after initially enrolling for treatment. We are therefore unable to comment on the outcomes of treatment.

Unfortunately we were not able to collect data on the ages of children enrolled for treatment; it is likely that a percentage of children were older than one year and therefore should not be included in 'expected cases' for the year referred to. However, this is likely to occur every year and so should not invalidate the figures.

### Recommendations

- Support for national programmes for clubfoot by international, government and NGO level organisations should be increased
- Capacity for collecting and sharing data should be increased, facilitated by:
  - Agreement of a standardised set of data to be collected on an annual basis
  - Willingness of organisations and individuals to collect and share data
  - Possibly use of shared data collection tools
  - Inclusion of a wider range of respondents in future surveys

- Outcomes of national programmes should be rigorously evaluated to determine numbers of children successfully completing treatment
- Older children with clubfoot must not be forgotten as these currently make up the greatest burden of disability. Strategies to address neglected clubfoot should be developed and implemented.

## Conclusions

In 2011, progress had been made towards reducing the global burden of disability caused by clubfoot treatment through programmes implemented in LMIC. The impact of these programmes is increasing. However, the numbers of children accessing the treatment they need as a proportion of expected cases worldwide remains low and efforts to provide interventions already known to be effective in treating these children must be increased. Better data collection and long-term research studies are essential to demonstrate the effective reach and outcomes of programmes for clubfoot.

Data collected by Michiel Steenbeek and Rosalind Owen  
Written by Rosalind Owen, May 2013

**Appendix 1:**  
**List of survey respondents by country**

<b>Continent</b>	<b>Country</b>	<b>Organisations providing data</b>
<b>Africa</b>	Burundi	CCW*, ICRC**
<b>Africa</b>	DRC	CCW, Handicap International, CBM
<b>Africa</b>	Eritrea	ARCHEMED
<b>Africa</b>	Ethiopia	CCW, ICRC
<b>Africa</b>	Ghana	CCW
<b>Africa</b>	Kenya	CCW
<b>Africa</b>	Malawi	CCW
<b>Africa</b>	Niger	CCW
<b>Africa</b>	Rwanda	CCW
<b>Africa</b>	Sierra Leone	CCW, Prosthetics Outreach Foundation
<b>Africa</b>	Togo	CCW
<b>Africa</b>	Uganda	Uganda Sustainable Clubfoot Care Programme
<b>Africa</b>	Zambia	CCW
<b>Africa</b>	Zimbabwe	CCW, Zimbabwe Sustainable Clubfoot Care Programme
<b>Asia</b>	Afghanistan	CCW, ICRC
<b>Asia</b>	Bangladesh	Walk for Life, Zero Clubfoot
<b>Asia</b>	Cambodia	CCW
<b>Asia</b>	India	CCW, miraclefeet, CBM, ICRC
<b>Asia</b>	Laos	COPE
<b>Asia</b>	Nepal	Hospital for Rehabilitation of Disabled Children
<b>Asia</b>	Solomon Islands	National Programme
<b>Asia</b>	Vietnam	Prosthetics Outreach Foundation
<b>South America</b>	Brazil	miraclefeet
<b>South America</b>	Dominican Republic	CCW
<b>South America</b>	El Salvador	CCW, On His Path
<b>South America</b>	Guatemala	CCW
<b>South America</b>	Haiti	CCW
<b>South America</b>	Honduras	CCW
<b>South America</b>	Mexico	ICRC, miraclefeet
<b>South America</b>	Nicaragua	miraclefeet
		*CCW Cure Clubfoot Worldwide
		** ICRC International Committee of the Red Cross

**Appendix 2:**  
**Country level programmes: Percentage of expected cases needing treatment enrolled in 2011**

Continent	Country	Number enrolled for Treatment 2011	Expected number of babies with clubfoot	%age of expected cases enrolled
Africa	Burundi	136	514	26
Africa	DRC	343	3272	10
Africa	Eritrea	95	234	41
Africa	Ethiopia	753	4688	16
Africa	Ghana	710	820	87
Africa	Kenya	680	1653	41
Africa	Malawi	843	778	108
Africa	Niger	75	999	8
Africa	Rwanda	501	501	100
Africa	Sierra Leone	111	248	45
Africa	Togo	72	295	24
Africa	Uganda	718	1972	36
Africa	Zambia	494	734	67
Africa	Zimbabwe	150	462	32
<b>Africa total</b>		<b>5681</b>	<b>17170</b>	<b>33</b>
Asia	Afghanistan	653	1435	46
Asia	Bangladesh	2631	4373	60
Asia	Cambodia	124	448	28
Asia	India	2003	29924	7
Asia	Laos	157	203	77
Asia	Nepal	321	782	41
Asia	Solomon Islands	33	19	174
Asia	Vietnam	110	1855	6
<b>Asia total</b>		<b>6032</b>	<b>39039</b>	<b>15</b>
South America	Brazil	90	4315	2
South America	Dominican Republic	179	235	76
South America	El Salvador	47	129	36
South America	Guatemala	6	448	1
South America	Haiti	137	285	48
South America	Honduras	109	246	44
South America	Mexico	40	2604	2
South America	Nicaragua	50	131	38
<b>South America total</b>		<b>658</b>	<b>8393</b>	<b>8</b>
<b>Total</b>		<b>12,181</b>	<b>64602</b>	<b>19</b>
<b>Percentage enrolled</b>			<b>18.86</b>	