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Development and Evaluation of the ‘Getting Sorted’ Self Care Workshops for Young People with Diabetes

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SECTION 1 - INTRODUCTION

The report describes a journey that was taken by a group of young people in Bradford who happen to have diabetes when asked what they would like to see in an expert patient programme. The enthusiasm, energy and inquisitive nature of young people are captured in the design of a self care model that clearly reflects and values their thoughts and views. The first part of this journey is to set the scene and put the project into context through exploration of the shift in chronic disease patterns.

The second half of the 20th century and the beginning of the new century sees more people living into their seventies and eighties and beyond. As a result there has been a shift in the disease pattern in England from acute disease to chronic long term illnesses such as diabetes mellitus, asthma, heart disease, stroke, mental illness and other conditions. 17.5 million adults in Great Britain are now living with a chronic or long term condition. By 2030, long term conditions in the over 65's will more than double.

The NHS and social service providers are now faced with redesigning services that meet the changing demands of an ageing population [DoH, 2004]. Strategies for managing long term conditions [LTC] within the NHS are not new. Approaches such as 'queuing and watchful waiting'; 'gate keeping '; 'case management'; 'primary prevention' and 'self care' have all been utilised in the past with varying degrees of success [Robinson and Steiner, 1998].The key aim of disease management is to take a more proactive approach to managing a disease in order to improve the likelihood of favourably altering its natural history. Therefore a more comprehensive and integrated approach is required with outcomes that consider and include improving quality of care and thus quality of life for the individual and thereby reducing the cost of management of each individual [Plocher,1996]

Little has been done to prepare people for the long term management of their disease. They face challenges in coping with discomfort and disability and carrying out treatment programmes on a regular basis. People need to modify their behaviour to minimise undesirable outcomes, adjusting their social and work lives to accommodate their symptoms and functional limitations and deal with the emotional consequences. For their care to be effective, they must become adept at interpreting and reporting symptoms, judging the trends and tempo of their illness and participating with health professionals in management decisions [Lorig et al 1999].

The Key influence on the development of the NHS Expert Patient Programme [EPP] was based on work undertaken by Kate Lorig in the 1970's. Lorig was a post-graduate student at Stanford University and it was there that she formulated the idea that self-management courses could be run more effectively by people who had personal experiences. Primary aims were to help people develop self-management skills such as problem solving and goal setting and to promote the development of skills to help people gain confidence and take control of their condition and their lives

The government's commitment to help people living with a long term condition to maintain their health and improve their quality of life through EPP was set out in The White Paper Saving Lives: Our Healthier Nation [DoH, 1999] and The NHS Plan [DoH, 2000]. These both set out a vision for a new more patient centred approach. Following from this was a government report focused on tackling the impact of LTC. The Expert Patient: a New Approach to Chronic Disease Management for the 21st Century was published in Sept 2001. The recommendations within the report sought to identify ways in which new relationships could be developed between the NHS and the people it served. One in which health professionals and patients are seen as genuine partners and who are empowered with information and skills to enable them to contribute ideas to help in their treatment through self-management programmes led by people who themselves live with a LTC, to enable them to increase their confidence, knowledge and skills.

The development of EPP using a model of lay led self-management was established in 2002 by the Department of Health as a result of the findings of the Expert Patients Task Force headed up by Sir Liam Donaldson. The programme was based on the model developed by Kate Lorig at Stanford University Patient Centre that was adopted by the NHS who then purchased the license. The EPP was created to provide lay led self–management as part of NHS provision. The Pilot phase commenced in 2002 and integrated into mainstream services across all PCT's in England in 2004. Between 2004-2007 EPP's will be mainstreamed within other NHS areas and by 2007 each PCT must have arrangements for user led self-management programmes for key chronic conditions to be delivered and / or commissioned.

By late 2003 the apparent emerging success of the adult lay led self-management programmes have acted as a catalyst for the demand from health care professionals for the same programmes to be available to young people 12-18 years who have a long term condition [DoH,2001].There are no young people's EPP's currently operating in the UK. The investment in such a programme for young people is not desirable but essential. The World Health Organisation [2005] articulated a response to the growing concern of the increased demands of chronic disease management:

> **'…. This places new long term demands on health care systems. Not only will chronic conditions be the leading cause of disability throughout the world by 2020 if not successfully managed they will be the most expensive problems faced by our health care systems'**

SECTION 2 – BACKGROUND

After the introduction of the adult EPP's in the U.K., many healthcare professionals expressed interest in developing a programme for teenagers. The government's national target on supporting people with a long term condition clearly articulates the need to ensure that children and young people are able to access EPP's [DoH, 2005]. There has been an unprecedented public debate in the last five years about services for children and young people and their families. The public message that was endorsed by consultation was Every Child Matters [DfES, 2003]. This began a fundamental shift in the government's commitment to children's health which is clearly reflected in the Change for Children agenda and the need to ensure every child is healthy; safe; can enjoy and achieve; can make a positive contribution and can achieve economic well-being.

The National Service Framework for Children and Young People, specifically standards three, six and eight, clearly recommends that the Expert Patient Programme should be accessible to young people [DoH, 2004]. The key objectives are to support young people to mange their condition in a way that suits them. EPP's need to be developed around the unique needs of young people and be sensitive to the differing views of 12 to 18 year olds. It is also crucial to develop a programme that is flexible and creative to ensure young people are engaged. It is only through true participation and partnership working with young people that service provision can be designed around their needs. The important differences between adults and young people are that the locus of self-management and decision making shifts from the parents and health professional to the child through later childhood and adolescence. There is also the need to consider planned transfer of care for young people to adult services. An EPP could prepare young people to take control over the management of their care and control over their lives.

A government-funded Pilot Project was undertaken to trial the Adult Chronic Self-management Programme with young people in four areas throughout the UK in January 2004 and was completed in January 2005 [Hawley, 2005]. The aim of the project was to elicit the views of young people on the changes needed in the programme to make it relevant to their needs. Unexpectedly all four sites failed to recruit enough participants to run the programmes. The main reasons identified were that it was found that the format of the EPP was not consistent with the needs or wants of the age group but the course content matched up with the issues they had highlighted.

The government funded further research and consultation with young people [which matched the findings of many national consultations with teenagers] which established that one day workshops which included a fun element as well as the issues on self-management were their preferred choice [Hawley, 2005]. To this end a workshop was devised using the input of young people and trialled in Oxford with a group of 10 participants with a range of chronic conditions. The workshop was delivered by two young facilitators who had received training. The feedback from all involved on which parts of the workshop were successful and what changes needed to be made enabled a programme to be written.

The first of three structured self-management workshops are now ready to pilot across the UK. The proposal is to train a group of young facilitators and deliver the workshop in six pilot sites across the UK. The major advantages of this workshop over existing ones are:

- it is generic in nature;
- it is not labour intensive;
- it is comparatively cheap to run;
- It lends itself very easily to being rolled out as a national project capable of being delivered by both the voluntary and statutory sectors;
- It uses techniques which allow participants to rehearse skills thus re-enforcing the learning process.

The Bradford Expert Patient Project

Yorkshire and the Humber Strategic Health Authority [YHSHA] and Bradford and Airedale PCT also recognised the need to develop, implement and evaluate an Expert Patient Programme for young people. The development of an EPP would address the key policy drivers in line with the Change for Children agenda and specifically meet the unique needs of young people with a long term medical condition to bring about, proactively, a fundamental shift in the way that chronic disease is managed that would enable young people to take an active role in their care. The development of an Expert Patient Programme can only be achieved through working in true partnership with young people, listening to their views and experiences about how the condition impacts on their lives and what they would like to see in the programme to develop their knowledge, skills and confidence to take effective control over their lives. An EPP potentially could address both the medical issues of self-care and the psycho-social issues for example in medication adherence, communication skills and problem solving.

The proposal in Bradford was to develop, implement and evaluate an Expert Patient Programme for Young People with diabetes and to include the young people themselves in its development. It was essential that the programme was designed to meet the unique needs of young people as their opinions and views were crucial and shaped the content, format and delivery of the programme. The programme was also delivered by three young adult facilitators aged 18-22 who themselves have diabetes. The facilitators attended a recognised DoH funded EPP tutors' training programme and received training from an expert outdoor activity specialist this equipped them with the necessary knowledge and skills to facilitate the programme. It is envisaged that the 'Getting Sorted' Self Care model, that was developed from the data obtained will inform future local and national development of a generic Expert Patient Programme that may be accessed by all young people with an identified long-term condition

Research questions generated

- How does Expert Patient Programme fit in with already established Health Care provision?
- Do Young People think that Expert Patient Programme would have a positive impact on their health and wellbeing?
- What age is Expert Patient Programme best delivered at?
- What Expert Patient Programme is the most relevant to Young People?
- What do Young People want in an Expert Patient Programme?

Aims

- To undertake a scoping exercise to develop and pilot a Young Person's Expert Patient Programme
- To establish and evaluate a pilot project with an identified group of Young People

Objectives

- To establish young people's perceptions on the impact of an Expert Patient Programme on their health and wellbeing
- To enable young people to identify what they want in an Expert Patient Programme
- To develop a model based on young people's needs
- To identify key skills and experience required for young people's Expert Patient Programme facilitators
- To find out at what age is most beneficial for young people to engage in an Expert Patient Programme
- To examine how Expert Patient Programme will complement and add value to existing services for young people with chronic long term conditions.

SECTION 3 – RESEARCH METHODS

Reflected in all key government policy related to the Change of Children agenda is an overarching message that engaging children and young people, as partners in care, through true participation in relation to the development, implementation and deliver of future services, is crucial to ensure services best fit their needs and not that of professionals, through listening and acting on their views as seen through their eyes [DfES, 2003; DfES, 2004; DoH, 2004a; DoH, 2004b]. Billings [2000] stated over the past decade there has been a rapid growth in a community development approach to health to help readdress inequalities in health by facilitating a collective response to 'community defined health needs'.

This approach could potentially enable young people to have an effective voice in decisions that affect their health and well-being. Through adopting this approach article 12 of UN Convention on the rights of the child could also be met;

> **'... Children and young people should be involved in all decisions affecting their lives' [UN, 1989].**

Sudbery and Noyles [1999] pointed out that it is common that services are developed for a child or young person and are determined by other people, particularly professionals who tend to equate problems associated with young people as a burden. This could potentially lead to situations in which young people are seen as an object of concern, or care, and not a citizen with rights. The success of the project therefore lies in enabling young people to express their views and experiences of what it is like to live with a long term condition. One of the key requisites of the project is to support a group of young people to develop, implement and deliver an expert patient programme:

> **'A programme written for young people, by young people' [Webster, 2006].**

The choice of methodology was required to reflect this principle in order to obtain the views and experiences of a group of young people who are living with a long term condition about what they considered were the major problems or issues that needed to be addressed in an EPP programme and what format they considered would be most effective to deliver a programme that will potentially meet their unique health needs. The project design and methodology was chosen for a number of reasons. Firstly, there is an increasing demand to ensure that community health improvement initiatives are based on evidence of need and effectiveness, and that research evidence obtained from the project could potentially support the decision making process and promote future sustainability of an EPP for young people both locally and nationally [Billings,2000].

Secondly, part of the evaluation process supported the need for accountability to ensure that interventions did have positive health benefits for those young people taking part, and that those benefits would enhance their knowledge, skills and confidence to self-manage [Fawcett, 2000]. Evaluation approaches have also been used extensively in community based initiatives where true community participation is crucial to enable young people to have a voice in decisions that affect their health and well being [Billings, 2000].

In order to obtain data that would most effectively elicit the views and experiences of young people with diabetes a qualitative survey utilising an Action Evaluation approach was used and provided an overarching theoretical and methodological framework. The methodology was informed by a framework developed by Fawcett [2000] for Bradford Social Services to provide staff with a tool to support and carry out evaluations. The creation of an evaluative framework allowed for exploration of the impact and effectiveness of an EPP for young people, ensuring information obtained had a local purpose and value. This approach will initially gather baseline qualitative data in the form of views and opinions of young people's experiences of living with a long term condition in order to design EPP. Clear aims and objectives which served as a key point of comparison with the outcome information were set in each individual workshop and used as a schedule for the post interviews.

As Action evaluation functioned in a ‘bottom up’ rather than ‘top down’ way it allowed for an inclusive rather than an exclusive exercise as it actively included young people as well as senior managers whose recognition, backing and support were vital to ensure that the findings can be fed into organisational plans. The partnership activity enabled young people to be involved and retain control of the process while being able to demonstrate the achievement of agreed aims and outcomes or put forward details of where aims and outcomes were not achievable. The framework that consists of four questions was adapted and used to guide the project. A project plan was then developed utilising the above framework:

- Where are we now? -understanding the current situation and health need
- Where do we want to be?-looking at priorities and opportunities
- How will be get there?-identifying project activities and factors influencing delivery
- How will we know we have been successful?-in relation to setting up, monitoring and evaluation.

Data collection and analysis.

The project used planned focus group interviews as a method of data collection across 15 High Schools across Bradford and Airedale. It emerged from the discussions that young people preferred to call focus groups ‘talking groups’ so the term was adopted throughout the project. The data collated furnished the content and format of delivery of the self care model. The ‘talking groups’ allowed young people relatively free scope to explore and elaborate on their own views and experiences and through group synergy valuable and meaningful data was generated [Robinson 1999; Lucasey 2000; Webb and Kevern 2001; Webb 2002; Mansell 2004].

The ‘talking groups’ were facilitated by the three facilitators and supported by school nurses and the principal researcher. The views and opinions were obtained directly from young people as to what they felt the core generic contents of an expert patient programme should look like to enable and facilitate their empowerment through self-management of the impact of their condition on their health and well-being. The focus group trigger questions were based on and rooted from the work already undertaken by Kathy Hawley [2005] [see section four]. The aim of the ‘talking group’ was discussed with the group and a set of ground rules were established. Thomas et al [1995] advocates the use of ground rules that the group can take ownership of. Permission was sought form young people and parents/carers to tape record the discussion.

The qualitative data generated from the ‘talking groups’ was reduced using simple content analysis. The three facilitators with the support of the principal researcher identified the key themes through listening to the recordings. This was felt to be an appropriate level of rigor to evoke key themes that represented the core building blocks used to construct the content and format of delivery of the programme. It was felt that the facilitators were the most appropriate people to critically appraise analysis and refine the key emerging themes with support from the principal researcher. The key themes and related statements were then used to construct the ‘Getting Sorted’ Self Care programme in the form of four workshops. The title emerged from the discussions with young people that expressed difficulties relating to the title ‘expert patient and programme’.

Sampling method.

The key to the success of this approach was dependant on the expert knowledge and co-operation of young people taking part in the project as the focus of the project was aimed at gaining an in-depth knowledge which helped formulate the themes that formed the key building blocks within the programme. A purposive sampling approach was adopted in order to bring together young people who share similar views and experiences of living with a long term condition. It was necessary to ensure that those young people who were selected would be able to use their personal views and experiences to contribute effectively to ‘talking group’ discussions and best inform the project.

Access of Sample

Research undertaken by Hawley [2005] found that the most successful response to the EPP project came from young people who had diabetes. It was felt that the services provided were well organised and supported. As recognition and ease of access to a group of young people was crucial to the success of the project, young people with Diabetes were chosen as the sample group as the numbers of young people with the condition was relatively high within the locality and easily access to the sample could be gained as a comprehensive database has been collated across the district. The diabetes team were contacted at two sites: St Luke's Hospital and Airedale General Hospital. [111] potential participants' were identified at St Luke's and [26] at Airedale General Hospital. A total population of [137] potential young people between the ages of 12-17 were identified. The numbers of young people; their date of birth; secondary schools they attended and the PCT will form the basic information required at the initial stage of the project.

DIABETES TEAM	**NUMBERS POTENTIAL PARTICIPANTS**	**3 OR MORE YP IN HIGH SCHOOL WITH DIABETES**
St Luke's Hospital	111	51
Airedale General Hospital	26	23
	137	**74 = 54% TOTAL SAMPLE**

Due to the complexity of preparing for, and organising the talking groups, it was crucial that the research sites were identified as quickly as possible. All young people initially identified were considered to take part in the study. On closer examination of the data it became clear some high schools had between three and seven young people across the age range with diabetes and a number of schools had only one young person. It was felt to be too disruptive to those young people to take part in a talking group in another school and also to be time consuming to access the entire total sample as the project was time limiting.

The research team with support and guidance from school nurses took the decision to undertake talking groups in high schools with three or more young people who had diabetes. A total of 15 sites across Bradford and Airedale were identified. A total of 74 potential participants were identified out of a total sample of 137.

HIGH SCHOOL	NUMBER OF POTENTIAL YP	YP ATTENDED	MALE	FEMALE
Queensbury	6	2	2	
Buttershaw	8	4	2	2
Hanson	4	2	2	
Thorton	8	5		5
Tong High	8	4	4	
Carlton Bolling	4	4	2	2
Laisterdyke	4	4	3	1
Dixons	6	3	3	
Catherdral	3	1		1
Oakbank	4	2	1	1
Holy Family	3	2		2
Parkside	3	3	2	1
South Craven	4	2	1	1
Bingley Grammar	3	1	1	
Ilkley Grammar	6	2	1	1
Total number	**74**	**41**	**24**	**17**

How young people were approached and recruited.

- Initial telephone contact was made with the identified sites to introduce the principal researcher who gave a brief overview of the project.
- Letters were sent to all school nurse leads and link school nurses across the district giving details of the project and seeking their willingness to participate.
- A letter was sent to all Head Teachers of the 15 sites giving an overview of the project criteria and seeking permission to undertake the talking groups in school.
- A joint letter from the principal researcher and the Paediatric Consultant was sent out to the parents of all potential participants giving details of the proposed expert patient programme and a consent form where appropriate.
- All potential young people were sent out a detailed patient information sheet using appropriate language that reflected their age group and a consent form
- Both parents and young people were given the opportunity to discuss the project through face to face contact.

How young people were involved

- Initial informal discussion about the project with the link School Nurses was undertaken.
- The group read the Patient Information Sheet and covering letter and those that wanted to take part gave their consent.
- Consent was also obtained from parents and carers
- The young participants were prepared for the ‘talking group’ by listening to a short overview of the project. They were also asked to set their own ground-rules and then actively take part in the talking group.
- Some young people when asked volunteered to make comments on the model that was emerging.
- 9 young people volunteered to take part in the pilot.
- All the 9 young people that took part in the pilot actively participated in the ongoing evaluation of the model.

- 4 out of the 9 actively took part in presenting the findings to 70 delegates across the region
- One young person actively took part in presenting the findings to a Healthy Schools Conference.
- Young people actively took part in delivering the findings of the project to 25 organisations across the region.

Recruitment of the three young adult facilitators

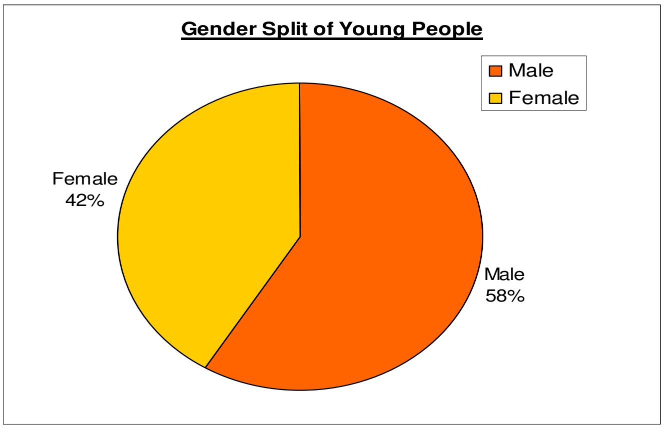
The Key influence on recruiting young adults with a long term condition was based on the evidence of work undertaken by Kate Lorig in the 1970's formulated the idea that self-management courses could be run more effectively by people who had personal experiences. It was also felt that the participants would relate and be more responsive to a young adult with similar experiences and learn from them more effectively than professionals.

The adult diabetes team was contacted and the principal researcher gave an overview of the project and the potential commitment required from the potential young adult recruits. It was agreed that at the next out-patients clinic appointments the Clinical Nurse Specialist would introduce and discuss the project to all those young adults that attended. Six names were put forward. Three volunteered to take part in the project. An honorary contract was set up by Bradford and Airedale PCT for each young adult to recruit them into the research team. All three facilitators and the principal researcher undertook a DoH approved EPP tutors course to enable them to facilitate the programme. As the findings of what young people wanted in the programme were strongly focused on an activity based model the three facilitators and the principal researcher undertook further training in facilitating simple and complex group activities lead by an Outdoor Orienteering and Activities Specialist Trainer.

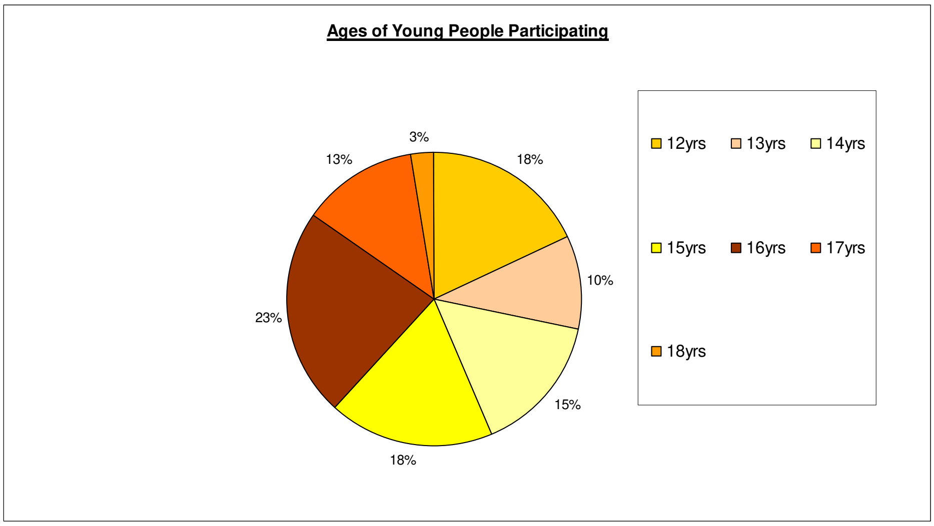
SECTION 4 - FINDINGS

General Information

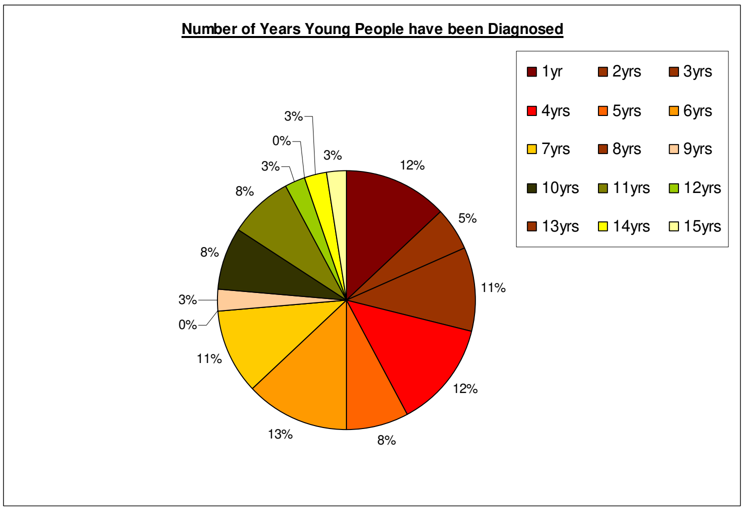
Fifteen high schools took part in the project and the young facilitators we were able to talk to 41 young people with diabetes aged between 12 and 17.The graph below illustrates that a higher proportion of male participants took part in the project, than female participants.



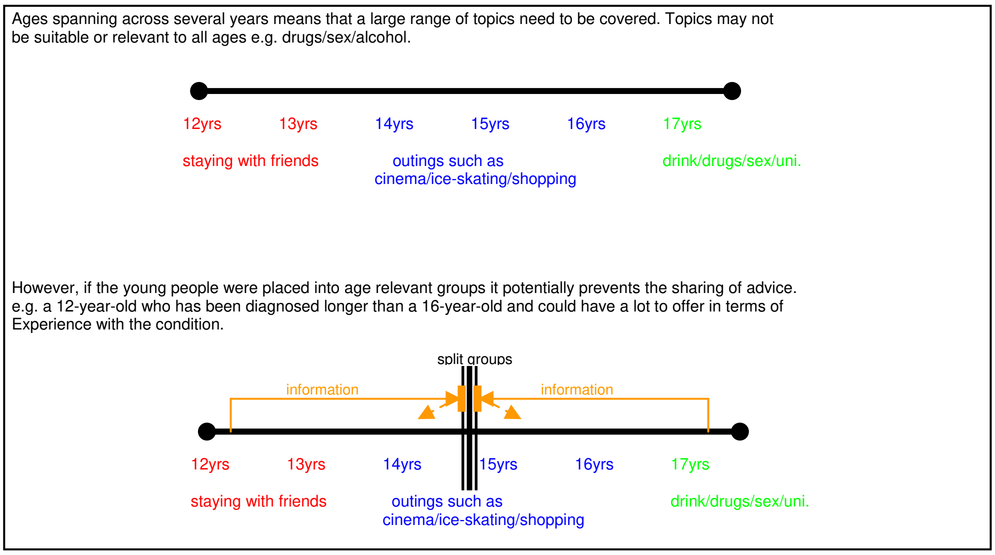
The highest proportions of young people participating were those aged 16 years. The lowest proportions of those attending were those aged 18 years. This could be due to the fact that most young people of this age consider themselves ‘sorted’. There is a fairly even spread of participants across the other age groups.



The length of time young people have been diagnosed is variable. The graph below shows that the highest proportions of young people have been diagnosed for six years. The length of time a young person has been diagnosed did not necessarily correlate with the age of that young person in relation to how well they were able to self manage their diabetes.



It was observed in the workshops that a young person of 12 who had been diagnosed for a number of years was able to advise and support a 16 year old who had been recently diagnosed. Dividing the workshops into age ranges as suggested in several of the 'talking groups' to ensure age appropriate discussion and advice could be offered may have lost the positive impact and outcomes offered across all four workshops. A diagram to capture a young person's journey to self care came out of the workshop discussions [appendix 1]


Ages spanning across several years means that a large range of topics need to be covered. Topics may not be suitable or relevant to all ages e.g. drugs/sex/alcohol.

However, if the young people were placed into age relevant groups it potentially prevents the sharing of advice. e.g. a 12-year-old who has been diagnosed longer than a 16-year-old and could have a lot to offer in terms of Experience with the condition.

Development of the ‘Getting Sorted’ Self Care Model: Content of the Self Care Model.

In the ‘talking groups’ young people were asked two key questions and took part in a group activity to draw out from them what they felt were the key problems and difficulties they had faced living with diabetes:

1. What have been the problems or difficulties you have faced in your daily life from having your condition? (Or ask them)

   What bugs them about having diabetes?

ACTIVITY

Get the group to write down some of the problems: give them at least 5 minutes to write something down.

Go around the group and let them tell you what they have written.

2. If we asked you to write a new self care programme what topics would you include that would help support you to manage the problems and difficulties you have told us about?

Nine key topics emerged from the ‘talking groups’ that young people identified as the key problems and difficulties relating to the impact of diabetes on their lives and felt should be included in the content of the workshops. Their views are summarised below.

Key Topics	Supporting Topics	Quotes from 'talking groups'
1. Diabetes the condition itself	**Overall**	'diabetes itself is rubbish' 'so much to deal with everything changes' 'can't eat what you want'
	Injections	'painful-bloody hurts' 'restrictive time of injections needs to fit in' 'need a safe place to do them need privacy'
	Emotional/Mental Well-Being	'embarrassed, shy did not want to talk about it' 'nervous' 'worried' 'rebelled against it' 'ashamed'
2. Impact on life	**Friends:**	'Want to be able to stay out' 'Issue of where to do injections' [need to find places when you're out] 'Felt friends would not want to know me' [consistently mentioned]
	• **Positive side**	'Friends very important / provide support' 'Friends need to know what to do and how to help' 'Sharing with friends can help – therefore less stressful' 'Get more attention at home and at school'
	• **Negative side**	'Losing friends because I need more attention' 'Find it hard to make friends' 'Make fun of me' Bullied 'she has to go out again'
	Play	'Issue of having to be back for injections – restrictive 'need to fit in' 'Can't stay out for long' 'Feel like you're 'working your life round stuff'

		‘Interrupts sports’
	Concerns about the future	‘Worries about manual work’ ‘Drinking’
	Other:	‘Need extra support when starting school’ ‘Need place to go to when you don’t feel well’
3. Control	**Trust**	‘I am not trusted’ ‘Parents not trusting you’
	Choices	‘Not able [allowed?] to make own choices’ ‘They [parents?] never ask how you feel’
	Need people to listen	‘Need to be listened to ‘Doctors don’t talk to kids, only the parents’ ‘let me have a life’
	A need to be independent	‘Need to be independent – but family take over’ ‘Do not like being told what to do ‘Want to manage condition themselves’ ‘Want to be able to stay out’ ‘Not allowed to go to the shop’ ‘Depends on my blood sugar levels whether I’m allowed to go out or not’
	Need to be able to self-manage	‘need to know what to do’ ‘How to cope at school’
	Need for the right information at the right time at the right level	‘Felt you learnt as you go along’ ‘You learn to deal with things when you get more and more information’

4. Labelling and relationships with others	**Labelling**	‘People staring’ [think talking about injections]
	Need to be seen as a person in my own right not a condition	‘People [parents?] focusing on Diabetes all the time’ ‘Lack of focus on other issues that might be affecting me’ ‘Not recognising themselves’ ‘Thought friends would fall out with me thinking I was different’
5. Acceptance		‘Am used to it now’ ‘Accepting it will be there for ever’ ‘It is for life but need to realise it should not stop us doing things’ ‘Need to feel it’s okay to have diabetes’ ‘Rebelling against the condition’ ‘When found out people not that bothered – that was better ‘starting getting better’ ‘Originally shy about telling friends – but then it was okay’ ‘You can’t deal with it on your own’ ‘Need people to understand’
6. Parents	**Not trusting**	‘Family untrusting’ ‘Tell you what to do all the time’
	Focus on the condition	‘Don’t ask me things all the time’ ‘Always asking stuff to do with diabetes’ ‘checking up’
	Over protective	‘over protective’
	Not listening	‘Not listening’
	Need for independence	

	Coping strategies	‘Need independence’ ‘My Mum has all the information’ ‘How to deal with other people’s fears and anxieties’
7. Information	**Scared**	‘Scary thing is not knowing / not knowing what to say’ ‘It’s scary not knowing’
	Fear and anxiety	‘Lack of understanding about what is happening to them’ ‘When 1st diagnosed did not know what was happening ‘Confused, kept on asking questions ‘What’s a pancreas?’
	Communication	‘Did not know how to tell my friends’ ‘Need to know what to do to avoid hospital admissions’
	Gaining new knowledge and skills to self-care	‘Learn to deal with things when get more information’ ‘Learn a lot as you go along’ ‘Need people to understand what Diabetes is about and how it affects me / people make assumptions’
8.Coping mechanisms		[In general, a lack of awareness about coping mechanisms – not sure what strategies they need] ‘Rebelling against the condition by doing the opposing’ [being told what to do has the opposite effect] ‘Being independent’ ‘Being able to stay out of hospital/to play a way of doing this’ ‘Different between those recently diagnosed or not’
9. Role models		‘Learn from other people that have the condition’

Development of the ‘Getting Sorted’ Self Care Model: What the Self Care Model should look like.

Young people were asked three key questions in the ‘talking groups’ about how the programme to establish what they wanted the programme should look like:

3. What do you think would be the best way for us to deliver the programme: what would be the best way for you to learn?
4. When do you think would be the best day/time to deliver the programme?
5. Where would you like it to be?

Young people highlighted seven key points that provided the building blocks for the design of the ‘Getting Sorted’ Self Care Model. These are captured in the table below:

Key points	**Additional points to consider**	**Quotes from talking groups**
1. THE IDEA OF IT		‘Good idea’ ‘Brilliant idea’
2. WHAT DOES IT NEED TO LOOK LIKE?		‘Fun’ ‘Not boring’ ‘Exciting’ ‘Want to ‘do things’ ‘Need to be listened to’
3. WHERE?		‘Easy access / local / near home’ ‘Somewhere fun’ ‘Not in a classroom or school’ ‘Not at home’ ‘Not in hospital’ ‘Not a lesson’

		‘Leisure centre’ ‘Music centre’ ‘Swimming pool’ ‘Comfortable in school’ [1 or 2 stated school was ok]
4. WHAT DO YOU WANT TO DO?	**Challenging things** **Things could not do**	**Activity based:** ‘Rugby’ [hold at Bradford Bulls ground] ‘Rock-climbing’ ‘Swimming’ ‘Canoeing’ ‘Walking’ ‘Football’ ‘Ice-skating’ ‘Horse-riding’ **Other:** ‘Bowling’ ‘Cinema’ ‘Theme park’ ‘Music’ ‘Animals’
5. WHO WITH?		‘In small groups’ ‘People with same condition’ ‘On my own’ ‘Own age group – 12 – 15 and 16 – 18’ ‘Others said different ages together’ ‘No parents’

6. WHEN?		‘After school’ ‘Not school-time’ ‘Not weekends/weekends’ ‘All day’ ‘Lunchtime’ ‘9 – 5pm’ ‘Once a year’ ‘Regularly after been diagnosed’
7. TOPICS TO COVER	**Condition dependant information/things you don’t know?**	**[condition dependent information]** ‘learn things we don’t know’ ‘Where to inject’ [when out] ‘Where to inject’ [on body] ‘How to avoid hospital admissions Strategies to stay out’ ‘Managing diet’ ‘What is a pancreas’
	Impact of diabetes on future years	‘Drinking safely’ ‘Going out’ ‘University’ ‘Exercise’ ‘Career / work’ ‘Relationships’ ‘Pregnancy’ ‘Drugs’
	Body image issues	‘Weight’ ‘Injection sites’ ‘Doing inject’

	Communication	‘How to tell other people – including friends’ [communication skills] ‘How to deal with Doctors’ ‘Journey from diagnosis to being sorted’ ‘Everyday life stuff’ ‘How to be independent’
	Gaining confidence	‘Self-esteem / self-belief’ ‘Need to realise it does not stop us from doing things’ ‘Talk about Journey from ‘diagnosis to been sorted out’ ‘How to be independent’
	Need to break the ice difficult to talk to strangers	‘Need to break the ice difficult talking to strangers’
	To be able to take part in sports and other activities	‘To be able to take part in sports / other activities’
	Involving friends	‘Participants mentioned involving friends [or do we just empower them to tell their friends?’ ‘Issue of involving parents’ [raised by research team, not participants]

The ‘Getting Sorted’ Self Care Workshops.

From the tables above four self care workshops were developed. The aims format and content of the workshops were based on the information young people provided in the ‘talking groups’. The aim of the workshop dictated the choice of the sessions and physical activity within each workshop.

WORKSHOP	AIMS	KEY TOPICS AREAS	SESSIONS	AIM OF THE PHYSICAL ACTIVITIES UNDERTAKEN
WORKSHOP 1 **GETTING TO KNOW EACH OTHER**	To ensure young people feel safe and comfortable in the group setting	Ability to work with others Share experiences Form friendships	**Maintain a reflective diary**[colourful diaries provided] **Complete the ‘Circle of Friends’ activity** **Draw a body** Draw around a group members body and write on post its impact of their condition on their mind and body **Telling their story**	To help the group get to know and trust each other: • Sheep and Shepard • Rollerball • Swamp
WORKSHOP 2 **GETTING SORTED**	To help young people feel more in control and become more independent and responsible. Focus on relationship with parents and their condition	Feel more in control Become more independent Feel more responsible	**‘Confessions of a diabetic’**. Stupid things you’ve done in regard to your diabetes **Three Scenarios- living with diabetes** Presented to group to get them to explore positives and negatives and seek solutions based on: • Going out with friends • Your parents don’t trust you • Not coping	To focus on making young people take responsibility of themselves and to be more in control: • Reef Knot • Cone Orienteering • Mine Field

WORKSHOP 3 **COMMUNICATION AND RELATIONSHIPS WITH OTHER**	To help the young people to improve their relationships with their peers family and professionals.	Ways to improve relationships Communicate more effectively	**Crag Rats role play** • Friends scenario • Medical scenario	Emphasis on communication skills and team work: • Team Radar • Toxic Tubs
WORKSHOP 4 **FEELING 'SORTED'**	To help enhance the young peoples self/esteem/sense of self-worth and to work towards gaining a positive body image.		**Dream & Goals** • The Future • Develop an action plan **Guest Speakers** • Two young Leeds Rhinos players	Activities chosen by young people To undertake the last activity of the day with young people To present hoodies to young people

Evaluation of the 'Getting Sorted Self Care Workshops

The use of an evaluative framework within the project allowed for verification of the impact and effectiveness of the 'Getting Sorted' Self Care Workshops on young people that took part in the pilot on their health and well being. Clear aims were set in each individual workshop which served as a key point of comparison with the outcome information and was used as a schedule for the post interviews. This evaluation provided some evidence of the positive impact of young people on the health and well being and did not set out to measure the long term impact on the condition itself.

The framework for evaluation included formative evaluation in the form of recorded written feedback from young people about the workshops to enable changes to be made to the workshops and summative evaluation through post interviews that took place six weeks after the last workshop. The evaluation schedule included:

Formative feedback

Workshop 1 and 2

Young people we asked to say what the best things about the day were and what they wanted to do over the next few weeks

A Graffiti board was made available where suggestions and ideas could be posted up throughout the day

Workshop 3

The young people were given opportunity to put forward their ideas of activities for workshop 4 allowing young people to make choices and take control

In workshop 4

Young people were asked:

What they have learnt

About the workshops

One thing to change

One thing to keep

Any absolute no's

Summative Feedback

The table below illustrates the positive impact the workshops had on those young people that attended. It shows that the workshops met the aims they set out to achieve and provided a comfortable and relaxed atmosphere in which the young people were able to share their experiences of diabetes and have fun.

Young peoples' written feedback recorded from the workshops

Workshop	Aims	Findings	Supporting Quotes
1 **'Getting To Know Each Other'**	**To ensure the young people feel safe and comfortable in the group setting so that they can begin to work together.**	- Young people didn't feel labelled	'good not to be medically labelled' 'good not to focus on condition but as a person'
		- Enjoyed games activities	'enjoyed games' 'I felt I had gained trust, co-operation and communication through the activities'
		- Able to share problems and experiences	'makes a change to be listened to' 'sharing problems' 'talking with one another' 'first time I have had chance to talk about how I feel – don't usually have people to talk to at school'
		- Socialised	'enjoyed getting to know each other' 'socialising with others'
		- Felt safe	'felt safe to talk about parents, school, clinic'
		- Felt like others understood	'felt like other understood' 'reassuring to know how others feel and going through same things'
2	To help young people	No changes required – all	

‘Getting Sorted’	feel more in control of their condition, become more independent and be more responsible.	outcomes met	
3 **‘Communication And Relationship With Others’**	To help the young people improve their relationship with their peers, family and professionals. It aims to help them communicate better – whether that’s to tell people about their diabetes or ask more questions.	• Activities helped promote teamwork and communication • Drama was an effective way for the young people to recognise the support systems available to them	‘toxic tubs helped communication because of the difficulty of the task’ ‘toxic tubs emphasised teamwork’ ‘liked the drama’ ‘relate to it especially Cragrats [theatre company] real life situations could really relate to them and how we looked at sorting out the issues’
4 **‘Feeling Sorted’**	To help enhance the young peoples self-esteem/sense of self-worth and to work towards gaining a positive body image.	• Gained experience • Not alone • Talk more • Don’t have to explain feelings • Understand condition • Dreams & Goals activity enabled young people to pan for the future • Activities related to diabetes	‘experience mingled with other diabetics’ ‘don’t have to explain how ?I feel’ ‘understand condition within my life’ ‘the goals and dreams session was really useful’ ‘get to see the steps involved’ ‘brainstorm goals and ideas’ ‘found it difficult at first to think of goals and drams straight up, the group discussion helped’

The young people attended post-workshop interviews where they discussed each of workshops and whether, to them, they had been successful or not. As the supporting quotes illustrate in the table below, the workshops succeeded in providing the right support and guidance for the young people. This enabled them to develop self-confidence and trust, therefore learning to take control of their condition and feel more positive about the future. The interviews provided the young people with time to reflect on their experiences and comment on future developments regarding the programme.

Post Interviews with the Young People that took part in the pilot workshops

Question	Quotation evidence
Did we make you feel comfortable?	'yeah really comfortable' 'chatted…nothing pressurising just chatted' 'really relaxed' 'yeah definitely' 'got on well' 'trustworthy' 'yeah we played a couple of games' 'fairly, bit nervous at first' 'got the gist' 'yeah we just played games and got to know each other'
Did the workshop help you feel more in control of your condition?	"I think that acting drama group came in and that really helped…had something to relate to' 'Drew a picture of a person and put arrows at different parts of the body where diabetes effects them, bruising form injections and things like that' 'Lots of people didn't know what things were…helped' 'I don't think it made me more in control I think it was just cos we were all talking about it, it was better to know how other people felt and compare ourselves' 'you were all diabetic it was so much better cos we could all relate to each other'

	'a little bit but you're already in control of it before you actually go there' 'you just like getting to know how other people handle it as well' 'totally' 'yeah' 'we drew a big picture with all our friends , people we know and sort of support us and stuff' 'yeah. I was ok with it anyway but for other people who go on it.'
Do you feel better able to communicate with others?	'yeah like I said before we just talked and that helped' 'we were blindfolded and had to trust..that was good – trust building' 'yeah definitely, definitely' 'we could all just get on and communicate and say everything and stuff' 'depends if someone asks, if someone asks I'm not just gonna turn look at the weird' 'well if people want to know why not ell them?' 'yeah' 'yeah, I think they [Cragrats] did quite a bit just understanding from the doctors point of view how they sort of feel about appointments and then you know what you're feeling but not what your parents might be thinking or doctors' 'I had another appointment at the hospital I was much more confident at talking to the doctor' 'I went to a doctors appointment and told them the truth for once'
Did the workshop help to increase confidence and self esteem?	'yeah and also it was kind of a conclusion to the whole things' 'we just sat down and talked a lot and talked about what we thought of it' 'I can't think of anything wrong with it' 'we all felt confident by the end of it' 'that was the best thing abut it' [sharing experiences?]

	‘you did come to terms with it and you thought look we have to deal with this and have to face it and stuff’ ‘it was good yeah’ ‘I think we’re all confident it’s just when you first get it, it knocks a lot of that confidence’ ‘you can’t go to one workshop and after 6hours say yeah I’m the most confident guy in the world’ ‘you have to build your confidence up over time’ ‘yeah’ ‘I think so….by that point we all sort of knew each other all good mates’ ‘I can do my own injections’ ‘I’m able to talk to my parents you know like to back off’ ‘you’ve got other people to talk to who are friends who have got diabetes’ ‘I told the doctors and they said I’ve got guts cos they don’t know anyone who’s told them how it is before’

SECTION 5 - LESSONS LEARNT

Engagement of young people

The aim of this section is to reflect on the journey the project has taken and to highlight what when well and what could be done differently and learn and share from these experiences to support and enhance further research. The Bradford project was a pilot and was dependant on adopting a method that reflected the principles of engagement that enabled young people to be actively involved at every stage of the research project as reflected in all key government policy related to the Change for Children agenda.

Utilising the innovative Evaluative Framework created by Fawcett (2000) allowed for inclusively and as a result a large amount of data was gathered from young people. Careful consideration would need to be given if replicating the study to ensure that the only the required number of ‘talking group’ sites were accessed to meet the aims of the project or until saturation was reached. That said the focus of the project was to engage as many young people with diabetes as possible to give them opportunity to have their voices heard and contribute to the development of future service provision

The creative use of getting young people involved in analysing the data through listening proved invaluable as young people identified issues and questions that the research team overlooked. As young people gave their own perspective they analysed and categorised the data differently from the research team using their own language. For example the word ’ getting sorted’ ‘sorted’ was used frequently throughout the talking groups and used to form the title of the self care model.

The key message that has emerged from the project is the positive benefits of engaging young people at every stage of the process resulted in the development of an innovative self care model that was written ‘by young people for young people’ There were opportunities at every stage of the research process for true engagement and their views and opinions have been valued throughout. The young people that participated were genuinely excited and enjoyed been actively involved in issues that affected their own and their peer’s lives this message clearly came out in the summative and formative evaluation.

The focus of the project was to involve young people ‘in’ research and not undertake research ‘on’ young people. This led to the design and delivery of a creative and innovative self care model.

SECTION 6 - CONCLUSIONS AND RECOMMENDATIONS

Overall the findings are very positive and much has been learnt about what young people want from a self care programme. The development of services locally for young people with a long term condition is at its infancy and how this model will shape future service provision is not yet known. This is an exciting and challenging time for organisations across the region to adopt and continue to develop and deliver self care workshops for young people with a long term condition.

Future challenges

It is likely that the self care model developed with young people with diabetes can be transferable to other condition specific groups and it is likely that the model would be successful if utilised. Although the evaluation indicated positive health outcomes for those young people that attended the pilot workshops future research required to develop and refine the model. Recommendations for future work are:

- To repeat the process involved in developing the Bradford 'Getting Sorted' Self Care Workshops for young people with diabetes in order to develop a 'Getting Sorted' programme for young people with asthma;

- To implement and evaluate the effectiveness of the 'Getting Sorted' Self Care Workshops with young people with asthma;

- To compare the usefulness of the 'Getting Sorted' Self Care Workshops for young people with asthma, with that of young people with diabetes.

The key message from young people from the project is:

'Ask and listen to children and young people'

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APPENDIX 1

A Young Persons Journey to Self Care