



# Lothian Self Management Programme Evaluation

Executive Summary  
August 2015 – July 2016



## Executive Summary

**Action for Sick Children Scotland (ASCS)** has worked for over thirty years to improve the standard of healthcare for children and young people in hospital and community settings. It has campaigned for greater involvement of children, young people and their families in decisions and shape of future health services in Scotland. Its work is carried out in partnership with parents, carers, healthcare professionals and most importantly with children and young people themselves.

## Introduction

**The Lothian Programme is the third Self Management Workshop Programme to be developed and delivered by ASCS to help children and young people (CYP) with a range of long term conditions to stay healthy.** The Project is funded for 18 months (August 2015 – Dec 2016), with a budget of £42k; this evaluation covered the period August 2015 – July 2016.

**The 8 anticipated outcomes** were that CYP would:

- Have increased confidence and self-esteem.
- Have increased communication skills and ability to be open about their condition to their peers, health and education professionals.
- Have increased knowledge of support available and be better able to make informed decisions about their illness.
- Be more socially included and feel less 'different' to other children and young people.

**The target** was to deliver a minimum of 3 Programmes to 20 CYP, with 6-8 participants in each Programme, during the year August 2015 to July 2016. This target was achieved (apart from being 1 CYP short) and further augmented by: the 33 referrals achieved, a waiting list of 13 for Programmes planned for autumn 2016 without further publicity, and 2 participants repeating Programmes and 3 wanting to repeat in the autumn.





**The evaluation** drew on 7 sources of data collected by the Project Team, augmented by the External Evaluator through phone interviews with CYP, parents and clinicians, a focus group and an interview with the Project Officer.

**The development** of the project included building working relationship with NHS Lothian clinicians; improving the referral process including improving the referral process and updating and refreshing workshop structure and materials which had been devised for an earlier ASCS Self Management Project (Stay Well Lanarkshire). The Programme was extensively publicised, primarily through NHS channels. Following referral or self-referral a home visit was made to put the CYP and parent at ease, identify any special needs and define Personal Goals. Programme 1, based on the previous Stay Well Project, acted as a pilot, leading to significant changes to both content and delivery, the main one being to split each of the first four workshops into two shorter workshops to minimize the impact of missed workshops and participant fatigue.

**Programmes 2 and 3** comprised 4 half day workshops, followed by a fifth longer one, held in a multipurpose room at the Royal Commonwealth Pool, Edinburgh. Workshops followed a different theme each week with a focus on interactive approaches and play, and each workshop ended with a fun activity. New features included the added emphasis of paired working and the introduction of relaxation and social boards. Various relaxation techniques was also used revive energy through activities such as the 2 minute 'get me up' and 2-4-6 breathing exercise.

Parents were also invited to join the group for lunch at the end of workshops so they could interact with each other. One young person, who participated in all 3 Programmes, was invited to return as a peer mentor in Programmes 2 and 3. Staff tried out various ways to encourage social interaction between participants outwith the sessions. This resulted in a p trip to a panto performance; pizza and ten pin bowling; and a tour at Camera Obscura.

### Example of workshop themes and activities

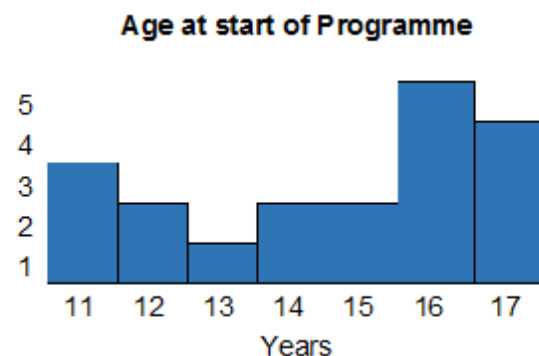
Workshop 1 – Getting to know each other	Workshop 2 - Living with a LTC	Workshop 3 – Learning about change	Workshop 4 – Dealing with problems	Workshop 5 – Feeling good	Workshop 6 – Celebration activity!
Graffiti Wall – names, interests, hopes and fears	NHS Structures – Our healthcare team	Change Cycle - How do we deal with change?	Worry bags – what are our worries and what do we do with them?	Pacing – what does this mean and how can I do it?	Group photos and Feedback – how did you get on?
Setting group ground rules and individual goals	EACH Charter – Our healthcare rights	Relating to others – reflecting on stories	Getting inspiration from others	Get cooking – make your own lunch!	Fun activity to finish off the workshops!
Listening to Whispers - Communication	Intro to Relaxation Techniques		What's my story?		
	Communication and Listening		Relaxation activity		

## Profile of the Participants

The 19 participants included a13 females and 6 males, and an average age of 15 years.

Programme	Male	Female
P1	2	5
P2	0	7
P3	4	4
Overall Total*	6 (32%)	13 (68%)

\*Excludes CYP who participated in more than one programme.



They cited a range of long term conditions including Anxiety; Asthma, Arthritis, Bowel syndrome; Polycystic Ovary Syndrome; Cerebellar Ataxia (after Brain Tumour); Cerebral Palsy; Chronic Fatigue/ME, Chronic Lung Disease, Chronic Pain, Chronic Renal Failure; Congenital Insensitivity to pain with anhydrosis; Diabetes (Type 1), Eczema; Epilepsy, GI dysmotility, Hearing difficulties; Osteogenesis Imperfecta Type 3 (Brittle bone disease); Spina Bifida; Steven Johnson Syndrome and Sturge Weber Syndrome.

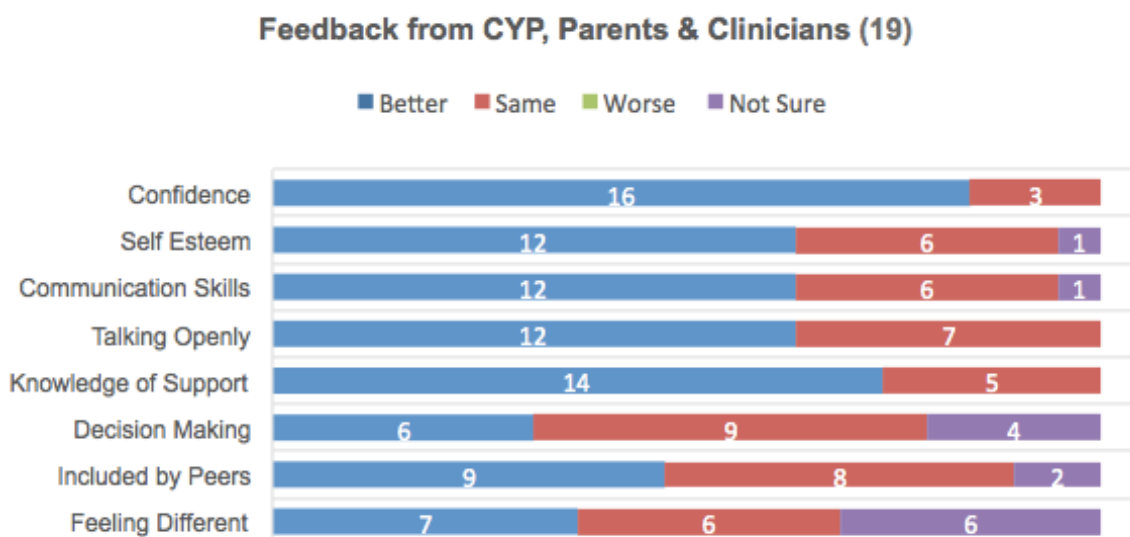
A minority had a physical (5) or learning disability (2), while for 2 English was their second language.

# Results

## 1. Project Outcomes

**Achievement of Project outcomes** was explored in 3 ways a) Telephone Interview by Evaluator; b) Self-ratings of outcomes by CYP at the end of Programme 3 and c) Evaluation interview with Project Officer. Furthermore, participant's quality of life was also evaluated before and after the programme.

- a) Feedback from **telephone interviews** taken from 7 CYP, 7 Parents and 5 Clinicians shows that on average, a majority (69%) of the 19 interview respondents (including CYP, parents and clinicians) felt there were improvements in 5 of the 8 Project outcomes for CYPs: confidence, self-esteem, communication skills, being able to talk openly about their condition, and knowledge of support available. Confidence was rated as the area most affected with 84% of all respondents noting an improvement. Furthermore, an average of 39% respondents reported improvement in the other 3 outcomes: making informed decisions about their condition, being included by their peers, and feeling less different to their peers.



**The chart shows that a majority of the 19 interview respondents felt CYPs had made improvements in the following 5 outcomes as follows:**

- 84% rated improved confidence
- 63% improved self-esteem
- 63% improved communication skills
- 63% improved ability to talk openly about their condition
- 74% felt they had improved knowledge of support available.

The average improvement across this group of 5 outcomes was 69%.

In addition respondents reported improvement in the other 3 outcomes:

- 31% rated improved decision making around their condition
- 47% felt CYP were more included by their peers
- 38% felt CYP felt less different to their peers.

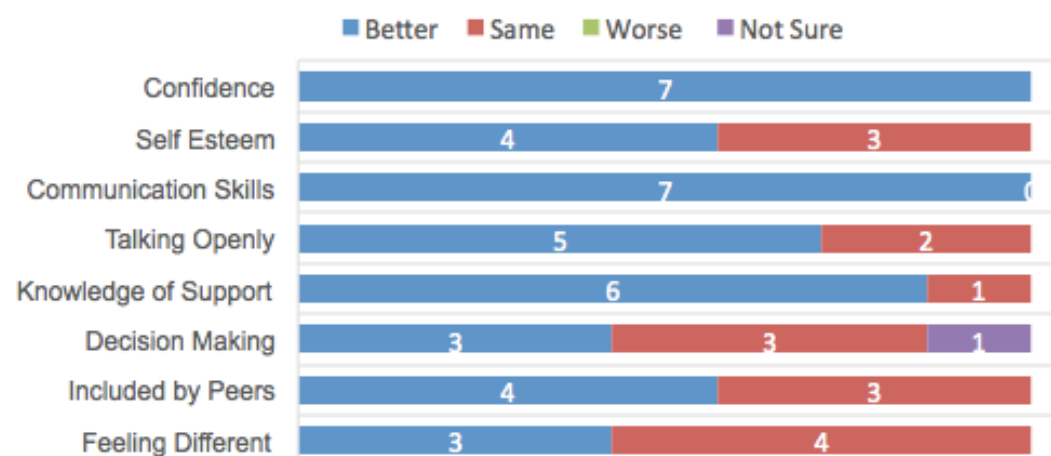
The average improvement across this group of 3 outcomes was 39%.

**The average improvement across all 8 outcomes was 58%.**

## Comparison of feedback from CYP, parents and clinicians

This page and the two that follow compare the rating results from the three groups interviewed illustrated by typical examples of achievement.

### Feedback from 7 CYP on their own progress



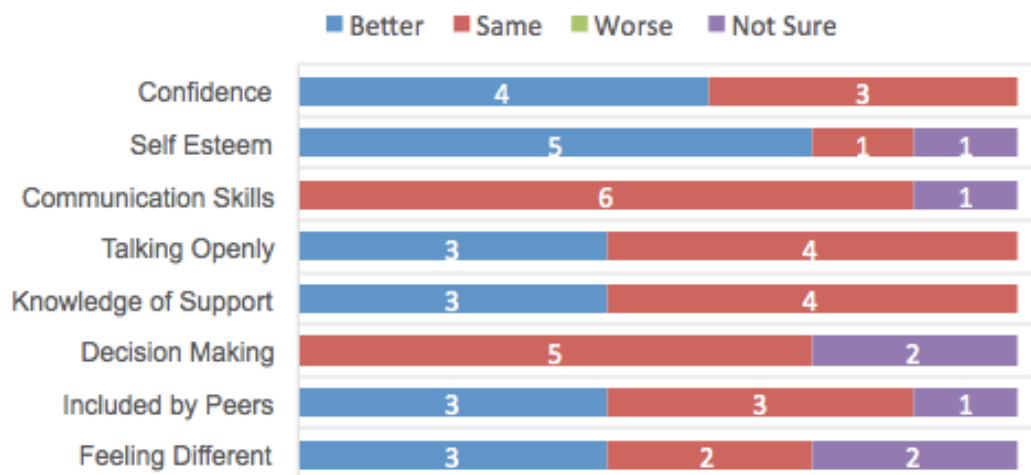
CYP self ratings of their progress were positive, including:

- 100% of CYP felt they had increased confidence
- 100% also felt that their communication skills were better
- 86% said their knowledge of support was better
- 43% were able to make decisions about their condition
- 57% felt more included by their peers
- 43% felt less different to their peers.

**An average of 69% of CYP felt that they had made an improvement across all 8 outcomes.**



## Feedback from 7 Parents on their child's progress



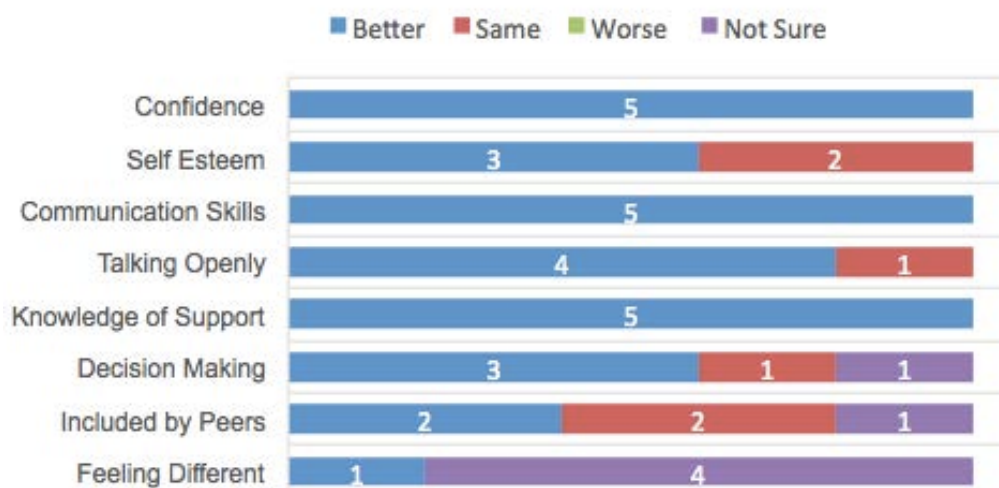
There were some differences in parents' and CYP results, for example, 43% of parents felt that their child's knowledge of support had improved compared with 86% of CYPs. A higher proportion of CYP and clinicians reported that the ability to talk openly about their condition was better. **All CYP** reported an improvement in confidence while 57% of parents reported this to be the case.

**An average of 38% of parents reported an improvement across all 8 outcomes.**





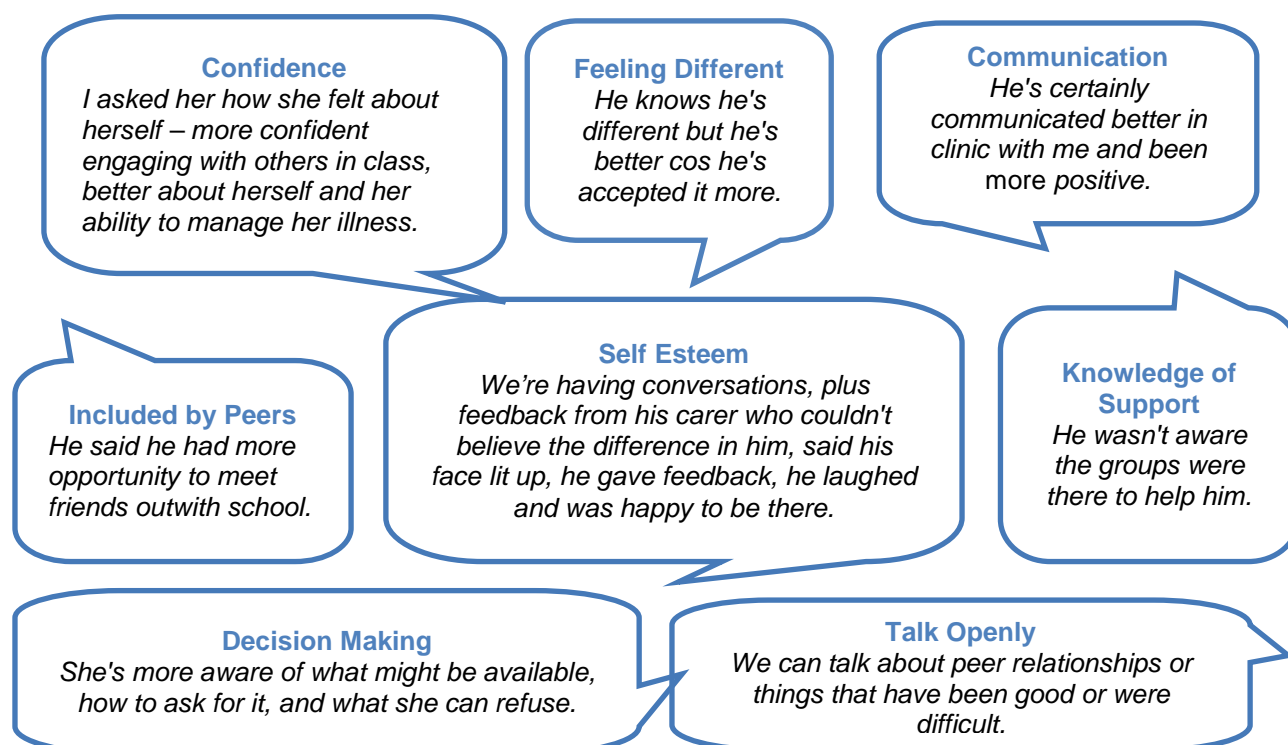
## Feedback from 5 Clinicians on their patient's progress



Clinician scores were the most positive and more consistent with the scores reported by CYP. However, some clinicians were not able to comment on certain aspects for example, feeling different or included by their peers. All clinicians reported that confidence, communication skills and talking openly about their condition had improved.

An average of 73% of clinicians reported an improvement across all 8 outcomes.

Two clinicians and two parents highlighted other things going on for CYP, such as treatments and therapies, making it difficult to attribute the source(s) of improvement.



### b) Self-Rating by CYP:

Feedback from a focus group with CYP in Programme 3 was obtained and participants were asked to rate themselves against the 8 Project outcomes at entry and exit. Comparison of average entry and exit ratings by 5 CYP shows significant improvements for 2 outcomes: feeling included by peers, and being 'Okay with who I am' (i.e. less different) for 4 more outcomes the scores indicate small improvements, for example, talking openly about their condition and confidence.

### c) Ratings by the Project Officer:

The Project Officer was asked by the Evaluator for her assessment of the overall impact of the Programme on all participants. The Project Officer's impression was that CYP had made a lot of improvement in six outcomes mainly with confidence and feeling less different to their peers. Moderate improvement was also noted on two outcomes relating to knowledge of support available and making informed decisions about their health.

d) **Quality of Life ratings** completed by 13 CYP at entry and exit, show small but significant increases in all 4 dimensions of their health-related life.

## 2. Goals and Hopes

**All 7 CYP interviewed reported progress towards their Personal Goals.** This suggests more improvement than the entry/exit scores which varied considerably and in some cases were at variance with the interview ratings. **Overall, goals around school and career predominated followed by making new friends/meeting people.** Making friends and meeting new people also featured strongly in the group list, whereas the schools/career goals only feature in Personal Goals.

#### Group Goals: Programme 2

- To make friends
- Make friends and have fun
- To get better at coping
- To help other people
- Relax and get better and dealing with things
- Cope better

#### Group Goals: Programme 3

- Meet new people in similar situation as me
- Become less anxious
- To have fun
- Share my experiences and help others
- Relate to others
- Gain confidence
- Get out of the house

**A majority of parents and clinicians reported progress towards their Hopes for the Programme.**



### 3. What Participants, Parents and Clinicians liked the most

The main thing CYP, parents and clinicians liked best was that CYP had an opportunity to be with others with long term conditions, to meet new people and provide peer support.

#### CYP

- *I could come here and talk about my illness and everyone could relate. MW*
- *That I could learn better ways of coping and could talk to people my age. CM*

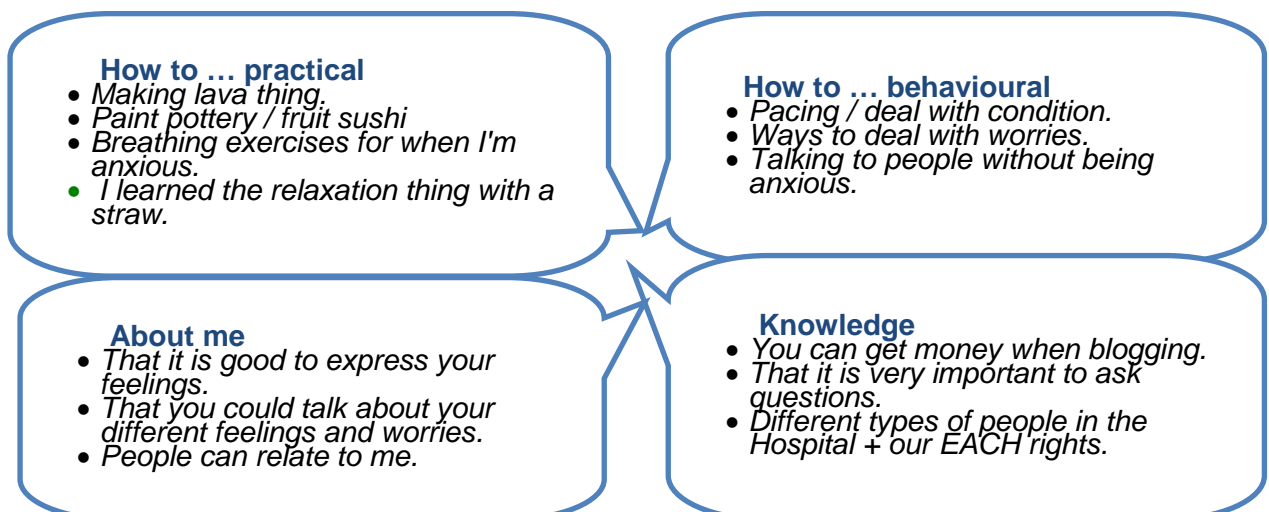
#### Parents

- *Loved the fact he was with people that understood him and that he felt comfortable in the group. Parent of KP*
- *Parents weren't included in the group... I think that was actually a very good thing, that made it focus on her and the other girls. She has been to so many appointments and places where I end up being the one that does the talking, but this is very much focused on her. Parent of CM*

#### Clinicians

- *It's something that can be almost immediate rather than a six month wait for a psychology appointment. Diabetes Clinician*
- *Very helpful for the treatment I was giving because it reinforced anxiety management strategies such as breathing relaxation distraction. Guided Self Help Clinician*

**Individual workshop evaluation** also highlight that CYP enjoyed the workshops and engaging in practical activities, learn coping methods and knowing where to get further support and information.



#### 4. What Participants, Parents and Clinicians liked the least

**There were very few things they disliked. The main thing** was that the workshops and programmes were too short and they would have liked to engage for a longer period.

##### CYP

- *Have more workshops in the Programme – every week instead of fortnightly (**all 5 CYP in focus group**)*
- *Once we all had finished the sessions we all kind of miss each other, I think, so it would be good to have more opportunities to meet as a group with Simita and Dani, in a social way. Maybe once every two or three. **TM***

##### Parent

- *It would be good if it could have been longer for more weeks, maybe 8. It helped getting her out of the house, and would give more chance to get to know everyone better. **Parent of CS***

##### Clinicians

- *Some way of engaging children in an ongoing way, and providing that support on an ongoing basis. **Guided Self Help Clinician***

**Further indicators of success** included: a good average attendance rate of 73% by CYP who were variously constrained by their health, fatigue and hospital appointments; and a majority of participants reporting; enjoyment of workshops, 'Great' workshop leaders, the workshops being the right length, and they learned new things. The one consistent suggestion was for more/longer workshops, and **all 19 CYP, parents and clinicians would recommend the Programme to others.**

Moreover, six of the 7 parents interviewed felt that the programme had a **positive effect on parents and families.**

##### Happier

- *Instead of feeling excluded she was included, that made her happier and that makes us happier. **Parent of CM***
- *It makes me really happy to see my daughter happy, and the satisfaction that she's going out and doing something useful, and she's enjoying herself.*

##### Helps us

- *He's taken more responsibility, that helps. **Parent of CF***
- *It's a big thing for her to be leaving home, and to know that the area to do with her health is taken care of, it frees the family up to support her in other things. **Parent of TM***

##### Less stress

- *With her making more of an effort to get out it's beneficial to the whole family cos it's a stress on all of us. **Parent of CS***

##### Not so anxious

- *It's lifted a burden off my family, knowing he's confident, I'm not so anxious. **Parent of KP***

While the **main impact for clinicians** was to give them another option for their patients; a group experience that complements other treatments.

- *Gives me another treatment modality, which seems to be helpful, it broadens my options, I think it's very appropriate to learn from other people how they are adapting to chronic illness, probably much better than seeing a doctor.*  
**Psychiatrist**
- *Gives me a place I can refer people to, to get peer support that I can't provide through 1 to 1 sessions. It has had a huge effect in improving the range of services I can offer.*  
**Guided Self Help Clinician**
- *An opportunity to offer something immediate, positive and enjoyable*  
**Diabetes Clinician**
- *My role is 1 to 1 and the group was a group, so it brought a different experience to go to a group.*  
**Play Specialist**
- *It made our life easier because he's positive about the outcome.*  
**Renal Nurse**
- *NHS [Lothian] has tried to set up a group for children with long term conditions for a number of years. Now they have a group where they can refer CYP to meet others with different long term conditions in a group setting.*  
**Specialist Nurse at PNF**

## Learning and challenges

**Project staff used an approach of review, learn and refine** throughout the Project, so much of the learning was already absorbed in the evolved Programme 3, including some from the evaluation process. Remaining challenges related to fluctuating attendance; need to keep awareness of the programme high amongst health professionals; becoming sustainable and mainstream; encouraging referrals of younger children. (The 8 – 11 year olds Programme was postponed due to insufficient referrals).

**Clinicians** would like to see online referral if data protection could be addressed. There were also suggestions to receive feedback at the end of the programme.

**The evaluation** also raised some challenges including: obtaining complete entry/exit data, accommodating changing goals in the monitoring process, and addressing the varied rating results for Project outcomes and Personal Goals.

## Conclusion

The Lothian Self Management Project met its target of delivering 3 Programmes in the year August 2015 – July 2016. 22 CYP (or 19 unique individuals) took part in the Programme almost meeting the target of 20 participants, and augmented by further achievements that went beyond the targets: 35<sup>1</sup> referrals achieved during the year. A waiting list of 10 for Programmes planned for autumn 2016 (achieved without additional publicity); 2 participants repeated Programmes, and 3 participants would like to repeat in September.

The high level of referrals shows that the multi-pronged approach to publicity and awareness, mainly through various channels within NHS Lothian, was effective, and that the Project has built up a momentum of awareness and demand for a self management programme.

These results alone point to a successful Project, which is further evidenced by a range of other results and feedback.

- The average attendance rate of 73% by 19 participants in the 3 Programmes is good, considering that most absences were due to: not feeling well enough to attend, hospital appointments or family commitments.
- There was very positive feedback from CYP where all participants reported that they enjoyed the workshop, majority commented that they found the workshop Leaders 'Great' and felt that the workshop was the right length. CYP also reported that they had learned new things.
- There was one consistent suggestion for improvement from respondents of all parties: to have more / longer workshops.
- **All 19 CYP, parents and clinicians interviewed and all contributors to the CYP Focus Group would recommend the Programme to other CYP with long term conditions.**

## Recommendation

*It is recommended that:*

- 1. This successful Programme is continued so that more children and young people can be helped to manage their long term conditions in a safe and nurturing group setting.**
- 2. Project staff consider the various suggestions for improvement made by CYP, parents clinicians and the Evaluator.**
- 3. Further delivery of Self-Management Programmes aims to further address the 4 outstanding challenges identified, where possible:**
  - Accommodate fluctuating attendance.
  - Address the need to periodically remind health professionals about the Programme.
  - Become sustainable and mainstream.
  - Encourage referrals of 8-11 year olds.

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<sup>1</sup> Includes 13 people on the waiting list for the September 2016, and 3 waiting to go on a Programme for 8-11 year olds

## Case Studies

### A) Tuscany (17)



Tuscany found out about the Programme through her Art Therapist, and filled in the referral form to join Programme 1 in October 2015 when she was 17 and in her final year at school.

She has had rheumatoid arthritis for six years. It makes her joints very sore, and being unable to exercise much, her muscles are weak so she can't walk far. She had a laptop at school, and extra time for exams.

*Before the first session I felt a bit apprehensive because I'd not done anything like it before, I didn't know anyone there apart from Simita who I'd met once. It's a relaxed environment, not like school where you have to follow certain rules, and you have to act in certain ways, you can just be yourself and be really comfortable. I became happy to go to the sessions.*

The **most helpful sessions** for her were: pacing your energy, evaluating how I cope in different situations and learning about the different hospital staff.

*After Programme 1, Simita spoke to me over the phone saying they're doing the workshops again and because I'd done it before she'd like it if I could come again and make the new participants feel a bit more welcomed and relaxed and share things.*

She enjoyed this role, and may add it to her CV. She also participated in Programme 3, and had a full attendance at all 3 Programmes.

Her main Personal Goal for Programmes 2 and 3 was to improve her confidence, and by the end she said:

***I've gained more confidence around new people about talking about my condition. Usually I would not really say anything or do anything, but if I would come to the group now with some new people I would feel more confident to talk to them.***

*Once we all had finished the sessions we all kind of miss each other, so it would be good to have more opportunities to meet as a group with Simita and Dani, in a social way.*

The most helpful sessions in the later Programmes were: learning how to relax and de-stress, and meeting people in similar situation so we can all share our experiences together.

*All my exam period was stress free. I'm going to College to study Business at Glasgow Kelvin College. I'm more open now to talking about my experiences of arthritis. A couple of months ago I was a bit scared about going to college, 'cos it's the first time moving out and having to fend for myself, but now I feel more excited and I'm not worried any more.*

Tuscany took the initiative in getting some of her needs met: *I'm getting a laptop for college from a charity called Scottish Network for Arthritis in Children, also I'll be allowed to take it in to college with me every day to type notes.*

**Tuscany would recommend the Programme to others: *Because you meet people in similar situations to you, so you don't feel so lonely and isolated.***



## B) Cameron (13)



Cameron was referred to Programme 3 through RHSC. He has Type 1 diabetes which means daily injections and blood tests, but he doesn't let that interfere with his active life.

He's a carer for his Mum, and goes to a Young Carers' group where he enjoys activities like go karting and laser quest.

**While he felt a bit nervous about meeting new people on the Programme, he soon got to know everyone all and felt confident with them.**

Cameron participated in 4 of the 6 Sessions. At the start, he had two Personal Goals: to play in a football team, and healthy eating, and felt the Programme helped him make a little progress towards playing football, and more progress towards healthy eating by eating more veggies for lunch and snacks.

Looking back on the Programme, he also wanted to get to know other people, and improve his confidence, and he felt he made progress on both those fronts.

The things he liked most were: *When we were doing breathing techniques, and good information and I enjoyed what we were doing. Also: The cooking, we made cauliflower couscous then healthy truffles, I enjoyed just making things.*

His Mum hoped he would meet new people, and get to play in a football team, and what she liked best was that he did *get to know people*.

Cameron's Healthcare Practitioner hoped he would boost his self-confidence, find ways to live as normal a life as possible, meet others, know he's not doing this on his own, and look at things in a more positive way. She felt he made a little progress towards boosting his self-confidence.

Here are some of the changes Cameron has noticed about himself: *On a Saturday I never used to get up till 12 o'clock, with the groups I've been getting up earlier. I'm more confident talking to other people about my condition. Before I never used to talk to people I didn't know, and at the groups I spoke to everybody, and I didn't know any of them. Now I get involved with others, I went on a trip to Alton Towers a couple of weeks ago and in groups I started to do stuff with my friends.*

His Mum has noticed: *He's getting on better; He's been going out a bit more, and He's taken more responsibility, and that helps me.*

His healthcare practitioner reported: *He's certainly communicated more and been more positive; He said he had more opportunity to meet friends outwith school, and He did say he hoped he'd be able to go back.*

She also felt it gave him the opportunity to be part of a group, have something to look forward to with some structure, and time when he's not worrying about his Mother's health.

**Cameron would recommend the Programme to other young people: *Because it's really good, and it helps people build their confidence.*** He hopes to return to the next Programme in September because he liked it so much last time.