In our first year we:

Secured an office space – we can be found at Longfield Hall, 50 Knatchbull Road, London SE5 9QY – 0203 879 9535

An overview of the project and what it has achieved in the above reporting period:

The Sickle Cell South London Link project funded by the Big Lottery Fund is providing free activities, information resources and workshops, building capabilities of existing support groups and developing 4 new support groups across the South Thames Regional Sickle Cell & Thalassemia network (STSTN). During Year 1 the project held a Launch Event (February 2017) at Lewisham Hospital and had a range of guest speakers talking about topics such as transitioning between children & adult services, raising awareness and were delighted that the Lewisham & NHS Choir performed!

Provided 29 activities During year 1 we provided 29 activities and 4 information workshops to children/young people and adults in relation to Sickle Cell Disorder (SCD). The workshops for children covered cooking & nutrition and discussing sickle cell, pain management, stress management using puppets for younger children

Held information workshops for children and adults

A talk was given by a welfare adviser on benefits, employment and disclosure at our Education Workshop – parents/carers were given a talk by Professor Simon Dyson on Care Plans, Sickle Cell & School Support

We built working relationships with the South Thames Network – image of map included

We developed flyers and marketing materials and disseminated this information so people knew we were here!!

We recruited 22 new volunteers for the project using our launch event, social media and making contact with volunteer organisations.

We planned and held a launch event – image of the choir and video

This was attended by support groups, service users, NHS Staff and community organisations.

Sickle Cell South London Link Project End of Year 1 Report September 2017

An overview of the project and what it has achieved in the reporting period:

The Sickle Cell South London Link project funded by the Big Lottery Fund is providing activities, information resources and workshops, building capabilities of existing support groups and developing 2 new support groups across the South Thames Regional Sickle Cell & Thalassemia network (STSTN). To date the project has provided 26 activities *(Appendix B),* provided 2 information workshops to children and young people in relation to SCD, and a further 2 workshops to adults/carers on Employment & Education. The project has also recruited 22 volunteers, of these volunteers we have some adults who live with SCD and others who have either Sickle Cell Trait, or a member affected by SCD or do not have SCD or trait or a family member affected but wish to support the project activities and raise awareness. Currently developing two new support groups and will be holding building capabilities workshops for existing support groups, as well as Educational Information Workshops for service users.

From September to February the South London Community Manager worked to set up the project (producing flyers and leaflets for publication purposes, undertaking outreach to inform and make links with external NHS stakeholders, community organisations, service users and schools to get the project off the ground) with the support of an internal member of staff worked one day a week (Friday's) in the South London Office to help with some of the overload and to support the Community Manager, this was agreed as an interim support post until a new person had been appointed.

Over the first year we have made strong links NHS Stakeholders, Service users, Community Organisations, Schools, (in our target boroughs). We will continue to work on engaging families, as well as adults, teenagers/young adults and children living with Sickle Cell Disorder. We will continue to work and build relationships with local community organisations and stakeholders to develop and build on relationships already established. We have successfully made strong links with target hospitals (Kings College Hospital, Guys Hospital, St Thomas Hospital & Lewisham Hospital) as well as others in the South Thames Sickle Cell & Thalassemia Network such as St Georges and Croydon Hospitals and local community services such as Wooden Spoon House based in Kennington. This service consists of, Consultants, Specialists Nurses, Genetic Counsellors, Welfare Advisor.

We have made some contact with Schools (primary and secondary) across the 3 boroughs & local universities via email communication, telephone and posting leaflets and posters about the Sickle Cell South London Link Project as requested by the schools.

We built up a database of 70 service users so far. From the 70 service users we have asked how they heard about us it has been through 3 mediums, hospitals, our Sickle Cell Society Facebook page, launch event and via support groups. We have also had a project website page added to the organisations website (Sickle Cell Society) which is under development, where people can find out more about our project as well as register for more project information.

Extent to which the work has been/continues to be informed by the community:

The South London Community Manager and Community Worker are continuing to build and forge relationships with the Specialist Sickle Teams across the STSTN. We ask service users what activities; topics they would like to be covered or to attend as well eval uate what activities service users would like to attend. For the children's activities, we ask children what they would like every time they register electronically for an activity, and have delivered most of the activities requested. We also ask adult service users what they would like to see delivered and suggestions such as employment and education workshops have been requested.

Project Progress update:

During Year 1, we have provided 26 activities for children living with SCD. Using evaluation forms we report the following:

70 participants were asked:

Question	measuring	Number achieved Target
Did you make new friends today? Strongly Disagree 1 to Strongly Agree 5	1c - People with SCD report feeling less isolated and more engaged in their community	45
Did you enjoy the activity? Strongly Disagree 1 to Strongly Agree 5	1c - People with SCD report feeling less isolated and more engaged in their community	65
Did the activity make you feel more confident? Strongly Disagree 1 to Strongly Agree 5	2c - People with SCD and their families reporting increased knowledge and confidence to maintain a healthy and active lifestyle	55
Did you learn new things today? Strongly Disagree 1 to Strongly Agree 5	2b - People with SCD and their families reporting increased knowledge and skills to manage their condition	58
Would you like to do other activities like this? Strongly Disagree 1 to Strongly Agree 5	4b - People with SCD and their families reporting improved confidence to take up additional services or take-up and maintain employment	65

The data above demonstrates that the project has met its outcomes of reducing isolation and engaging individuals living with SCD in their communities.

Volunteers

Target in Year 1 – To recruit 20 volunteers

Target Met – 22 volunteers recruited for the project

22 volunteers have been recruited of which 12 volunteers have SCD or a family member. Two of the volunteers, who both have SCD, assist with administration by inputting of data onto our systems. One has begun assisting with outreach by contacting employment organisations and schools to generate interest for our workshops on employment and education. All other volunteers have assisted with children activities as an additional adult keeping children together and applying to the activity.

9 volunteers said that they have met new people and feel more part of the community. Some comments made were:

- Having more people to talk to.

- It has helped with my CV.
- Be an example for children living with sickle cell.
- I don't have or haven't known anyone with sickle cell but now I'm more aware of it and I joined the foundation because I deeply felt the need to give back to the community and those who suffer.
- Opportunity to get out of the house.

Support Groups

In the first year we have developed two new support groups:

Snack & Chat Support group for Parents/Carers & Children living in Lambeth, Lewisham & Southwark – Parents/Carers meet approximately every 3 months to share, gain peer 2 peer support and make new friends – this is also an opportunity for parents to meet other parents with children living with SCD.

We helped Bromley NHS Trust develop a new support group for parents/carers of children living with SCD.

Bromley Sickle Cell Team asked if we can help them set up a support group for families living in the borough as this is a group that is isolated and currently do not have a support group.

Bromley Health Care & Sickle Cell South London Link (SCSLL) Fun Afternoon Event

This was a joint event hosted jointly by Bromley Health Care and SCSLL and 18 individuals attended. The event consisted of a variety of fun games and activities together with entertainment of a comical magician who held the attention of both the children and the adults. A buffet of food, desert and drinks was provided.

Valuable feedback was collected for similar activities in the future. A child expressed to its mother that 'it was the best day ever!'

Moving forward into Year 2 (September 2017 – September 2018) we will:

- Continue to run free activities for children
- Provide workshops for adults & children covering various topics such as:

  Employment & Benefits, Education & Care Plans, Stress Management, Relaxation, Teenage Transition, Self-Esteem & Confidence, Pain Management
- Provide workshops for new and existing support groups to network, connect, and learn from one another
- Develop two more new support groups in conjunction with Kings Hospital & St Thomas Hospital, for disabled adults living with SCD and parents/carers and children
- Provide support and workshops for teenagers

To find out more about our project please contact donna.prendergast@sicklecellsociety.org or call 0203 879 9535.

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