

Innovating for Improvement

Celebrating Difference: Improving psychological well-being in children and young people living with chronic physical illness

Barts Health NHS Trust



Project title:

Celebrating Difference: Improving psychological well-being in children and young people living with chronic physical illness



Lead organisation:

Barts Health NHS Trust



Partner organisations:

East London NHS Foundation Trust



Chickenshed Theatre



Project leads:

Tara Shea and Dr Jennie Robertson

Contents

About the project

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Part 1: Abstract	3
Part 2: Progress and outcomes	4
Part 3: Cost impact	20
Part 4: Learning from your project	22
Part 5: Sustainability and spread	
266	
Appendices	
288	

Part 1: Abstract

This project sought to improve psychological well-being of children and young people (CYP) with chronic physical illness, and their carers, through an innovative group intervention based on narrative therapy and therapeutic play which utilised theatrical performance and encouraged the development of CYPs' stories focused on their strengths and abilities.

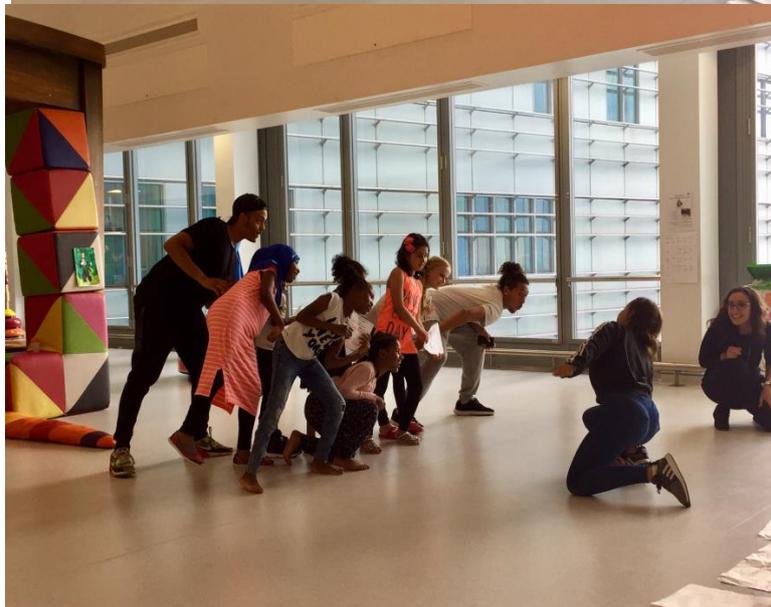
Groups were attended by 47 CYP with a mix of conditions being treated at the Royal London Hospital through Barts Health NHS Trust. Participants overwhelmingly reported that it was incredibly helpful to meet others who understood their experiences. All CYP, carers and referring clinicians would recommend the group to others. Preliminary quantitative data analysis suggests improvements in CYPs' experiences of depression and anxiety following the intervention, with some deterioration 3 months later. CYP and carers self-reported improved psychological well-being after the groups which had reduced at follow-up, but was generally improved from pre-intervention. This may suggest a need for sustained therapeutic support of CYP and their families.

Major challenges included: practical hurdles to CYP and carers' attendance at the groups; obtaining outcome measures from participants; and struggles accessing project funds through the Trust. Having a clear agreement at outset with finance and key Trust members, and identifying key supporters to assist with difficulties would have been beneficial.

Although financial constraints mean that the intervention cannot continue in its present form without external funding, it has been agreed within the Trust that an on-going support group for CYP and carers to discuss challenges and share strategies would benefit patients.

Figure 1. Photographs of children and young people attending the group





Part 2: Progress and outcomes

The intervention

Health Heroes is an innovative one day, one off group intervention for children (6-11 years) and young people (12-17 years) living with chronic illness and their carers, which incorporates narrative therapy, therapeutic play and drama, tailored to the developmental needs of children and young people. The group was offered to separate groups on 8 days over 15 months during school holidays. The intervention was offered to CYP with varied health conditions and was also delivered directly to carers. The group was facilitated by a range of professionals and co-ordinated across two teams, the Play Team led by Tara Shea and the Paediatric Liaison Team (PLT), where Dr Jennie Robertson is employed. The PLT is provided by East London Foundation Trust and provides psychological and psychiatric support to CYP and their families accessing services at the Royal London Hospital. A breakdown of the day's activities is summarised below in Table 1.

Data collection

We evaluated the project using a range of outcome measures (see Appendix 1) before and after each group (immediately post-intervention and at 3 months' follow-up), including: impact of current difficulties; psychological well-being; healthcare management; and quality of life. These measures were used consistently throughout the project.

The Project Team completed a Plan-Do-Study-Act (PDSA) cycle at the end of every group, and a reflective journal was kept throughout the project. Group attendance rates and demographic information were also captured.

Table 1. Breakdown of the intervention

Time	Activity			Facilitator
	Child	Young person	Carers	
10-10:30am	Registration			Project Assistant
10:45-11:30am	Ice breakers			Group Leads and Facilitators
	What is a superhero? What challenges do superheroes face? How are we like superheroes? Development of superhero characters	What is a hero? What challenges do heroes face? How are we like heroes? Development of identity boards		
11:30-12:30	What are you the challenges you face? What are the initiatives you use to manage these challenges?	What are you the challenges you face? What are the initiatives you use to manage these challenges?		
10.45 – 11.30			Free time, (optional sheets to complete to stimulate thought about challenges faced as carer of CYP with a chronic illness)	
12:30-13:30	Lunch			All
1:30-3:15	“Bringing to life” of superhero characters for a performance	Development of preferred identities for a performance		Chickenshed Theatre
1.30 – 3.15			Facilitated group discussion about challenges faced as carer of CYP with chronic illness and coping strategies	Group Leads
3:15-4:30	Performance and certification ceremony			All

Project outcomes

Group attendance rates

Table 1. Attendance rates

Group	Attended	Cancelled	Did not attend
Children (n=38)	28 (74%)	4 (11%)	6 (16%)
Young people (n=29)	19 (66%)	3 (10%)	7 (24%)
Total (n=67)	47 (70%)	7 (10%)	13 (19%)

- 67 CYP and their carers agreed to attend the intervention of which 47 (70%) attended.
- Reasons for non-attendance included: conflicting commitments on the day; not wanting to miss school; difficulties getting time off work; difficulties arranging child-care for siblings; anxiety around participation; and illness.

Demographic information

The demographic characteristics of participants are provided in Appendix 2, and summarised in Figures 2-6. The data suggests that the intervention was acceptable to a range of ethnicities and medical specialties, as well as males and females. The lower number of young men than young women who attended the intervention might reflect referring clinician's thinking about psychological well-being in relation to gender, or may be connected with how young men felt about being part of, or aspects of, the group intervention, but without collecting specific data, it is not possible to draw any conclusions on this point. One feature of the cohort sample is that it is heavily skewed by referrer interest in and knowledge about the group. For example, we had a high number of haematology patients attend the group as a result of having an enthusiastic and engaged clinical psychologist working in the haematology team.

Figure 2. Participant gender

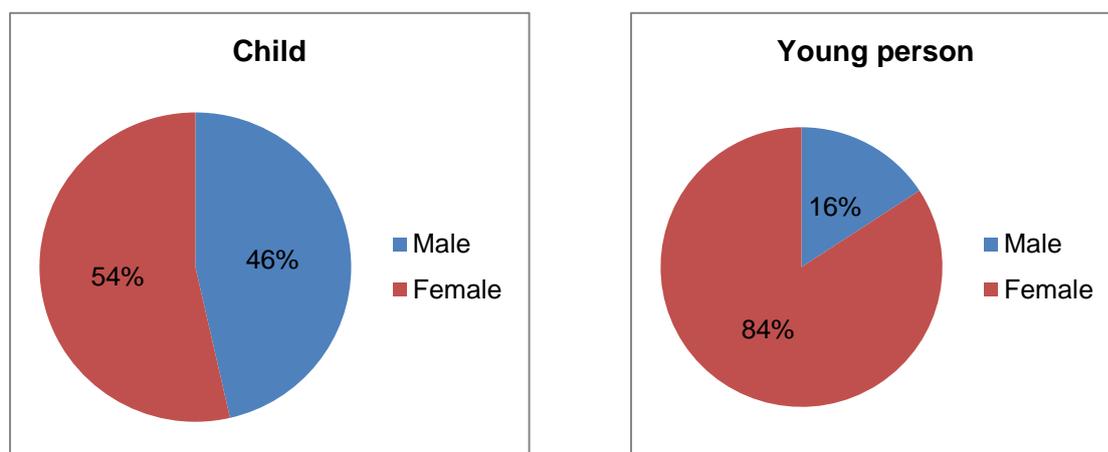


Figure 3. Ethnicity of participants by group

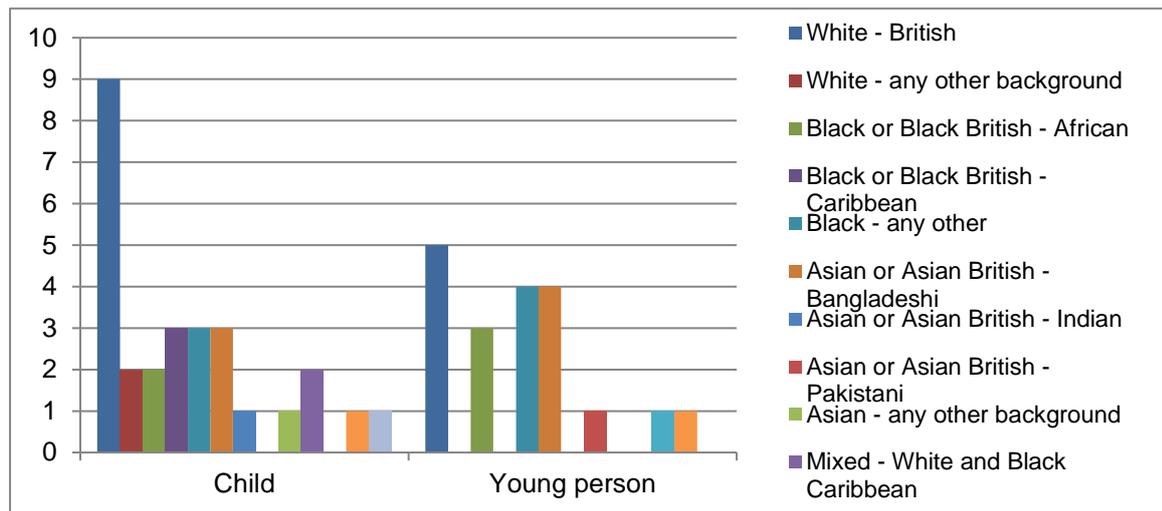


Figure 4. Medical specialty management by group

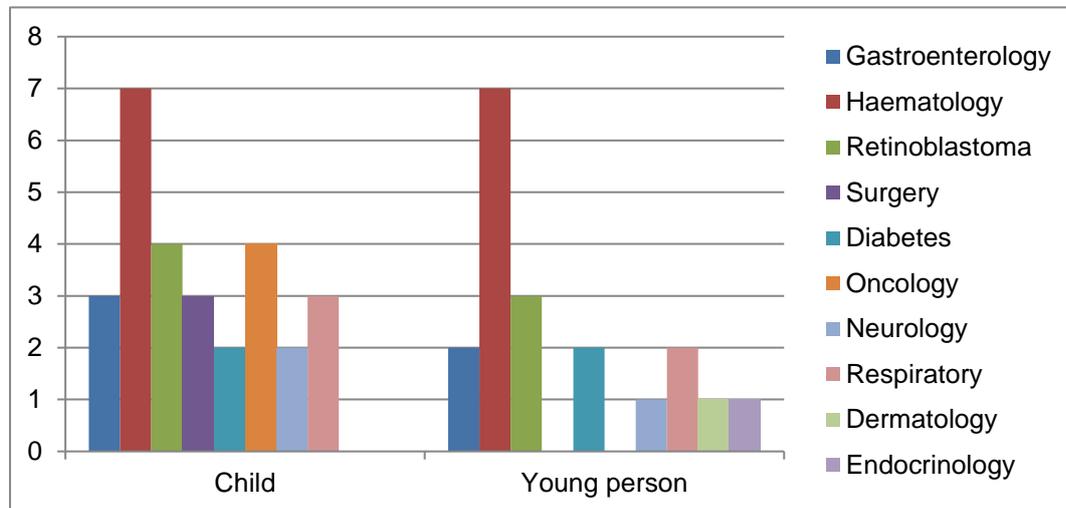


Figure 5. Referring profession by group

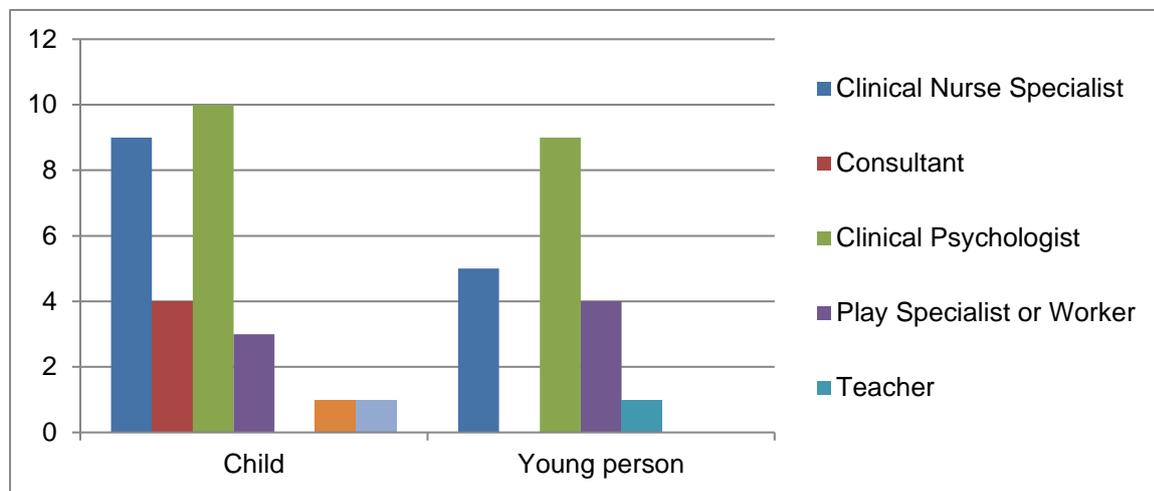
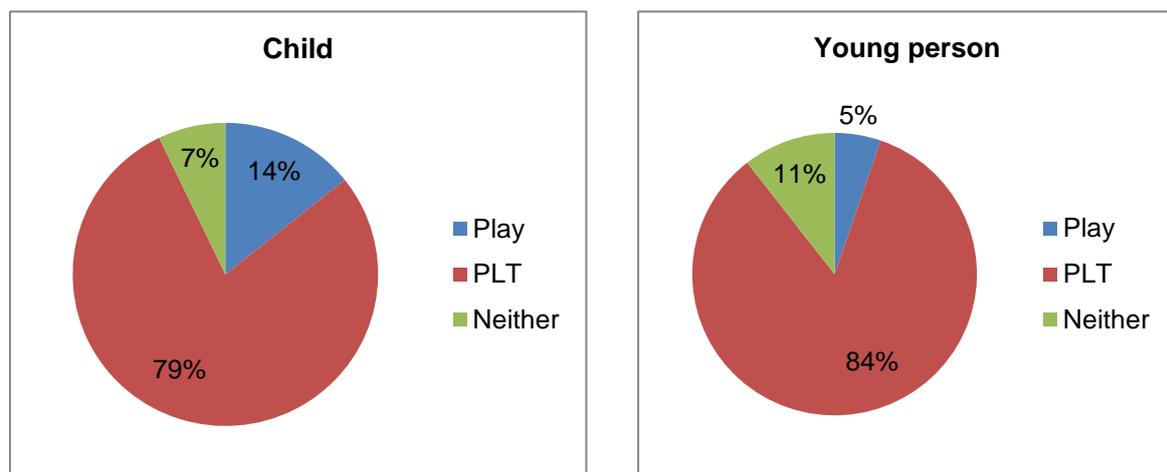


Figure 6. Previously referred or currently open to psychosocial services at the Royal London Hospital



Outcome measure data

Average scores collected pre- and post-intervention and at 3 months' follow-up are provided (Appendix 3). Trends are described below; these must be interpreted with caution as the data set is incomplete (sample sizes are detailed in Appendix 3). In particular, the follow-up data is sparse due to not yet being at 3 months follow-up for the final 3 groups. Changes to physical functioning could also account for changes observed.

The impact of the intervention is summarised in table 2, below.

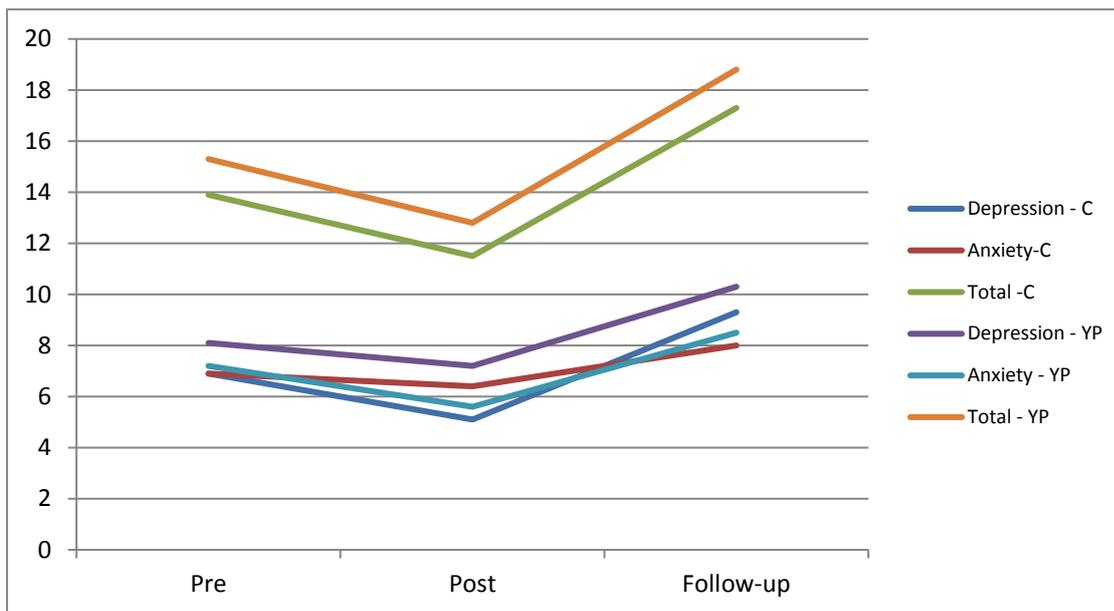
Table 2. Summary of outcomes

Measure	Children		Young people		Clinicians
	Following group	3 months post	Following group	3 months post	3 months post
CYP's psychological wellbeing (depression and anxiety – PI-ED)	Improved	Reduced (but in excess of baseline)	Improved	Reduced (but in excess of baseline)	Improved
Carer psychological wellbeing (depression and anxiety- HADS)	Improved	Returned to baseline	Improved	Reduced (but in excess of baseline)	N/A
Quality of life (PedsQL)	Improved	Reduced (but in excess of baseline)	Slight reduction	Further reduction	Improved
Carer assessment of CYP's quality of life (PedsQL)	Slightly reduced	Improved (return to baseline)	Slight reduction	Further reduction	N/A
Healthcare management (Likert)	Reduced	Improved (but below baseline)	Improved	Reduced (but in excess of baseline)	N/A
Carer assessment of healthcare management (Likert)	Reduced	Further reduced	Improved	Returned to baseline	N/A
Impact of health condition (GOMS)	Improved	Further improvement	Improved	Reduction in improvement (below baseline)	Improved
CYP satisfaction with CYP intervention	83% found it helpful		80% found it helpful		N/A
Carer satisfaction with CYP intervention	92% found it helpful		100% found it helpful		N/A
Carer satisfaction with carer intervention	85% found it helpful		100% found it helpful		N/A
Would recommend group?	100%		100%		100%

CYP psychological well-being

CYP experiences of depression and anxiety improved post-intervention, but deteriorated 3 months later (PI-ED). We are unable to report on the changes to psychological well-being for children (aged 6-7) due to incomplete data at post-intervention and follow-up (CORS). Both CYP and carers self-reported improved psychological well-being after the groups (see Appendix 3) although this had reduced at follow-up, it was generally improved from pre-intervention. Referring clinicians reported that they noted improved psychological well-being for CYP at 3 months (Likert).

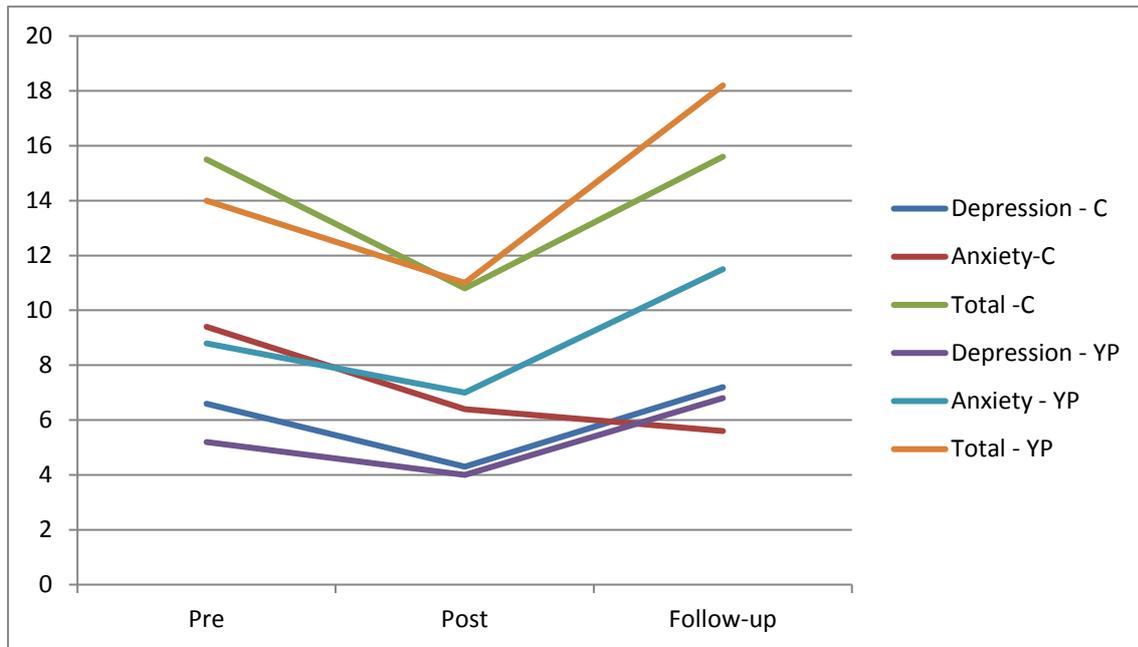
Figure 7. CYP self-reported depression and anxiety (PI-ED)



Carer psychological well-being (HADS)

Experiences of depression for carers had improved after the group, but deteriorated at 3 months. Experiences of anxiety for carers also improved post-intervention. These improvements were maintained for carers of children, but decreased for carers of YP.

Figure 8. Carer self-reported depression and anxiety (HADS)



Quality of life (QoL)

QoL measures for children improved following the group, although these had reduced at 3 months. Children's carers reported a slightly reduced QoL for their children following the group although this had improved to only marginally below pre-intervention levels at 3 months. For YP, there was a slight deterioration post intervention which fell further at 3 months. Carers of YP reported improvements in quality of life although these had fallen below the starting point at 3 months (Peds-QL). Clinicians reported improved QoL for CYP at 3 months (Likert).

Figure 9. CYP quality of life (Peds-QL)

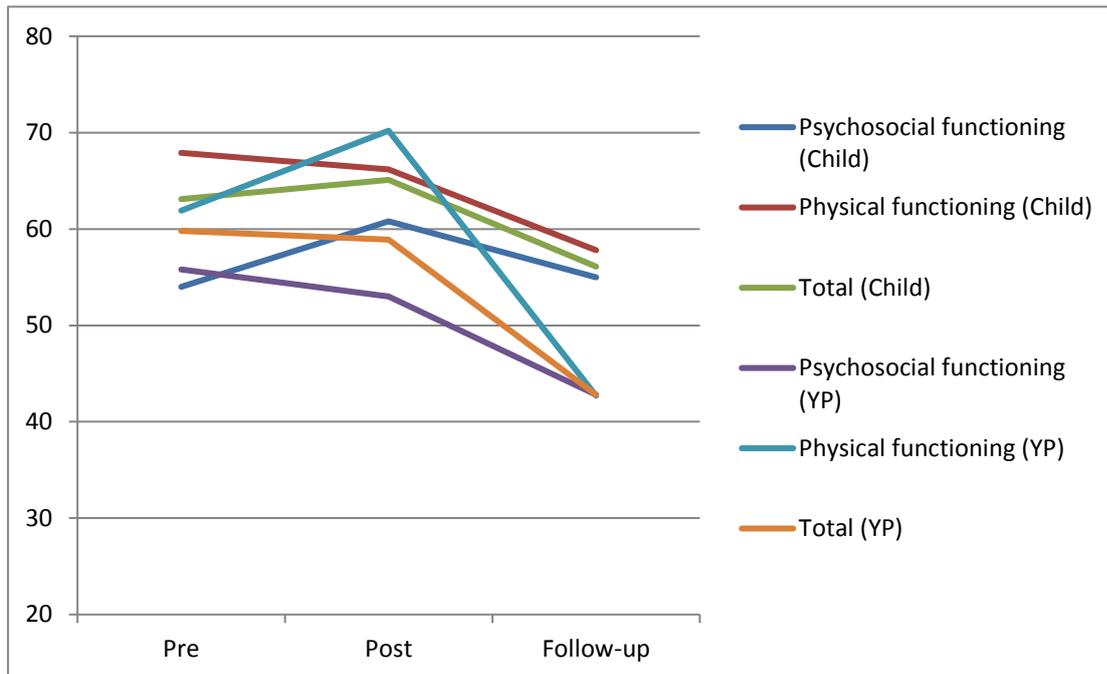
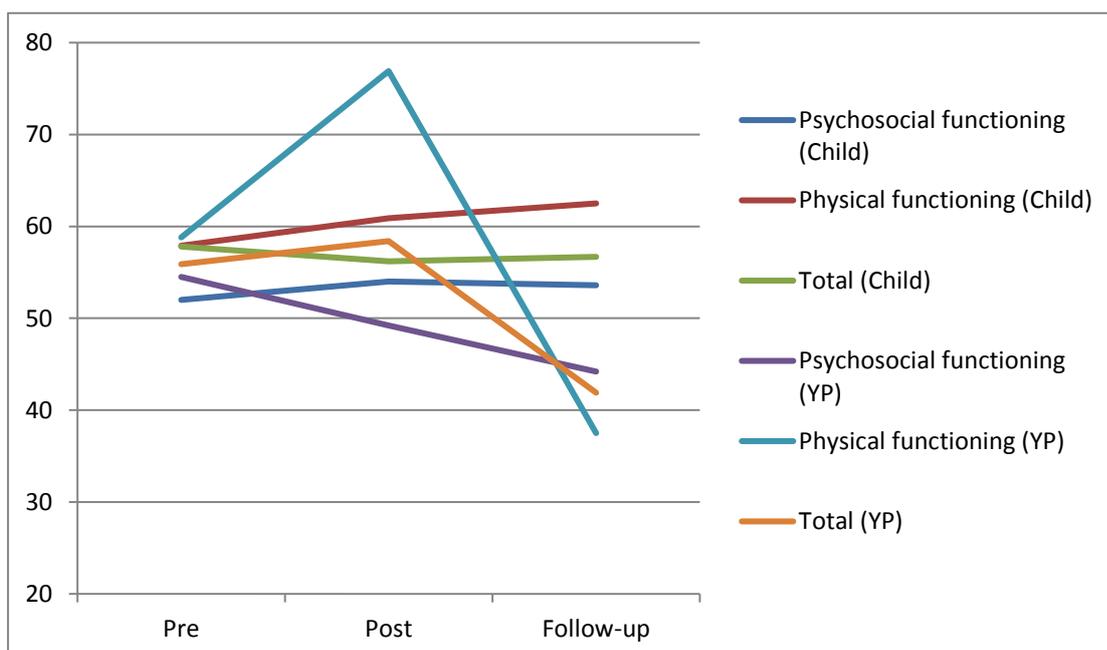


Figure 10. Carer assessment of CYP quality of life (Peds-QL)



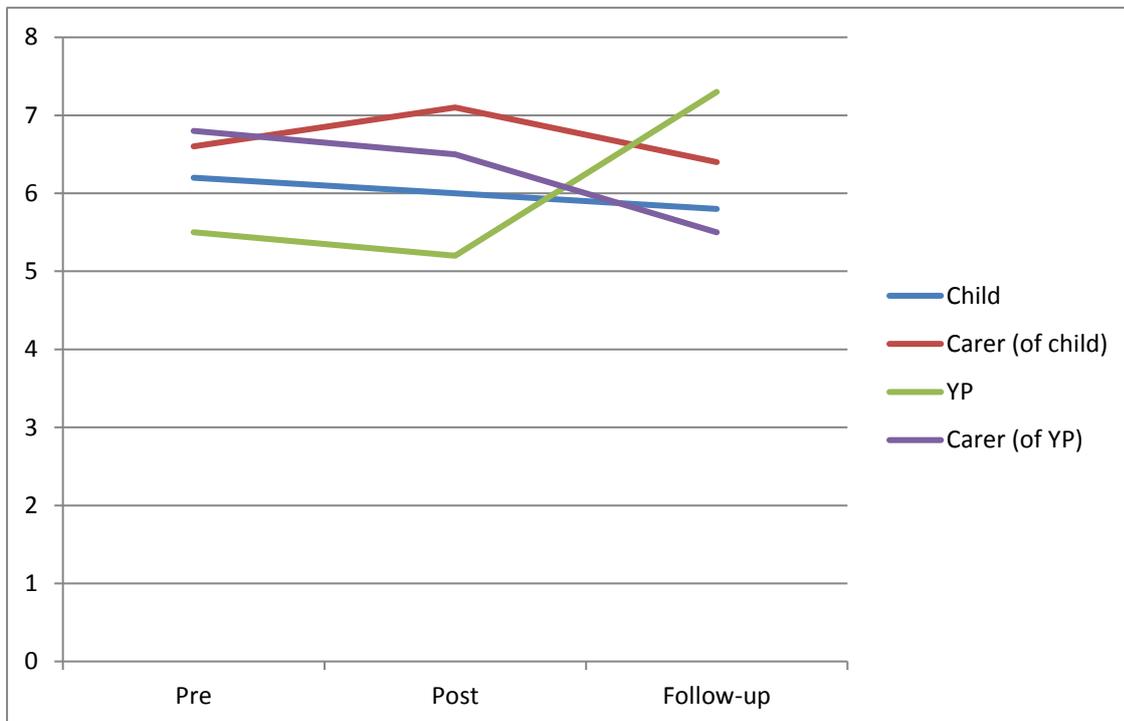
Healthcare management (Likert scale)

In relation to the management of their condition, children experienced a decrease following the group, which improved at 3 months. However their carers reported a decline at both post-intervention and follow-up. YP and their carers initially noted an improvement after the group, but this wasn't maintained at follow-up. Clinicians noted improvements in CYP's health management at 3 months

Impact of health condition (GOMS)

Children reported a reduction in the negative impact of their condition following the group and at 3 months. YP noted a less significant impact of their condition post-intervention, but this had increased at follow-up. Inversely, carers felt that the impact increased for children and reduced for YP post-group, however, save for YP themselves, all others felt that there had been a decreased impact at 3 months. Clinicians reported a reduction in the negative impact of the health condition at 3 months.

Figure 11. Impact of health condition (GOMS)



Satisfaction with the intervention

The majority of children (83%) and YP (80%) found the group helpful. This was echoed by the carers who reported the group to be helpful (children 92%; YP 100%) with all reporting that the intervention was tailored to the CYPs' needs. The majority of carers also reported that the carer intervention was tailored to their needs (carers of children 85%; carers of YP 100%). All CYP and carers would recommend the group intervention. All clinicians reported that the group had been helpful to YP, with 85% seeing benefit for children. All clinicians reported that they would recommend this group.

Summary

The experiences of the impact of the group were mixed with some benefits being noted post-intervention but not maintained at 3 months. This might highlight the need for sustained therapeutic support to integrate resilience strategies into daily life. For some participants, focussing on their experiences initially resulted in worsened symptoms, which may highlight the need for intervention to support CYP to express concerns and challenges about living with a chronic illness. Different participant groups had different perceptions about the impact on well-being. It may be that CYP, carers and clinicians have different perspectives on, or definitions of, “the problem” faced by CYP.

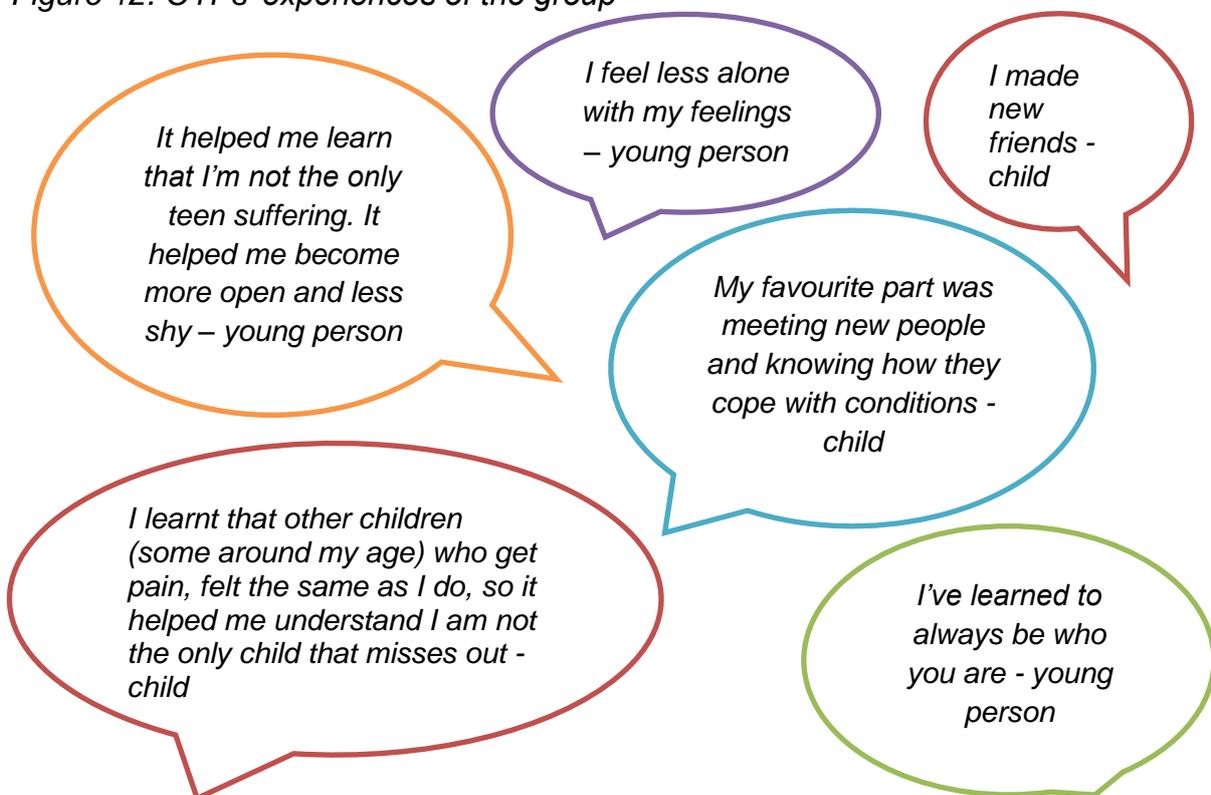
Qualitative data

At the end of each group, the CYPs' experiences of living with chronic illness, and the experiences of carers were documented as key categories (Appendix 4). Examples of the identity boards and superhero characters developed are in Appendices 5-6.

Experiences of the group

The groups were positively experienced by almost all children who enjoyed making new friends; learning coping strategies; playing games; doing theatre work; talking about feelings; learning about their condition; and having fun. The YP reported that they liked the staff who led the group, playing games, and making posters but they did not all enjoy doing theatre work as they felt shy or did not like performing. Some children shared wanting to talk more about their conditions, including rehearsing responses during medical procedures. Not every child felt comfortable discussing their feelings.

Figure 12. CYPs' experiences of the group



The CYP reported hearing about others' experiences and learning new coping strategies as helpful. Carers reported that the group helped CYP to feel less alone and to talk about their condition and feelings, and that this boosted their confidence. All carers said the group had helped them to feel less alone, and had given them an opportunity to talk.

Three months' later, CYP reported continuing to feel less isolated, more confident in being themselves, and more confident in their ability to cope with challenges. The group helped some CYP and carers recognise that they needed more support, which they are now accessing through the Project Team. Carers reported being more appreciative of how CYP managed their illness.

Figure 13. Carers' views on how the CYP experienced the group

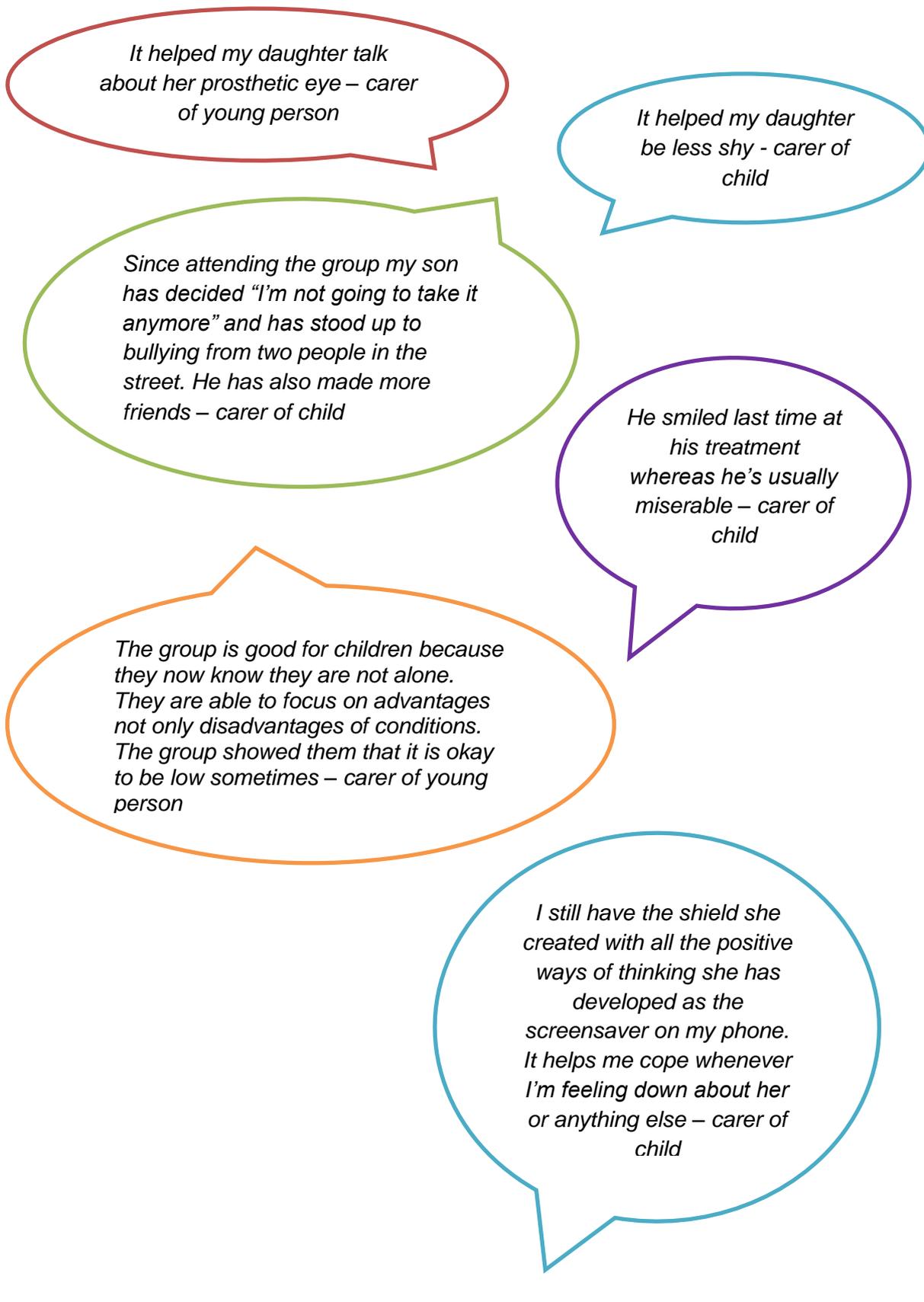


Figure 14. Carers' experiences of the group



Part 3: Cost impact

The PLT provides a service that is commissioned by Barts Health NHS Trust and provided by East London NHS Foundation Trust. The Play Team is commissioned to Barts Health NHS Trust by the Clinical Commissioning Group/NHS England. The service is paid for through funding provided by the commissioners. The current cost of service provision is covered by the salaries of the existing PLT and Play services.

The cumulative spend on the project as at end of October 2017 amounted to £43,207.00; leaving a balance of £16,949.50. Of the balance of £16,949.50 there is a proposal to spend £13,337.57; bringing the total spend to £56,544.60 with potential underspend of £3,611.90 at the end of the project life (see Appendix 11 for financial report template). Each group cost approximately £800 to deliver. There was no direct financial impact on any other service, and the Project Team had their cost of participation paid for from the project budget.

The project was a trial of a more efficient way to deliver psychosocial services with better outcomes that will enhance the psychological experience of patients. We have not been able to quantify any cost savings as there is no distinct record of the cost of the existing pathway/service for comparison with the new pathway/service, and the relatively small scale of the project was not a sufficient basis on which to carry out a cost-benefit analysis. In addition, it is difficult to measure cost savings that may be spread across numerous services and budgets throughout the Trust, and it may be that other benefits of the group have not yet been observed.

We predicted that there may be additional cost savings to the Trust should the intervention lead to improved treatment adherence, improved quality of life, a reduced need for pharmacological and repeat interventions, and an improved patient-service relationship. We have not been able to reliably measure impact against these predictions but qualitative feedback from referring clinicians suggests that there may have been savings to the Trust in the following areas:

1. Reduced hospital admissions (one bed costs the Trust £350 per night);

“Parental and child anxiety had reduced dramatically. There have been no unrequired hospital admissions since X attended the group. Both she and her parents seem happier and more relaxed. This was a turning point of this family”

2. Improved adherence with medical procedures;

“He successfully completed the clinic test, which he failed previously and wasn’t even willing to attempt”.

“We have managed to have cannulas done with virtually no intervention.”

3. And improved engagement with services (which may be because of increased confidence in talking about CYP psychosocial wellbeing during clinic

appointments).

“Since the group she has started attending and been much more vocal during the Youth Empowerment Squad (a Barts Trust Youth Forum) meetings”

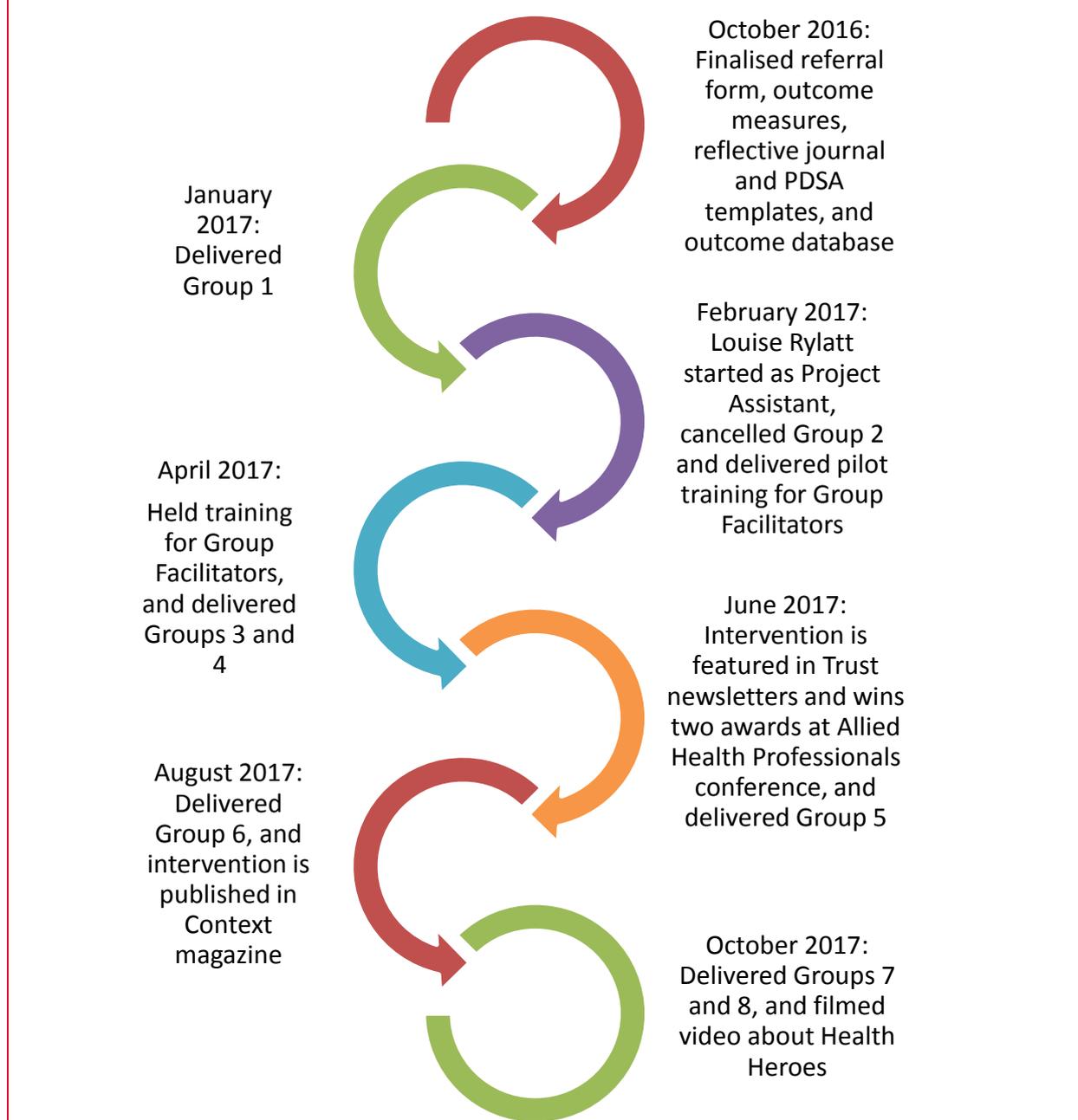
“I saw him recently for a clinical test and he came down to find me to ensure he would have support during the examination, was able to say what he needed and was comfortable talking to me and the doctor, which was very different from his last clinic appointment.”

Part 4: Learning from your project

Milestones

A table documenting key milestones is provided in Appendix 7. This table does not include regular meetings within the project team or other organisations. A visual representation of some of the key milestones of the project is also provided (see Figure 15). Highlights for the Project Team included Louise Rylatt joining the team, being featured in several publications, winning two awards, and filming a video about participants' experiences of the project. Perhaps our biggest milestone was identifying a need for psychosocial group support for CYP and their carers that was not previously provided, and both developing and delivering an intervention that was well-received by CYP and carers alike.

Figure 15. Key milestones over the course of the project



Key learnings

We kept a reflective journal to document the challenges encountered and our responses to them across the project. We also used PDSA cycles to reflect on the delivery of each intervention and to make planned improvements (see Figure 16 for key changes to the intervention). The key things we learnt in the areas of resource, processes, organisation, and service user involvement have been extracted and are reported below (for further detailed information about the specific learning associated with each of these areas, please see Appendices 8-9):

Resource

- Clear instructions on how to complete outcome measures helps improve return rates, as does providing accessible modes of returning information to the Project Team.
- The use of standardised templates in all correspondence with participants ensures consistent service provision.
- The availability of regular supervision at the start of the project would have assisted in building confidence in the application of narrative therapy within this project.
- Ensuring available resources for group refreshments was directly linked with positive user experience.
- Being able to offer childcare for siblings would have enabled a significantly greater number of potential participants to attend the group.
- Being available to offer further psychosocial support or signpost onto appropriate services was directly linked with user experience.

Processes

- Piloting of the selected outcome measures and co-completion of the measures with participants may have pre-empted challenges in obtaining complete data sets.
- Having clear processes in place for family contact during health emergencies is crucial.
- Improving the training for Group Facilitators (e.g. more “live” practice) may have increased numbers of potential Group Leads for the project.
- Regular team meetings support the project’s implementation by allowing the Project Team to address problems, review progress and take any corrective action.
- Promoting the project within and outside of the Trust sustains morale and improves shared learning.
- Having specified roles for the running of the project on the day ensures better service delivery.
- Improving processes for recruitment/referral to the intervention, specifically for YP, could improve participation rates.
- Including a specific focus on the branding of the intervention (including publication to protect intellectual property) is a key need.
- Holding de-briefs immediately after the running of the intervention as part of the PDSA process promotes optimum learning opportunities.

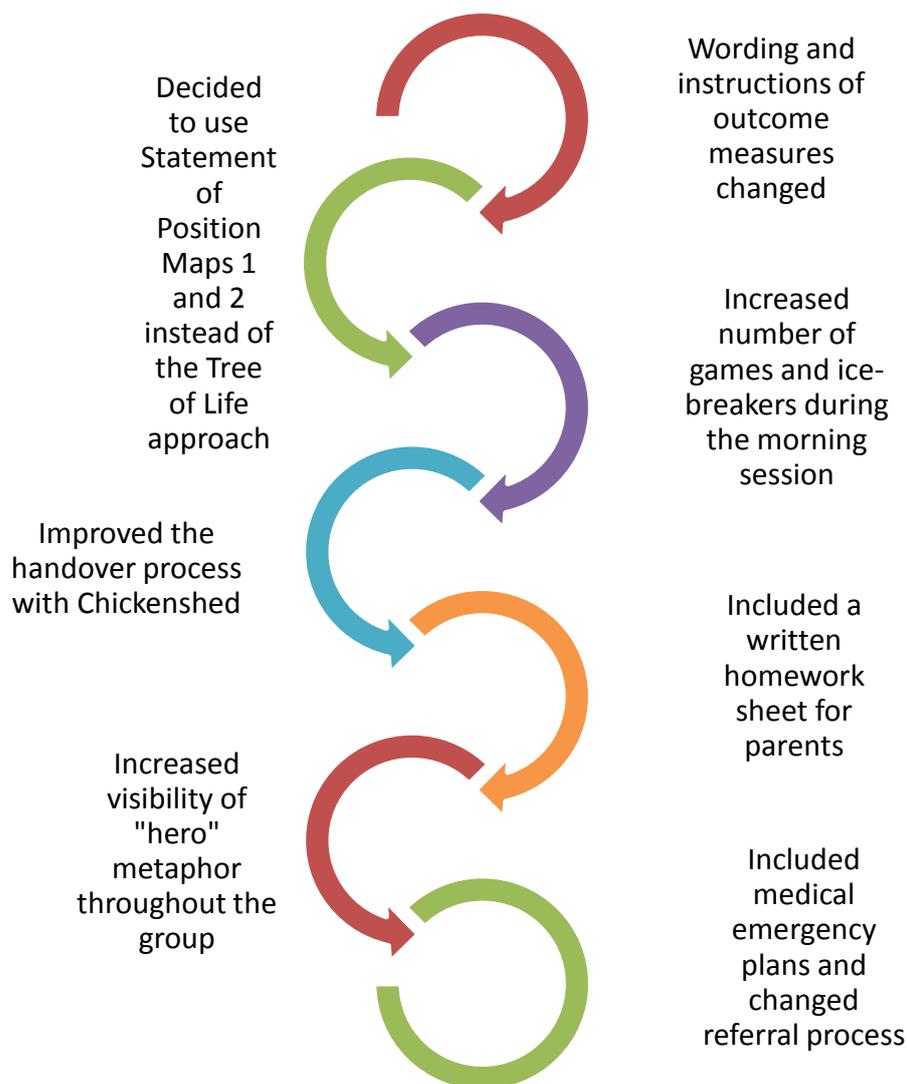
Organisation

- Identifying key “supporters” or “enablers” within senior management is vital to address difficulties within the project.
- It may be useful to have a “petty cash” pot in future projects to avoid challenges in accessing funds for materials and refreshments.
- Identifying a key clinical contact for each participant would have supported the sharing of information and data collection.
- Professionals from different disciplines can enjoy working together to deliver psycho-social interventions, and this multi-disciplinary team working can improve engagement with participants.

Service user involvement

- Collaboration with service users and carers is invaluable in the review process and refinement of the project design.
- Videos and using the written testimony of participants brings “life” to any project, and can empower participants.

Figure 16. Key changes to the intervention



Personal reflections

We felt extremely lucky to have been awarded the grant, though initially overwhelmed with the reality of the project and wondered if we'd be able to deliver its objectives. The support of The Health Foundation and the Support Consultants has been helpful and sustained the continuation of the project.

There have been some stumbling blocks along the way, including: obtaining data; accessing funds via the Trust; and having no computer access for six weeks as a result of the NHS cyber-attack. Issues in accessing funds have put the project and our reputation at risk as we have not always known if we would be able to: a) deliver the intervention; or b) deliver it as agreed. The support of the Divisional and General Managers has assisted our conversations with the Finance Department. Having a clear agreement with Finance and other key members of the Trust prior to starting the project, and having a petty cash fund, could have helped us to avoid any such obstacles and we would advise this for any future or similar projects.

We had some reservations over whether or not the hero metaphor would be acceptable to YP and encountered challenges in receiving referrals to the YP groups. In reality, we were moved by the YPs' response to the intervention, and greatly enjoyed working with them. In fact, we have been touched by responses of all the CYP and carers who have participated in the project. The impact of the project became particularly apparent when filming the video for The Health Foundation; hearing participants talk cemented how life-changing it was for many to meet others who understood their experiences, particularly carers.

The project has taught us a great deal about multi-disciplinary team (MDT) and partnership working. We were amazed by how many professionals from a range of disciplines were interested in the project, and wanted to facilitate it in some way. We have also learnt how to draw on our individual strengths and experiences. We are a small Project Team but have used shared working to make the project a success and to meet various deadlines. Our experience of the project suggests that it may be useful to set out expectations clearly with outside partner organisations from the start. As the project progressed we found the afternoon drama sessions felt less consistently tailored to the individual characters, strengths and abilities of CYP which may have affected the way in which the CYP's alternative stories were 'thickened' from a narrative therapy perspective.

We now face the challenge of having identified a clinical need but not having the resources to deliver the intervention in its current format. The process of doing this project was necessary in allowing us to identify the key "ingredients" necessary to provide an effective intervention. This knowledge, combined with the support of key members of the Trust, a bigger team, and a wider shared responsibility, will help us to sustain the benefits of the project for future participants.

Part 5: Sustainability and spread

Sustainability

The project has focussed attention on the importance of considering CYPs' mental health within a physical healthcare setting, as well as the well-being of their carers. This gives us a good rationale for sustaining the intervention but the current model requires adaptation.

The financial cost of the intervention in its current form (approximately £800 per group) is not sustainable in the long-term without external funding. In addition, the time costs of running the group (administration, following-up referrals, running the group as a small team, and the group as a full-day intervention) are not sustainable. Our outcome data also suggest that a full-day intervention is not necessary, and that the most beneficial aspect of the group is meeting others with shared experiences.

We met with the Acute Children's Therapy and Play Manager and the Managers of the PLT to discuss the potential options for future service provision for groups of CYP and their carers. It was agreed in the meeting that a rolling group for CYP and their carers to meet and discuss the challenges of managing chronic illness, and to share strategies, would benefit patients. Key features of such a group would include:

- Being strengths-based (but not necessarily using a hero metaphor) and using narrative therapy techniques;
- Being less time-intensive;
- Being open to "repeat participants";
- Being provided by a wider range of professionals within the Play Team and PLT;
- Being held regularly with the potential for YP to act as Group Facilitators for children;
- Having less outcome measures to complete;
- Having access to art materials;
- And having an identified Project Assistant to manage the project, as well as back-fill staff for clinicians running or facilitating the group.

There were mixed responses to the Chickenshed Theatre intervention, with some children enjoying playing games and making up songs, and the majority of YP feeling shy and not wanting to perform for others. In response to this, we have removed the theatre aspect of the intervention and suggested that future child groups should be held on days where existing therapeutic activities are happening within the Trust that the children can access immediately after the group in order to engage in therapeutic play.

Spread

Our approach to spread is primarily through dissemination of the outcomes and learning, and our strategy moving forwards will be focused on conferences, other events, publications and networking. We are also in the process of developing a treatment manual that will aide others in replicating the key benefits of the intervention. Below is a list of ways in which we have already publicised the intervention:

Conferences and meetings

The Project Leads have presented the group at numerous conferences and meetings, including: the National Association for Health Play Specialists Conference; The Allied Health Professionals (AHPs) Conference (Health Education England); The NHS Academy of FAB Stuff; and internal audit meetings within the Trust. The Project won two awards at the AHPs Conference: Best Overall Project and Best Contribution to AHPs in Action (see Appendix 10).

Publications

An article introducing the intervention was published in *Context* (a Family Therapy and Systemic Practice journal) (see Appendix 10) and we are in the process of producing a Webinar for the Association of Child Life Professionals. The group was also featured in two Trust newsletters (see Appendix 10): *Barts Bulletin* (Barts Health NHS Trust) and *Trust Talk* (ELFT NHS Foundation Trust). We have recently filmed a video about the intervention with group participants, which will be used for future advertising of the project.

Networks

The Project Leads have co-created a network for professionals using Narrative Therapy in Paediatric populations where the project learnings and outcomes will be shared. Key supports within Barts NHS Health Trust and ELFT have also been identified, and we will be inviting them to an event in which the project and its outcomes can be presented and discussed. We will also be sharing the learnings from the group with paediatric organisations.

Future opportunities

We are awaiting post-intervention data for the last two groups and follow-up data from the last four interventions. This data will help us to provide a more complete evaluation of the project outcomes. We will be presenting the full data set and our learnings in a published article for *Focus* (a scholarly journal promoting development of the Child Life profession) and possibly in other forums.

Appendices: Resources and appendices

Appendix 1. Measures used to assess outcome

1. *Psychological well-being.* The Child Outcome Rating Scale (CORS, Duncan, Miller & Sparks, 2003) is a self-report measure of problems with feelings, school, and relationships. Children aged six to seven years completed this measure. The Paediatric Index of Emotional Distress (PI-ED, O'Connor, Carney, House, Ferguson, & O'Connor, 2010) is a scale that screens children and young people for emotional distress. Carers and CYP completed the PI-ED for patients aged eight to 17 years.
2. *Quality of life.* The Pediatric Quality of Life Inventory (PedsQL, Varni, Seid & Rode, 1999) measures health-related quality of life in children and adolescents aged 0-17 years living with acute and chronic health conditions. Both carers and CYP completed the PedsQL.
3. *Carer psychological well-being:* The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a self-assessment scale developed to detect states of depression, anxiety and emotional distress in adults. Carers completed the HADS.
4. *Satisfaction:* Patients and their carers were asked about the acceptability of the intervention as well as overall satisfaction with the service delivered. Specific service evaluation questionnaires were developed for data collection (with separate CYP and carer versions).
5. *Change variables.* A short closed-response questionnaire was given to CYP, their referrers and their carers at three months' follow-up. Questions were asked about changes to the child or young person's psychological well-being, overall quality of life and healthcare management.

Appendix 2. Demographic characteristics of CYP group participants

Variable	Child (N = 28)	Young person (N = 19)
Age (M, range)	9 (7-13*)	14 (12-18*)
Sex (N, % of group total)		
Males	13 (46%)	3 (16%)
Females	15 (54%)	16 (84%)
<i>Ethnicity</i> (N, % of group total)		
White - British	9 (33%)	5 (27%)
White – any other background	2 (7%)	0 (0%)
Black or Black British – African	2 (7%)	3 (16%)
Black or Black British – Caribbean	3 (10%)	0 (0%)
Black – any other	3 (10%)	4 (21%)
Asian or Asian British – Bangladeshi	3 (10%)	4 (21%)
Asian or Asian British – Indian	1 (4%)	0 (0%)
Asian or Asian British – Pakistani	0 (0%)	1 (5%)
Asian – any other background	1 (4%)	0 (0%)
Mixed – White & Black Caribbean	2 (7%)	0 (0%)
Mixed – White and Black African	0 (0%)	1 (5%)
Other	1 (4%)	1 (5%)
Refused	1 (4%)	0 (0%)
<i>Religion</i> (N, % of group total)		
Roman Catholic	2 (7%)	1 (5%)
Christian Church	1 (4%)	1 (5%)
Islam	3 (10%)	5 (27%)
Church of England	0 (%)	2 (11%)
Other	2 (7%)	1 (5%)
Unknown	20 (72%)	9 (47%)
<i>Medical speciality</i> (N, % of group total)		
Gastroenterology	3 (11%)	2 (11%)
Haematology	7 (25%)	7 (36%)
Retinoblastoma	4 (14%)	3 (16%)
Surgery	3 (11%)	0 (0%)
Diabetes	2 (7%)	2 (11%)
Oncology	4 (14%)	0 (0%)
Neurology	2 (7%)	1 (5%)
Respiratory	3 (11%)	2 (11%)
Dermatology	0 (0%)	1 (5%)
Endocrinology	0 (0%)	1 (5%)
<i>Referrer type</i> (N, % of group total)		
Clinical Nurse Specialist	9 (32%)	5 (26%)
Consultant	4 (14%)	0 (0%)
Psychologist	10 (36%)	9 (47%)
Play Specialist/Play Worker	3 (10%)	4 (21%)

Teacher ∞	0 (0%)	1 (6%)
Physiotherapist	1 (4%)	0 (0%)
Speech and Language Therapist	1 (4%)	0 (0%)
<i>Previously known or currently open to:</i>		
Play	4 (14%)†	1 (5%)†
Paediatric Liaison Team	22 (79%)	16 (84%)
Neither	2 (7%)	2 (11%)

*A 12 year-old and a 13 year-old attended child groups and an 18 year-old attended the young person group as it was felt that their developmental needs would be better met by these interventions.

† This does not account for children who used the Play Team services whilst attending hospital (but who did not have a formal referral).

∞ We received one referral from a teacher who supports the educational needs of children living with disabilities and has close links with the Royal London Hospital We also accepted referrals from the school within the hospital. We did not actively seek referrals from schools outside the hospital but in the future we would welcome referrals from teachers who are aware that their pupils are paediatric patients at the hospital and whom they feel would benefit from attendance. These teachers would most likely learn of the intervention from the community nursing team.

Appendix 3. Outcome data at pre-, post- and 3 month follow-up

	Child			Young person			Total		
Variable	Pre	Post	Follow-up	Pre	Post	Follow-up	Pre	Post	Follow-up
<i>CYP psychological well-being</i>									
CORS = mean (N)									
Me	6.3 (3)	0 (0)	0 (0)	N/A	N/A	N/A	N/A	N/A	N/A
Family	8.2 (3)	0 (0)	0 (0)	N/A	N/A	N/A	N/A	N/A	N/A
School	8 (3)	0 (0)	0 (0)	N/A	N/A	N/A	N/A	N/A	N/A
Everything	6.5 (3)	0 (0)	0 (0)	N/A	N/A	N/A	N/A	N/A	N/A
PI-ED = mean (N)									
Depression	6.9 (19)	5.1 (12)	9.3 (6)	8.1 (13)	7.2 (5)	10.3 (4)	7.5 (32)	6.6 (17)	9.7 (10)
Anxiety	6.9 (19)	6.4(12)	8 (6)	7.2 (13)	5.6 (5)	8.5 (4)	7.1 (32)	5.3 (17)	8.2 (10)

Total	13.9 (19)	11.5 (12)	17.3 (6)	15.3 (13)	12.8 (5)	18.8 (4)	14. 5 (32)	11.9 (17)	17.9 (10)
<i>Carer psychological well-being</i>									
HADS = mean (N)									
Depression	6.6 (22)	4.3 (12)	7.2 (5)	5.2 (13)	4 (5)	6.8 (4)	6.1 (35)	4.2 (17)	7 (9)
Anxiety	9.4 (22)	6.4 (12)	5.6 (5)	8.8 (13)	7 (5)	11.5 (4)	9.1 (35)	6.6 (17)	8.2 (9)
Total	15.5 (22)	10.8 (12)	15.6 (5)	14 (13)	11 (5)	18.2 (4)	15. 1 (35)	10.9 (17)	16.8 (9)
<i>CYP quality of life</i>									
PEDS-QL = mean (N)									
Psychosocial functioning	54 (22)	60.8 (14)	55 (6)	55.8 (10)	53 (5)	42.8 (3)	54. 6 (32)	58.8 (19)	51 (9)
Physical functioning	67.9 (22)	66.2 (10)	57.8 (6)	61.9 (10)	70.2 (5)	42.7 (3)	66 (32)	66.3 (19)	52.8 (9)

Total	63.1 (22)	65.1 (14)	56.1 (6)	59.8 (10)	58.9 (5)	42.8 (3)	62. 1 (32)	63.5 (19)	51.6 (9)
<i>Carer of CYP PEDS-QL = mean (N)</i>									
Psychosocial functioning	52 (21)	54 (13)	53.6 (6)	54.5 (13)	49.2 (4)	44.2 (4)	53. 2 (34)	52.8 (17)	49.8 (10)
Physical functioning	57.9 (22)	60.9 (13)	62.5 (6)	58.8 (13)	76.9 (4)	37.5 (4)	58. 2 (35)	64.7 (17)	52.5 (10)
Total	57.8 (22)	56.2 (13)	56.7 (6)	55.9 (13)	58.4 (4)	41.9 (4)	57. 1 (35)	56.7 (17)	50.8 (10)
<i>CYP impact of problem</i>									
<i>GOMS = mean (N)</i>									
CYP	6.2 (17)	6 (10)	5.8 (6)	5.5 (11)	5.2 (5)	7.3 (4)	5.9 (28)	5.7 (15)	6.4 (10)

Carer	6.6 (21)	7.1 (9)	6.4 (8)	6.8 (10)	6.5 (4)	5.5 (4)	6.7 (31)	6.9 (13)	6.1 (12)
Clinician	7.5 (25)	N/A	6 (14)	7.5 (13)	N/A	5.8 (6)	7.5 (38)	N/A	6 (20)

CYP change variables

Likert scales = mean (N)

Quality of life	7.1 (17)	6.1 (10)	7.7 (6)	6.8 (12)	8 (5)	2.8 (4)	7 (29)	6.7 (15)	5.7 (10)
Healthcare management	8.2 (17)	7 (10)	7.7 (6)	7 (12)	8.4 (5)	7.8 (4)	7 (29)	6.7 (15)	7.6 (10)
Psychological well-being	6.1 (17)	8 (10)	6.5 (6)	6.2 (12)	7.4 (5)	6 (4)	6.1 (29)	7.8 (15)	6.3 (10)

Carer of CYP change variables

Likert scales = mean (N)

Quality of life	6.5 (20)	6.4 (9)	6.7 (8)	6.2 (12)	6.5 (4)	3.8 (4)	6.3 (32)	6.5 (13)	5.7 (12)
Healthcare management	8.4	8	7.5	6	8 (4)	6 (4)	7.5	8 (14)	7 (12)

	(21)	(10)	(8)	(12)			(33)		
Psychological well-being	5.4 (21)	6.9 (10)	5.6 (8)	6.5 (12)	6.5 (4)	6.8 (4)	5.8 (33)	6.8 (14)	6 (12)

Clinician of CYP change variables

Likert scales = mean (N)

Quality of life	5.6 (25)	N/A	6.2 (14)	5.8 (13)	N/A	6.2 (6)	5.7 (38)	N/A	6.2 (20)
Healthcare management	6.4 (25)	N/A	6.8 (14)	6.2 (13)	N/A	6.8 (6)	6.3 (38)	N/A	6.8 (20)
Psychological well-being	5.2 (25)	N/A	6.1 (14)	5 (13)	N/A	7.3 (6)	5.1 (38)	N/A	6.5 (20)

Appendix 4. Challenges in living with a chronic illness and strategies for managing them

Group of participants	Challenges	Strategies
<p>Children's experiences</p>	<ol style="list-style-type: none"> 1. Feeling different <ul style="list-style-type: none"> • Missing out on school • Feeling “exposed” • Missing out on social activities 2. Managing others' reactions <ul style="list-style-type: none"> • Managing others' assumptions • Being asked questions about their condition • Experiencing siblings and parents' reactions • Managing the stigma of illness 3. Being unwell <ul style="list-style-type: none"> • Looking different • Feeling stressed • Being in pain • Experiencing nausea 4. Managing procedures <ul style="list-style-type: none"> • Having needles • Having to take medication • Having surgery • Taking the journey to hospital 	<ol style="list-style-type: none"> 1. Educating others <ul style="list-style-type: none"> • Talking to others • Using social media • Providing education sessions 2. Developing life skills <ul style="list-style-type: none"> • Keeping well • Taking control • Finding solutions to problems • Keeping hope • Developing patience • Prioritising your needs 3. Developing a support network <ul style="list-style-type: none"> • Using parents as advocates • Talking to people you trust 4. Developing practical tips for managing illness <ul style="list-style-type: none"> • Managing operations • Developing mental strength • Taking medication • Managing needles • Hiding visible difference • Using games and rewards

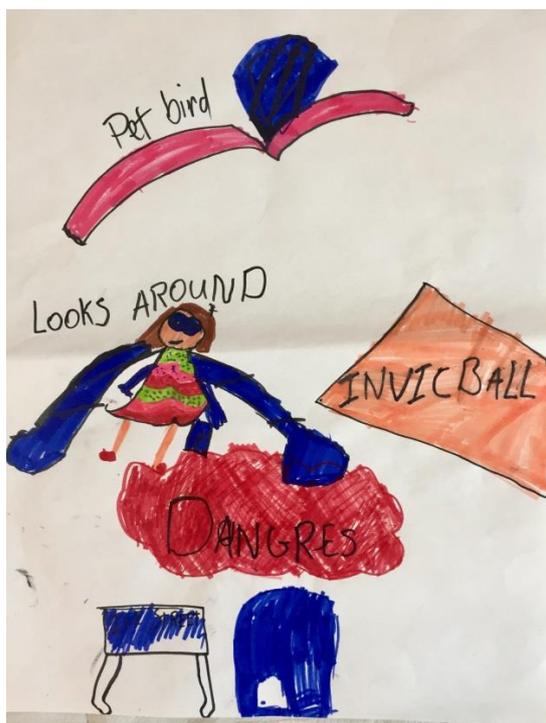
<p><i>Young people's</i> experiences</p>	<ol style="list-style-type: none"> 1. Managing others' reactions <ul style="list-style-type: none"> • Hearing negative comments • Experiencing people staring • Not wanting parents to worry 2. The emotional impact <ul style="list-style-type: none"> • Worrying about the future • Feeling misunderstood • Experiencing low mood 3. Practical challenges <ul style="list-style-type: none"> • Experiences changes in roles • Spending time at hospital • Being in pain • Having to have procedures and medication 4. Missing out <ul style="list-style-type: none"> • Missing out socially • Missing out on school • Missing out on sports 	<ol style="list-style-type: none"> 1. Managing inpatient stays and time off school <ul style="list-style-type: none"> • Distracting yourself • Having fun • Eating well • Catching-up with work • Staying connected socially 2. Getting support <ul style="list-style-type: none"> • Talking to friends • Asking parents for support • Using parents as advocates • Talking to teachers 3. Managing others' reactions <ul style="list-style-type: none"> • Ignoring unhelpful comments • Naming others' reactions • Educating others 4. Managing the condition <ul style="list-style-type: none"> • Using cognitive strategies • Taking physical comfort • Using time as a healer • Educating yourself • Managing medication
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<p><i>Experiences of carers of children</i></p>	<ol style="list-style-type: none"> 1. Feeling isolated and alone <ul style="list-style-type: none"> • Losing friendships • Losing support • Feeling misunderstood 2. The impact on family life <ul style="list-style-type: none"> • Experiencing a burden on relationships • Experiencing a loss of time together • Experiencing an imbalance in relationships 3. The emotional impact <ul style="list-style-type: none"> • Feeling “trapped” • Feeling bewildered • Feeling anger and a sense of unfairness • Feeling loss • Feeling tired • Experiencing emotional pain • Feeling guilt • Fearing for the future 4. The practical burden <ul style="list-style-type: none"> • Managing the unpredictability of illness • Managing the practicalities of illness 5. A changing role <ul style="list-style-type: none"> • Acting as carer • Acting as advocate • Acting as manager 	<ol style="list-style-type: none"> 1. Using knowledge as power <ul style="list-style-type: none"> • Talking to healthcare professionals • Gaining knowledge • Educating others 2. Building a support network <ul style="list-style-type: none"> • Using strangers • Sharing experiences with people who understand • Leaning on others • Keeping normality • Building alliances 3. Being prepared <ul style="list-style-type: none"> • Sticking to the plan • Having the “right people” around • Planning ahead • Relying on others 4. Adopting an attitude <ul style="list-style-type: none"> • Acceptance (getting on with it) • Allowing emotions • Trusting in time • Keeping a sense of humour • Keeping hope • Living for now 5. Putting the child first <ul style="list-style-type: none"> • Empowering the child • Using the child as a source of strength • Protecting the child
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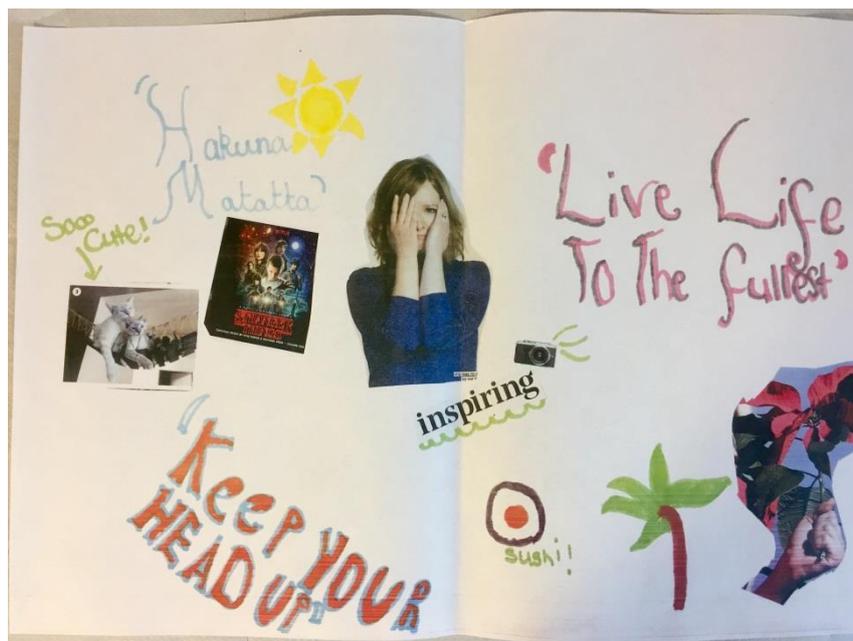
		<p>6. Building trust with the child</p> <ul style="list-style-type: none"> • Being honest • Preparing them • Giving explanations • Listening to them • Giving them reassurance <p>7. Taking time out</p> <ul style="list-style-type: none"> • Crying • Exercising • Relaxing • Maintaining a sense of self <p>8. Creating family time</p> <ul style="list-style-type: none"> • Spending time with siblings • Making family time
<p>Experiences of carers of young people</p>	<p>1. Managing others' reactions</p> <ul style="list-style-type: none"> • Unhelpful attitudes • Being labelled • Feeling let down • A lack of understanding <p>2. Feeling the emotional impact</p> <ul style="list-style-type: none"> • Feeling isolated • Feeling a loss of self • Worrying • Being in distress • Feeling under pressure to be “brave” <p>3. The practical burden</p> <ul style="list-style-type: none"> • Experiencing financial challenges • Managing unpredictability 	<p>1. Developing skills and knowledge</p> <ul style="list-style-type: none"> • Being strategic • Giving yourself time • Educating yourself <p>2. Taking time out</p> <ul style="list-style-type: none"> • Taking physical breaks • Taking mental breaks • Relaxing • Exercising <p>3. Seeking support</p> <ul style="list-style-type: none"> • Using friends and family • Getting professional help • Connecting with families in similar

	<ul style="list-style-type: none"> • Balancing family life <p>4. Feeling a sense of huge responsibility</p> <ul style="list-style-type: none"> • Feeling responsible • Being engaged in a battle with services 	<p>situations</p> <p>4. Adopting an attitude</p> <ul style="list-style-type: none"> • Prioritising • Trusting yourself • Getting “on with it” • Being inspired <p>5. Supporting the YP and their family</p> <ul style="list-style-type: none"> • Fighting for the YP • Talking to the YP • Giving the YP autonomy • Creating family time • Having fun as a family
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Appendix 5. Drawings of superhero characters created by child participants



Appendix 6. Identity boards created by young people participants



Appendix 7. Key achievements and milestones during the project

Date	Key achievements
2016	
<i>July</i>	<ul style="list-style-type: none"> • Attended National Association of Health Play Specialist conference to present Health Heroes proposal and pilot data
<i>August</i>	<ul style="list-style-type: none"> • Project Assistant job description created • Intervention referral form created • Outcome database created following discussion with Deanna Gibbs (Research Consultant) • Intervention dates agreed with Chickenshed Theatre • Applied to present at Child Life Conference 2017 (unsuccessful)
<i>September</i>	<ul style="list-style-type: none"> • Youth Empowerment Squad (service user group) reviewed outcome measure battery and reported that it was acceptable • Developed and finalised outcome measures and agreed on when they will be administered with Deanna Gibbs
<i>October</i>	<ul style="list-style-type: none"> • Finalised outcome database with Deanna Gibbs • Met with Chickenshed Theatre to talk about how child and young person versions of the group might be delivered differently according to different developmental needs of each group • Finalised templates for PDSA cycles and reflective journal • Started to think about “branding” of the group and obtained personalised logos • Attended Health Foundation launch event • Advertised for Project Assistant • Tara attended Narrative Therapy Level 1 training
<i>November</i>	<ul style="list-style-type: none"> • Had first meeting with Springfield Consultant (Louise Howell) • Interviewed and appointed Louise Rylatt as Project Assistant • Jennie attended Narrative Therapy Level 1 training • Invited to present Health Heroes at The Academy of Fabulous

	Stuff (NHS)
<i>December</i>	<ul style="list-style-type: none"> • Held meeting with Barts Communication team to develop Communications strategy
2017	
<i>January</i>	<ul style="list-style-type: none"> • Delivered Group 1 (child): attended by 9 children and carers • Louise Rylatt started as Project Assistant
<i>February</i>	<ul style="list-style-type: none"> • Held pilot training session for Group Facilitators: attended by the Play Team who reported that it was useful and accessible • Cancelled Group 2 (young person) due to low referral rates • Applied to run a workshop at the Narrative Therapy Conference (unsuccessful and offered a poster space instead. This was declined due to conflicting commitments)
<i>March</i>	<ul style="list-style-type: none"> • Met with Mamta Vaidya (Clinical Director of the Children's Hospital) to talk about promoting the intervention and subsequently updated Communications Strategy
<i>April</i>	<ul style="list-style-type: none"> • Held training session for Group Facilitators: attended by 24 people from different disciplines across the hospital of which X agreed to assist with the group delivery • Delivered Group 3 (child): attended by 7 children and 8 carers • Delivered Group 4 (young person): attended by 7 young people and carers
<i>June & July</i>	<ul style="list-style-type: none"> • Attended Health Foundation mid-point event • Jennie and Tara attended Narrative Therapy Level 2 course • Intervention is featured in Trust newsletters: Barts Bulletin (Barts Health NHS Trust) and Trust Talk (East London NHS Foundation Trust) • Attended University College London Hospital (UCLH) training event to discuss delivery of narrative therapy group interventions across sites and participate in mutual learning • Attended Allied Health Professionals (AHPs) Conference and won two awards: "Overall winner for contribution to AHPs into Action" and "AHPS into Action: Health & Well-being"

	<ul style="list-style-type: none"> • Delivered Group 5 (child): attended by 6 children and 7 carers
August	<ul style="list-style-type: none"> • Delivered Group 6 (young person): attended by 6 young people and 3 carers • Had first meeting with new Springfield Consultant (Richard Edgeworth) • Article published in Context magazine • Article accepted for review by Focus magazine • Webinar agreed for review with the Child Life Professionals association
September	<ul style="list-style-type: none"> • Tara and Jennie attended first module of Narrative Therapy Level 3 training
October	<ul style="list-style-type: none"> • Delivered Group 7 (child): attended by 6 children and 7 carers. The final performance was witnessed by Richard Edgeworth. • Delivered Group 8 (young person): attended by 5 young people and 5 carers. • Filmed video for Health Foundation Showcase event

Appendix 8. Key challenges or issues encountered during the project and our responses

Variable	Challenges or issues encountered	Our response
Resource		
<i>Outcome measures: accessibility</i>	<ul style="list-style-type: none"> • It became apparent from the first group cycle that the wording of certain questions was confusing for participants • One child found it distressing to complete the questionnaires • Some carers and CYP completed each other's questionnaires 	<ul style="list-style-type: none"> • The wording of some questions on some outcome measures was changed for clarity • We clarified in the instructions provided to participants that outcome measures did not have to be completed if they were distressing or for other reasons • The instructions on how to complete the measures were reviewed and clarified, and different colour paper was used for CYP and carer versions of outcome measures for clarity. Louise Rylatt also offered support in completing the measures
<i>Outcome measures: validity</i>	<ul style="list-style-type: none"> • Some participants were completing the pre- and post-intervention measures on the same day or within a very short time frame • Some clinicians feel unable to complete the follow-up measures as they do not have regular contact with the participants they referred • Some participants completed the measures 	<ul style="list-style-type: none"> • We verified with CYP and their carers that post-intervention measures should be completed within one week of attending the group • Where the referrer does not have regular contact with the participant, we have asked the clinician who sees the participant most regularly to complete the outcome measures • Interpreters aided some CYP and their carers to complete the outcome measures but this

	<p>in a language that was not their first language</p> <ul style="list-style-type: none"> • Some measures ask for ratings based on the previous month and others based on the previous week: this could invalidate any pre- vs. post- intervention comparisons • Some CYP were directed by their carers in their responses • Some responses may have been influenced by a relapse in health condition • In some cases, one carer completed one set of measures (e.g. pre-intervention) and another did the post-intervention measures 	<p>remains a potential confounding variable</p> <ul style="list-style-type: none"> • This is an oversight on the part of the project team and CYP and their carers have been asked to respond to the outcome measures as best they can using their current experiences • Carers were encouraged not to facilitate CYP in completing the measures and Louise Rylatt offered to adopt this role where possible • This is unavoidable but a potential confounding variable • The instructions for completing the measures were reviewed to include specific mention of the same person having to complete the pre- and post-intervention sets of measures
<p><i>Outcome measures: return rates</i></p>	<ul style="list-style-type: none"> • Participants were partially completing measures or not returning outcome measures 	<ul style="list-style-type: none"> • We verified that all pre-intervention measures had been completed in full when CYP and carers registered on the day of the intervention • We created “packs” for the post-intervention measures that were given to CYP and their carers to take home with them on the day of the intervention with stamped, addressed envelopes • We ensured that we had provided adequate postage on the return envelopes

		<ul style="list-style-type: none"> We liaised with the Post Room at the hospital to “chase” any missing outcome measures
<i>Funding</i>	<ul style="list-style-type: none"> We received incorrect and delayed payments from The Health Foundation at the start of the project We have had difficulties accessing the grant funds from Barts Health NHS Trust and continue to have inconsistent and conflicting information about this process. This has jeopardised the intervention delivery, led to delayed payments to organisations who are supporting the project, led to the delayed recruitment of our Project Assistant and led to many “wasted” clinical hours 	<ul style="list-style-type: none"> We liaised with The Health Foundation and resolved this issue We liaised with David Kovar (Divisional Manager) and the Finance Department who have helped us to address certain issues with some resolution. However, the situation remains tenuous and we intend to have a meeting with these parties in 2018 to discuss the difficulties we encountered throughout the project as well as the impact it has had on the project team and may have for any future projects delivered at Barts Health NHS Trust services
<i>Supervision</i>	<ul style="list-style-type: none"> Jennie received monthly Narrative Therapy supervision via Tower Hamlets Child and Adolescent Mental Health Services as well as personal supervision on a fortnightly basis but there were few opportunities for the project team to receive supervision specific to the group delivery 	<ul style="list-style-type: none"> The Institute of Narrative Therapy was contacted to provide private supervision but this did not come to fruition over the course of the project We received informal supervision over the course of the Narrative Therapy diploma training and on a training day with University College London Hospital We have joined a network of professionals using Narrative Therapy in paediatric settings which was established on November 15th 2017

<p><i>Setting the scene: materials</i></p>	<ul style="list-style-type: none"> • Whilst the children received “superhero” capes during the “graduation ceremony” at the end of the child group, we were unsure of a YP alternative • We felt that the Health Heroes metaphor needed to be “stronger” throughout the intervention delivery 	<ul style="list-style-type: none"> • We consulted with the Youth Empowerment Squad (YES) who suggested creating key-chains. These were sourced and provided to all YP who attended the group • We sourced logos for both the child and young person interventions and used these in all correspondence with group participants (including using envelopes bearing the logos) • We created a poster which read “Superhero cave” which was exhibited during the child group delivery, and put up pictures of superheroes and modern-day heroes around the group space • We considered the use of uniforms for Group Leads and Facilitators but did not have time to organise this
<p>Process</p>		
<p><i>Providing information and corresponding with CYP and their parents/carers</i></p>	<ul style="list-style-type: none"> • We were concerned about consistency in information-giving to participants across the project and found ourselves writing various versions of letters for the first two group cycles • Some families did not speak English as a first language 	<ul style="list-style-type: none"> • We created child and young person templates for all correspondence with group participants that were used across the project. We created electronic signatures so Louise did not need Tara and Jennie to be present in order to send information to participants • We obtained interpreters on the day of the intervention and, where possible, translated all correspondence into the necessary language

	<ul style="list-style-type: none"> • Not all carers knew the hospital well and felt “lost” during the morning session • Carers were anxious about not being able to contact the project team during the morning session 	<ul style="list-style-type: none"> • We provided carers with information on where to get refreshments locally or go shopping during the morning session • We provided all carers with a contact number they could use to speak to Louise Rylatt throughout the day and created a registration sheet to ensure that we had their contact details in the case of an emergency
<i>Multi-disciplinary team working</i>	<ul style="list-style-type: none"> • It was felt that only Tara and Jennie had the knowledge and confidence to lead the group 	<ul style="list-style-type: none"> • We delivered training to individuals from Speech and Language Therapy, Clinical Nursing, Play, Clinical Psychology, Psychiatry, Research Nursing and Physiotherapy in how to deliver the group. All reported enjoying the training and feeling confident to assist but not to lead on the group delivery
<i>Cross-organisation working</i>	<ul style="list-style-type: none"> • The quality of the relationship between the project team and Chickenshed Theatre fluctuated over the project. The Director of Chickenshed Theatre, Paul Morrall, did not lead the afternoon session after the third cycle of delivery and it was subsequently felt that the company were not “thickening” the work done in the morning, and were using their own ideas rather than those of the group participants. There was also some duplication of work with Chickenshed Theatre creating “shields” with the children in the afternoon session (which we had already done in the morning session) 	<ul style="list-style-type: none"> • We held meetings with Paul Morrall from which it was agreed to make changes such as creating “handover documents” (rather than using verbal handovers) for the lunch break that detailed participants’ own words and experiences, and which could be used by Chickenshed Theatre as a resource to work from in the afternoon. We also agreed that the shields created in the morning session of the child group would be used in the afternoon session. Paul also agreed to lead on another intervention. There was a noticeable improvement in service delivery after this

	<ul style="list-style-type: none"> • On several occasions we asked to delay our report deadlines for The Health Foundation as they coincided with group delivery dates (and therefore important learnings would not be included in the report) • Our Springfield Consultant changed mid-way through the project 	<ul style="list-style-type: none"> • The Health Foundation was flexible in allowing us to adjust the deadlines around our project timeline which was hugely helpful • We had an effective “handover” from Louise Howell to Richard Edgeworth which facilitated this transition
<i>Branding and ownership</i>	<ul style="list-style-type: none"> • Louise Howell suggested that our ideas could be open to being stolen and encouraged us to seek “ownership” of the project through branding and introducing the intervention in a written article • The name of the intervention was confusing with people calling it “Celebrating Differences”, “Health Heroes” or “Superheroes” 	<ul style="list-style-type: none"> • We obtained personalised branding for the group and wrote an article for Context explaining the rationale and hopes for the project • We tried to refer to the group as “Celebrating Differences” or “Health Heroes” in all our correspondence but “superheroes” appears to have stuck because of its brevity and recognisability
<i>Promoting safety</i>	<ul style="list-style-type: none"> • In Group 1 it became apparent that it was not always clear what to do if a child’s health began to deteriorate during the group, e.g. low blood sugars • In Group 4, participants discussed watching a popular TV show concerned with self-harm 	<ul style="list-style-type: none"> • An “emergency plan” was agreed between carers and Louise Rylatt when they agreed to participate in the group. This was verified in writing on a participant registration sheet on the morning of the intervention and shared with all Group Leads and Facilitators • We located a resource that had been distributed amongst ELFT CAMHS workers on

	<p>and suicide. This show was known within child and adolescent mental health services (CAMHS) as being a trigger of distress for many vulnerable CYP</p> <ul style="list-style-type: none"> • In Group 7, two participants were in close contact who were later found to be at risk of cross-infection (this had not been specified in one of the participant’s referrals) 	<p>how to talk about this show with young people. We shared this with all carers of the group participants, and notified them that the show had been discussed as a group</p> <ul style="list-style-type: none"> • We notified the participants’ relevant health teams, who informed their carers. We also completed a Datix form which registers clinical incidents in the Trust
<i>Low referral rates</i>	<ul style="list-style-type: none"> • We were concerned about referral rates to the group following the cancellation of Group 2 • Many carers were unable to attend the intervention as they had other children to care for (who were not permitted to attend) • Many potential participants could not attend the intervention due to conflicting commitments on the group dates, including school • Some young people reported that they did not want to go to a group for “disabled children”. Stigma may have therefore affected referral rates to the group, particularly for young people 	<ul style="list-style-type: none"> • We developed an information sheet about the intervention that was emailed to all healthcare professionals working at the hospital. We also sent regular emails advertising the intervention and asking for referrals, and attended psychosocial meetings across the hospital to recruit participants • Unfortunately, we could not provide childcare. Where possible, we asked if arrangements could be made to ensure a carer could attend the group • We tried to hold the group during school holidays but this was not always possible. We tried to move one intervention date but unfortunately Chickenshed Theatre had other commitments on that date • We tried to discuss this with young people on the phone but it was difficult to improve

	<ul style="list-style-type: none"> • One child was unaware of their diagnosis when they were referred to the group 	<p>engagement</p> <ul style="list-style-type: none"> • We did not accept referrals for CYP who were unaware of their diagnoses as this did not feel appropriate
<i>Communications</i>	<ul style="list-style-type: none"> • We wanted to promote the intervention 	<ul style="list-style-type: none"> • We met with the Communication team to devise a Communications Strategy which was reviewed with the Clinical Director of the Children’s Hospital • We promoted the group at various meetings and events around the hospital, and had articles published in the Barts Health NHS Trust and ELFT newsletters • We had an article published in Context magazine • We applied to two conferences but were unsuccessful • We presented a poster at the AHP Conference where we won two awards (see Appendix X)
<i>Running the intervention: on the day</i>	<ul style="list-style-type: none"> • It could be difficult to ensure that individual voices were heard within a group context for both CYP and carers 	<ul style="list-style-type: none"> • Efforts were made to individualise CYPs’ characters or identity boards as much as possible, e.g. not using tracing of “established” superheroes, and time was spent “warming up” the group and getting to know each other before talking about their experiences of illness (e.g. using ice-breakers, games and breaks).

	<ul style="list-style-type: none"> • The intervention delivery was much more disrupted when Louise Rylatt (Project Assistant) was not available • It became apparent that any learning from the day was lost if a de-brief was not held immediately after the group delivery • CYP worried that what they shared with the group would be shared with their parents/carers • In Group 6, many of the YP were very nervous and reluctant to attend. It was difficult to know how to manage this and how to achieve the balance of offering reassurance but not putting pressure on participants to attend • The intervention was felt to be less effective when participants or Group Leads or Facilitators were not present for the entirety of the intervention 	<p>Group Leads ensured that everyone was involved when asking questions as a group in both the CYP and parent/carer sessions, and managed any difficult group dynamics</p> <ul style="list-style-type: none"> • Scripts and schedules were used to try and minimise any disruption during the day • From Group 2 onwards all de-briefs were held immediately after the group and Group Facilitators were told their attendance was mandatory • Ground “rules” were devised with the group at the start of every session to establish the limits of confidentiality • Efforts were made to reassure group participants that being nervous was “normal” and that they could leave the intervention at any time. Anxiety may have prevented some YP from attending the group • We reiterated the importance that CYP and their carers attend for the full day and communicated with the hospital to ensure that they would not contact participants during the group. We also made it mandatory for Group Leads/Facilitators to be present for the entire intervention
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<p><i>Cyber-attack</i></p>	<ul style="list-style-type: none"> • A cyber-attack on Barts NHS Health Trust disrupted the group delivery as there was no access to computers for six weeks. This prevented us from being able to contact CYP and their carers, to send information to group participants, or to input data 	<ul style="list-style-type: none"> • There was little that could be done to address this.
<p>Organisation</p>		
<p><i>Providing follow-up support</i></p>	<ul style="list-style-type: none"> • Some participants were already known to the Play Department and/or Paediatric Liaison Team but raised new concerns over the course of the group. • Some participants were not receiving psychosocial support but had psychosocial needs that became visible over the course of the group. 	<ul style="list-style-type: none"> • The clinicians working with the family were informed of any new concerns or risks and appropriate action was taken. • Onward referrals to the appropriate services were made for these families and the medical teams they were under were made aware of any new issues or concerns raised during the group
<p>Service user involvement</p>		
<p><i>Seeking and using feedback</i></p>	<ul style="list-style-type: none"> • We wanted to ensure that the intervention was acceptable to participants • One parent said that they did not feel comfortable talking in a group and would like to be able to provide a written account of their experiences • Carers told us that they wanted to stay in touch with each other but didn't know how to arrange this 	<ul style="list-style-type: none"> • Feedback on every aspect of the intervention was sought through quantitative and qualitative feedback • We created a written "homework" that carers could hand-in rather than them talk about their experiences in a group • We created a contact sheet that parents/carers could fill-in if they were happy to be contacted by other carers

<i>Promoting participants' voices</i>	<ul style="list-style-type: none"> • We want to promote the voices of our participants. 	<ul style="list-style-type: none"> • We have interviewed group participants for a video about the intervention and will invite previous participants to future Health Foundation and Barts NHS Trust events to talk about their experiences.
<i>Involving participants</i>	<ul style="list-style-type: none"> • We want participants to feel a sense of ownership and involvement in the project. 	<ul style="list-style-type: none"> • We are considering asking previous group participants to attend as Group Facilitators in future group deliveries.

Appendix 9. Key learnings from the project

Variable	Key learnings
<i>Resource</i>	<ul style="list-style-type: none"> • Completing outcome measures can be confusing especially where there are multiple measures for different participants. Efforts to increase clarity and ease of access should be made, e.g. using different coloured paper to establish different versions and writing clear instructions. Where possible, measures should be translated to ensure that they are accessible to all participants, and support from a member of the project team should be available. • Improving the ease of sending information back to the project team (e.g. providing self-addressed and stamped envelopes) can support return rates of outcome measures. • It is important to have a standardised version of each document provided to group participants to ensure that there is consistency in service provision, and to provide this in different languages where appropriate to ensure clear communication. • Arranging regular supervision meetings at the start of a project may support the project team to feel more confident in their application of Narrative Therapy in the group delivery and to reflect on their experiences of the intervention. • It is important to have adequate refreshments for group participants to improve satisfaction with their experience of the intervention.
<i>Process</i>	<ul style="list-style-type: none"> • A “trial-run” of using the outcome measure battery may help to pre-empt any challenges in obtaining complete data sets. • Taking time to go through completed outcome measures with participants can ensure that measures are completely fully and any questions about their completion can be addressed. It may also reduce the potential bias introduced by CYP being assisted in measure completion by their carers. This could be the role of the Project Assistant. • Branding is important in creating a consistent narrative about the intervention; this can be reinforced

through the creation of logos, signs, and potentially uniforms. It is important that an intervention have a single name to avoid confusion (e.g. not “Health Heroes”, “Celebrating Differences”, and “Superheroes”).

- It is important to ensure that carers feel that they can both contact and be contacted by the project team to manage anxiety in leaving their child as well as to prepare for any potential emergencies. Having a key contact person and number is crucial.
- Running training sessions enables professionals from different disciplines to “skill-up” with new therapeutic skills and creates a pool of professionals to assist with the group delivery. However, training alone is not enough; further experience of the group is needed for individuals to feel confident about leading on the group delivery in the future.
- A ratio of two group participants to one Group Lead or Facilitator appeared to work well.
- It may be useful to have regular meetings with all partners on the project to share feedback on service delivery and address any concerns.
- Writing an article to introduce an intervention can enable the development of some “intellectual copyright”.
- It is important to have clear plans on how to manage medical emergencies for group participants with chronic illness, and to check any potential cross-infection risks with participants’ medical teams ahead of service delivery.
- It important to “warm-up” a group and spend time getting to know one another before asking “challenging” questions. This can be done through conversation, games and play. Making connections between participants’ experiences and interests can also promote relationship-building between participants, as can having enough time to “play” during breaks.
- It is important to be able to respond to any potential risks that arise in the group and to notify the appropriate persons (e.g. carers or professionals).

	<ul style="list-style-type: none"> • Recruiting young people to the intervention can be more challenging than recruiting children and may reflect the ways in which professionals think about young people in comparison to children, “buy-in” from carers of young people in comparison to carers of children, and different developmental needs. Alternatively, further thought may be needed with regards to how the intervention is marketed to young people which considers the role of stigma and which recognises the competing demands (e.g. school, academic pressures) that affect how accessible the group is for young people. • Providing potential referrers with written information about the intervention and regularly attending meetings where potential referrers are present can greatly improve referral rates. • Childcare provision could assist carers in being able to attend the group and prevent CYP from being unable to access the group. • Networking and attending events across the Trust were key to promoting it amongst hospital staff. Attending events outside of the Trust enabled us to make connections with projects across the country and improved shared learning. It also led to interest in the group being delivered in other contexts, and motivated the project team (especially when they won awards!). • The role of the Project Assistant is invaluable to the overall delivery of the day and should be re-assigned if the assistant is not available. • De-briefs should take place as soon as possible post-group delivery, and involve all professionals involved in the intervention. • Extensions on deadlines can be obtained from The Health Foundation and should be asked for if needed. • Group “rules” enable group participants to feel “safe” and provide containment. For some group participants, individual pre-intervention conversations may be useful to verify any concerns or anxieties they have about attending the group. • Ensuring full attendance for the entire day for both participants and facilitators is crucial to service effectiveness.
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	<ul style="list-style-type: none"> • Follow-up support should be available for CYP and their carers if needed.
<i>Organisation</i>	<ul style="list-style-type: none"> • It could be useful to identify the clinician with most regular contact with the individual child or young person to ensure the most reliable feedback is sought on their well-being and treatment management. • Group Facilitators enjoy working with professionals from different disciplines and being involved in a psychosocial intervention suggesting that similar future opportunities may be welcomed by hospital staff. • Identifying key “supporters” or “enablers” within the organisation is vital to address difficulties within the project (e.g. accessing funds) but is not always sufficient. Escalating concerns may be the only way to ensure that these difficulties are addressed. Alternatively, it may be useful to have a petty cash fund in future projects.
<i>Service user involvement</i>	<ul style="list-style-type: none"> • Consulting with service users is invaluable in improving service delivery and accessibility. • Videos and using the written testimony of participants brings “life” to any project, and can be empowering for participants. • Using participants in group delivery may be a particularly therapeutic and worthwhile endeavour.

Appendix 10. Examples of promoting and publicising the intervention

(a) Allied Health Professionals Conference poster



CELEBRATING DIFFERENCES

Introduction

- ★ We've developed an innovative intervention for working in a paediatric setting with children and young people aged 6-17 living with chronic physical illness, and their carers.
- ★ The intervention uses therapeutic play and narrative therapy skills, as well as a performance-based workshop that is delivered by Chickenshed Theatre.
- ★ We were awarded funds from The Health Foundation to deliver the intervention eight times (four groups for children and four for young people) during school holidays over a 15 month period between 2016 and 2018 at The Royal London Hospital.
- ★ Each group caters for up to ten patients and their carers.

Background

Whilst many paediatric patients and their families cope well with the demands of physical illness, this patient population is at increased risk of developing psychological problems when compared to healthy children, with estimates of psychological difficulty ranging from 10% to 37% (Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003; Meltzer, Gatward, Goodman, & Ford, 2000). Psychological difficulties in the context of physical illness can have negative implications for patients' prognosis, treatment adherence and outcome, and quality of life, and may lead to repeat procedures and increased use of pharmacology (Edwards & Titman, 2010). In addition, there can be a burden of caring for a child with both chronic physical illness and psychological difficulties.

There is growing recognition of the importance of addressing the psychological well-being of paediatric patients (e.g. National Service Frameworks for Children and Young People, DoH, 2003). The government strategy *No Health Without Mental Health* (DoH, 2011) set out objectives to ensure that the psychological well-being of paediatric patients is addressed alongside their physical health needs. Despite guidance and appeals for psychological support from patients and their carers, procedures regarding evidence-based psychological interventions for patients are scarce, and provision is inconsistent.

Our Services

- ★ The Royal London Hospital provides psychosocial support to its paediatric patients and their families and carers through its Play Department and Paediatric Liaison Team (PLT).
- ★ The Play Department is made up of both Health Play Specialists and Play Workers. It works to promote effective coping mechanisms through play, procedural preparation, procedural support, distraction therapy, education, and self-expression activities.
- ★ The PLT comprises clinical psychologists, psychiatrists, a social worker and a bilingual co-worker. It offers support to manage the emotional impact of living with a health condition.
- ★ Demand for both services outweighs supply. There are also severely limited psychological and psychosocial support provisions for paediatric patients at other Barts Health NHS Trust sites (e.g. Whipps Cross and Newham University Hospitals).

Improving Psychological Well-Being in Children and Young People Living with Chronic Physical Illness

Dr. Jennie Robertson¹, Tara Shea² & Louise Rylatt²
¹East London NHS Foundation Trust, ²Barts Health NHS Trust

Email us! celebratingdifferences@bartshealth.nhs.uk

The Intervention

The intervention utilises the concept of heroes as a metaphor to consider how children and young people use individual strategies (super-powers) to address the challenges they face. They develop hero characters who are "thickened" through group discussion, developing a performance with Chickenshed Theatre, and attending a graduation ceremony.

Clinical Day	Child/Young Person Session	Parent Session
10-10:30	Registration and introduction to the group	
10:30-12:30	Development of hero characters	Homework and free time
12:30-13:30	Discussion of challenges faced in living with chronic illness and strategies for managing them	
13:30-15:30	Pizza lunch provided	
15:30-16:30	"Thickening" of hero characters through play/drama	Discussion of challenges faced in caring for a child with chronic illness and strategies for managing them
	Performance and graduation ceremony	

Measuring Outcomes

We are assessing outcomes before and after each group delivery (immediately post-intervention and at three months' follow-up). The following measures are being used:

- ★ **Psychological well-being.** The Child Outcome Rating Scale (CORS, Duncan, Miller & Sparks, 2003) is a self-report measure of problems with feelings, school, and relationships. Children aged 6 to 7 years complete this measure. The Pediatric Index of Emotional Distress (PI-ED, O'Connor, Carney, House, Ferguson, & O'Connor, 2010) is a scale that screens children and young people for emotional distress. Children/young people aged 8 to 17 years complete the PI-ED.
- ★ **Quality of life.** The Pediatric Quality of Life Inventory (PedsQL, Varni, Seid & Rode, 1999) measures health-related quality of life in children and adolescents aged 0 to 17 years living with acute and chronic health conditions. Carers and children/young people complete PedsQL.
- ★ **Carer psychological well-being.** The Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983) is a self-assessment scale developed to detect states of depression, anxiety and emotional distress in adults. Carers complete HADS.
- ★ **Satisfaction with the intervention.** Patients and their carers are asked about the acceptability of the intervention as well as overall satisfaction with the service delivered. Specific service evaluation questionnaires have been developed for data collection and there are separate versions for children/young people and carers.
- ★ **Change variables.** A short closed-response questionnaire is given to patients and their carers at 3 months' follow-up. Questions are asked about changes to the child or young person's psychological well-being, overall quality of life and healthcare management.

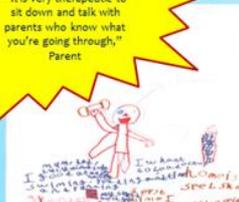
Conclusion

The long-term objective is to develop an intervention that addresses the psychological needs of our paediatric patients with chronic illness, and their carers, and improves their psychological well-being. The intervention would be permanently embedded across Play and Paediatric Psychology Services and delivered across all sites where Barts NHS Health Trust services are provided. We also hope to create a treatment manual and video that can be used in other paediatric settings to assist children and young people living with chronic illness.

It is highly likely that there will be a number of other positive outcomes, that may lead to cost savings for the Trust including:

- ★ Improved health outcomes;
- ★ Improved treatment adherence;
- ★ Improved quality of life;
- ★ A reduced need for pharmacological and repeat interventions;
- ★ An improved patient-service relationship; and
- ★ Improved liaison and working between medical teams.

"It is very therapeutic to sit down and talk with parents who know what you're going through."
Parent



"It has helped boost my confidence."
Child



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(b) Screenshot of intervention promotion in the Barts NHS Health Trust's Bulletin

Young patients at The Royal London celebrate their inner hero

Posted on Tuesday 2 May 2017



Acknowledging that real heroes don't always wear capes, The Royal London Hospital has launched a Health Hero Training Academy incorporating therapeutic play, drama, games and psychological therapy to celebrate the strength and abilities of its young patients.

"Due to their illnesses children frequently overcome pain and challenges such as missing school and friends, so we chose to celebrate the strength they show in never giving up," explained Tara Shea, play team lead at The Royal London.

Children are given the opportunity to discuss the challenges they face in living with chronic physical health conditions, as well as the strategies they use to manage, in order to promote their psychological wellbeing and build relationships with other children. Support is provided by a clinical psychologist from East London NHS Foundation Trust.

After spending the morning developing preferred hero identities based on their strengths and abilities, the children and young people work with Chickenshed Theatre to build on these further through song, drama and play. They perform as a group to their parents and healthcare providers, graduating as official Health Heroes in a ceremony where they are awarded capes or key chains, and certificates.

The workshops also involve supporting parents and carers through a therapeutic group session, and as well as the children and young people naming their own 'super powers' - such as courage, creativity and kindness - they also tell their parents and carers why they are their heroes, for example providing them with comfort, love and reassurance.

Tara continued: "Our young patients and their parents achieve small acts of greatness every day, each one is a hero."

"At the Health Hero Training Academy we celebrate what makes our patients different from other children, and identify their strengths as their super powers. It's a really fun and new approach, with a serious message aiming to boost their confidence in the real world."

Robbie, who is 11 years old and from Oxford, was diagnosed with Retinoblastoma five years ago. He attended a Health Heroes Training Academy in April, commenting: "Today was good for my confidence. The best bit was making friends with other children who have health conditions and talking to each other about it."

Erin, Robbie's mother, added: "This has been the first time in five years since Robbie was diagnosed that we have been around other children and parents. Robbie has had fun, and it has been good for me to speak to other parents and share ways to cope."

- News and Events >
- Newsroom >
- 2017 >
- 05 >
- #BartsAbility latest
- Changes to the appraisal system
- CQC inspection at St Bartholomew's Hospital this week
- Heart patients discharged quicker when treated by paramedics
- Mental health awareness week
- National Play Awards 2017/18
- New intranet survey
- New papers at St Bartholomew's, The Royal London and Mile End hospitals
- Spotlight on our strategy for the next two years
- Spotlight on...our amazing midwives and nurses
- Staff at Newham hospital celebrate improved CQC rating
- Young patients at The Royal London celebrate their inner hero**
- My Training >
- I want to >

(c) Screenshot of intervention promotion in the East London NHS Foundation Trust's Trust Talk Bulletin



TOWER HAMLETS TOGETHER
Partnership between health and social care



Tower Hamlets Together Celebrates Second Anniversary



TOWER Hamlets Together, the partnership of local health and social care organisations in the borough, celebrated its five-year anniversary of being awarded 'ranger' status to develop pioneering ways to provide care to its communities.

The Trust used the opportunity to get a celebratory cake and invited the new Tower Hamlets community health staff to a drop-in coffee morning with Chair Maria Gabriel, along with ELFT staff.

Back in 2015, NHS England invited health and social care organisations to bid for funding to become part of the NHS New Care

Models programme – established with the aim of exploring new and innovative ways to provide the best ever standards of care. This was in response to rapidly increasing demand for care from an ageing population as well as recognition of the opportunities to improve quality and efficiency through closer working between health and social care services.

Tower Hamlets was one of 50 sites nationally to successfully bid for funding which would support a three-year programme of work.

The Tower Hamlets Together programme comprises three main strands of work –

improving services for children and young people, improving services for adults, in particular those with a long term health condition or who are vulnerable to illness, and finally a focus on prevention and supporting people to lead a healthy life.

The partnership will enable local GPs to work much more closely with hospital and community trusts to offer more joined up health services in the borough and reduce duplication, and is seen as a unique opportunity to transform community health services.

Health Hero Training Academy for Children and Young People

STAFF from Tower Hamlets's Paediatric Liaison Team collaborated with Barts Health to launch a Health Hero Training Academy at the Royal London Hospital incorporating therapeutic play, drama, games and psychological therapy to celebrate the strength and abilities of its young patients.

Dr Jennie Robertson, Clinical Psychologist explained, "We recognise that children and young people living with chronic physical/health difficulties are vulnerable to developing and adopting illness-based identities at the expense of recognising their strengths and abilities and often under-achieve socially and educationally opportunities as a result of multiple medical appointments and hospital admissions. This can be detrimental to their psychological well-being and social development. In addition, the parents and carers of our paediatric patients can also be negatively impacted by the challenges of caring for a child with a chronic illness. We believe that all our patients and their parents/carers deserve, and we hope to recognise and celebrate this through the Health Hero Training Academy"



Summer 2017
AK care AK support AK not believe
5

- (d) Context Publication article (first page only, entire article attached with report covering email)

Celebrating differences: *Improving psychological well-being in children and young people living with chronic physical illness*

Jennie Robertson, Tara Shea and Louise Rylatt

Celebrating differences: Improving psychological well-being in children and young people living with chronic physical illness

The purpose of this article is to introduce an innovative intervention we have developed for working with children and young people living with chronic physical illness, within a paediatric setting. The intervention uses therapeutic play and narrative-therapy skills, as well as a performance-based workshop that is delivered by Chickenshed Theatre, and is currently being trialled at the Royal London Hospital. We were awarded funds from The Health Foundation to deliver the intervention over a fifteen-month period between 2016 and 2018. The development of the intervention and data collection is ongoing and we hope to submit our reflections and outcome data in a later issue of *Context*.

Chickenshed Theatre

Chickenshed is an inclusive theatre company that first began in 1974. Primarily based at their own purpose-built venue in North London, they create theatre for all ages and run successful outreach projects, education courses and membership programmes throughout the year.

The Royal London Hospital

There are over 15 million under-20s in England, making up nearly 25% of the total population. 14% of these have a chronic illness (NHS Youth Forum, 2014/15). Barts Health NHS Trust Children's Services sees nearly 100,000 children a year through the three emergency departments and makes up 9.1% of children and young people's emergency activity in London. The service also operates one of the largest children's hospitals (located at the Royal London Hospital site) in the United Kingdom. GLA projections show that the number of children aged 0-4 is projected to grow significantly in Newham (23%) and Tower Hamlets (18%) between 2011 and 2021. This means the local and national population being served by the service is growing both in terms of numbers and in complexity.

The Royal London Hospital provides psychosocial support to its paediatric patients (aged 0-17 years) and their families and carers through its play department and paediatric liaison team. Both teams work with inpatients and outpatients. Demand outweighs supply; over the last two years referrals to these services have tripled. There are also severely limited psychological and psychosocial support provisions for paediatric patients at other Barts Health NHS Trust sites (Whipps Cross and Newham University Hospitals).

The play department

The play department is made up of both health-play specialists and play workers. Health-play specialists work to promote effective coping mechanisms through play, procedural preparation, procedural support, distraction therapy, education, and self-expression activities. Health-play specialists along with play workers provide normalising and therapeutic play, age-appropriate toys and

resources, developmental play, support to patients, help to create a child-friendly environment, support for siblings and families, group play-sessions and events and specialist entertainment. They encourage the cognitive and emotional development of children facing a broad range of challenging experiences, particularly those related to healthcare and hospitalisation.

The paediatric liaison team

The liaison team comprises clinical psychologists, psychiatrists, a social worker and a bilingual co-worker. We offer support to manage the emotional impact of living with a health condition. Our work includes assessment and intervention for: health problems with an impact on emotional well-being; physical health problems with a psychological component; psychological assessment; psychiatric assessment; neuropsychological assessment; adjustment to illness; pain management; adherence to treatment; and consultation to health professionals, schools and other services.

Psychological difficulties in the context of paediatric healthcare

Whilst many paediatric patients and their families cope well with the demands of physical illness, this patient population is at increased risk of developing psychological problems when compared to healthy children, with estimates of psychological difficulty ranging from 10% to 37% (Glazebrook *et al.*, 2003; Meltzer *et al.*, 2000). Psychological difficulties in the context of physical illness can have negative implications for patients' prognosis, treatment adherence and outcome, and quality of life, and may lead to repeat procedures and increased use of pharmacology (Edwards & Titman, 2010). In addition, there can be a burden of caring for a child with both chronic physical illness and psychological difficulties.

There is growing recognition of the importance of addressing the psychological well-being of paediatric patients (for example, national service frameworks for children and young people, DoH, 2003). The government strategy *No Health Without Mental Health* (DoH, 2011) set out objectives to ensure that the psychological well-being of paediatric patients is addressed alongside their physical