CYP@Salford
Improving Outcomes for Children, Young People and Families

School of Health & Society
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Evaluation of BreathStars

Report

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The Research Team Profile

CYP@Salford is known for being a multi-professional, multi-agency research group with many external partners which is focused entirely on improving outcomes for children and their families. Our research spans health, social care and education; enhancing services, improving outcomes and evidencing impacts on children and families. Collaboration between health and social care professionals is a strength in the group, allowing rounded appreciation of families' situations and service responses. The research group works closely with colleagues in the NHS, Local Authorities, the Third Sector, and national networks. We have research links with international partners in Scandinavia, the Middle East, the Far East, Europe and Australia. CYP@Salford continues to build on its established reputation for collaboration with children and young people in education and research through a model based on working with young people and the promotion of active citizenship.

The University of Salford expert evaluation team is drawn from the Centre for Applied Research in Health, Wellbeing and Policy (CARe) which is known locally, nationally and internationally for its applied research into the interface between health, wellbeing, housing, criminal justice and social care (http://www.salford.ac.uk/research/care/homepage).

Expertise and Experience in Evaluation in the Field
The research group has extensive experience of evaluation research, with a particular focus on mixed-method, qualitative and impact evaluation. Whether local, regional, national or international, this work has often relied upon functional collaboration with multi-organisation partnerships. This has required expertise in the reconciliation of data from varied sources and in equally varied formats to allow for combined analysis of such complex data.

Professor Tony Long
Professor Long has managed a series of realist and impact evaluations involving cultural change in services and revisions of ways of working. These have provided the evidence for change and then measured the impact of change in approaches to persistently multi-service dependent families through family intervention projects and the UK Troubled Families initiative. A series of 13 evaluation studies with varied children's social services departments between 2006 and 2012 helped organisations to design the most effective and often innovative responses to vulnerable children, including a four-year longitudinal evaluation of services for neglected children. He also works to enhance the evidence base for improving the children's care workforce in health and social care, with projects to advise policy on health (Health Education England, English National Board, Department of Health) and social care (Children's Workforce Development Council, General Social Care Council).

Louise Bowden
Louise graduated as a Registered Nurse for Children in 2006 and has experience of care delivery in a variety of specialties including endocrinology, respiratory and neurology. Louise began her career at the Royal Manchester Children's Hospital where she gained an interest in safeguarding and caring for children with complex needs. To gain community experience in this field Louise worked as a special needs school nurse. Louise shows passion and care about giving children and young people a voice. A current research interest is identifying areas which will improve health and wellbeing outcomes for children and young people. Her key interests revolve around the area of safeguarding, advocacy and the effect that a long-term health condition can exert on the child and their family.

The BreathStars Initiative

A weekly singing group was established for children with asthma aged 7-12 years old living in Little Hulton and north Walkden. This was an experiment funded by Salford Clinical Commissioning Group as part of its Little Pot of Innovation Fund 2017 and Awards for All (Big Lottery Fund). The aim of the group, called BreathStars, was to test if singing improves the breathing of children with asthma. The project was delivered in partnership between Unlimited Potential, a social enterprise specialising in social innovation for happiness, Brightness Management ltd. (Heather Henry, who is a registered nurse who lives with asthma, was the project manager), and the Hallé, which was a non-financial partner that offered advice and support.

Children with a diagnosis of asthma (proxy indicator was needing a preventer inhaler) were recruited through schools, health, art and community organisations, which were visited individually by the project manager or the project volunteer (a mother from Swinton who works in Little Hulton). Updates were presented to the local Outreach and Engagement Group. A stall was set up in the Ellesmere Centre to engage families via puppetry ('the Big Bad Wolf has asthma and needs the children's help to use his inhalers') whilst they were shopping. Engagement work continued during the *Walkden in a Winter Wonderland* event at the Ellesmere Centre (all with permission). All schools and GP surgeries in Little Hulton and north Walkden were emailed about the project and three school assemblies and one school gate engagement activity were conducted to encourage children to come. A Facebook page was established with regular updates, including videography (with parental permission) being posted to the most popular local Facebook pages and also to Salford Online. A press release was also issued and ran in the Bolton News.

The children met weekly for an hour's singing. This was originally at Harrop Fold School, which offered a free room. When numbers remained low (4 children with asthma and their families) after the first term, the project manager contacted all parents to ask what would help. With car ownership low (or fathers still at work), a more central location was the most common request and the group moved to Little Hulton Library. It was also clear that parents had up to four children, some only toddlers, and actually arranging and getting to BreathStars was *"a big effort"*. The project team also focused on promoting the fun side of the activity via Facebook videos. Discussion with the neighbourhood management team revealed that low participation in community activities in Little Hulton is not unusual, while group membership rose with longevity. Persistence pays off.

After the move to Little Hulton Library, two new children joined but two children left. One left because their reason for coming was to see the project manager, who was not able to attend for two weeks (which were covered by the project volunteer) and one gave no reason, but lived outside the project area in Kersal, so perhaps found the travel distance too far. Children and families enjoyed the library as well as the singing, with some siblings choosing to stay in the library and some joining in the group.

External, independent evaluation was secured from the University of Salford, with all relevant data being made available, and access arranged to the group for additional data collection.

Evaluation Design

A mixed-methods realist evaluation approach was adopted,[1] attempting to measure what could be measured, and employing qualitative methods for aspects which could not be measured. This meant that the mechanisms by which outcomes were achieved and change was realised, as well as the influence of context in producing those outcomes, were of equal importance. Hard copy data was provided by the project manager in the form of wall charts of asthma control and responses to the Childhood Asthma Control Test, together with qualitative data from responses to three questions on a postcard from children, non-asthmatic siblings or friends, and parents. Interviews were held by the researchers with children with asthma, their siblings and parents using both audio and video-recordings. This was supplemented with data from telephone interviews with other stakeholders.

The varied nature of the data that was expected prompted the use of a framework analysis approach.[2] The frame for this was set by the facets of the project detailed below, and according to identification of mechanisms, outcomes and context central to realist evaluation.

Evaluation Objectives

1. To understand how the project makes a difference to children, families and communities.
2. To understand any measurable differences, especially regarding time off school, visits to GP or accident & emergency department, and ability to enjoy a normal life (such as participating in games and physical activity).
3. To highlight any unintended consequences (positive or negative), such as the knowledge, understanding and support (or not) of family members and the wider community.

Since this was a small project (in terms of numbers of participants), the emphasis was on learning from the initiative: the feasibility of the approach, the nature of the sample and the data that might be produced, and unpredictable factors which should be considered in future initiatives.

[1] Pawson R, Manzano-Santaella A (2012) A realist diagnostic workshop. *Evaluation* 18(2) 176-191.

[2] Ritchie J, Spencer L, O'Connor W (2003) Carrying out qualitative analysis. In Ritchie J, Lewis J (eds.) Qualitative research practice: A guide for social science students and researchers. Sage, London.

How the project made a difference to children, families and communities

Recruitment

It has been reported by the project manager in an exception report that recruitment was difficult. The area of Salford in which the project was located was known to have particular cultural and demographic features which made recruitment and engagement difficult. Families tend not to have the inclination or the means to travel far, and this, combined with a general lack of trust of external initiatives, made for a challenging experience from the start. However, due in part to the established presence in the area of the project manager, as well as relocation to a more central venue, it was possible to recruit families - partly on a rolling basis. Indeed, in the postcards, three entries urged the recruitment of “more people” while another recommended “Inviting more children so even more fun”.

Extensive marketing of the choir had been undertaken through every available avenue, but participating mothers stated that they knew of other mothers who expressed interest when told, but had otherwise no knowledge of the opportunity. Other stakeholders felt disappointed that local NHS organisations and GP practices had not played a more active role in identifying and recruiting participants. Identification by GP systems would be simple, and this could be supplemented by community children’s nursing teams if NHS buy-in could be secured. Another solution, suggested by one of the music experts was to refocus in one primary school in order that greater coherence might be achieved and critical mass established to realise the “buzz” from group achievement. This would also ensure that resources produce a greater return. It would be likely that families would live locally enough for attendance to be easy, and many families would know each other. However, whether this would depart from the intended non-service oriented and informal community development ethos needs to be considered.

Asthmatic Control

While the quantitative measures were not able to detect these changes, both children and parents reported notable improvements in asthmatic control. Coughing was reduced, particularly at night, for two children. One child was taking his inhaler less frequently and was out of breath less often. Another reported taking the blue intervention inhaler as often as before, but only as a preventative rather than to abort an asthmatic attack. None reported wheezing so there was no change in this. Understandably, children and parents found it difficult to quantify the reported changes, but they were in no doubt as to the existence of the improvement.

Impact on the Family

Two children acknowledged that their sibling with asthma used to keep them awake or disturbed their sleep sometimes because of coughing, but this was less common since joining the choir. They felt less tired as a result. Two mothers who were interviewed reported having more time to spend on their other children since the child with asthma seemed to require less attention.

Measurable differences, especially regarding time off school, visits to GP or accident & emergency department, and ability to enjoy a normal life (such as participating in games and physical activity).

Compliance
Compliance with the measures was variable. The Child Asthma Control Test (CACT) was completed more consistently than the wall chart asthma poster. However, neither was completed such as to provide rigorous data. With the limited number of participants, this was not an issue, but learning for further projects was clear.

Part of the problem was failure to complete repeated measures. This is a perennial issue with self-completed diary-style instruments. One of the briefest and simplest instruments had been selected for us; the project had already adopted a time-sampling approach (one week of daily recording at three points in the project) which is known to improve compliance; and a fun, child-oriented wall-poster was provided. Though reported only by one parent, the task may have been subordinated in the daily routine of child care and forgotten, or may have been the impact of a child prevaricating until the task was forgotten. Ideally, an electronic means of recording would be used with remote prompting if the task is not completed. This would require internet access and appropriate hardware which may well not be available to many in the communities targeted by the intervention. Phone calls as reminders may prove counter-productive and are often ineffective anyway since they are no guarantee of compliance. That the CACT was completed better suggests that adults may be more compliant than children, and this CACT data encompasses the detail in the wall chart. Perhaps the wall chart data is superfluous and could be amended to report only problematic episodes.

The second issue was that the reported data showed hardly any change. One child reported having had a cold which prompted a change in wall-poster score. The reporting period may have been too short to capture changes. Moreover, an essential feature of asthma is seasonal variation for individuals who respond differently to hot or cold, perennial allergens, and annual bouts of infections such as influenza. These pose major challenges to asthmatic control. It would not be possible to factor this into the project since too many variables would be at play. In the absence of a 12-months project timeline, time sampling for periods of low challenge to asthmatic control is probably necessary, but this risks minimal variation in symptoms.

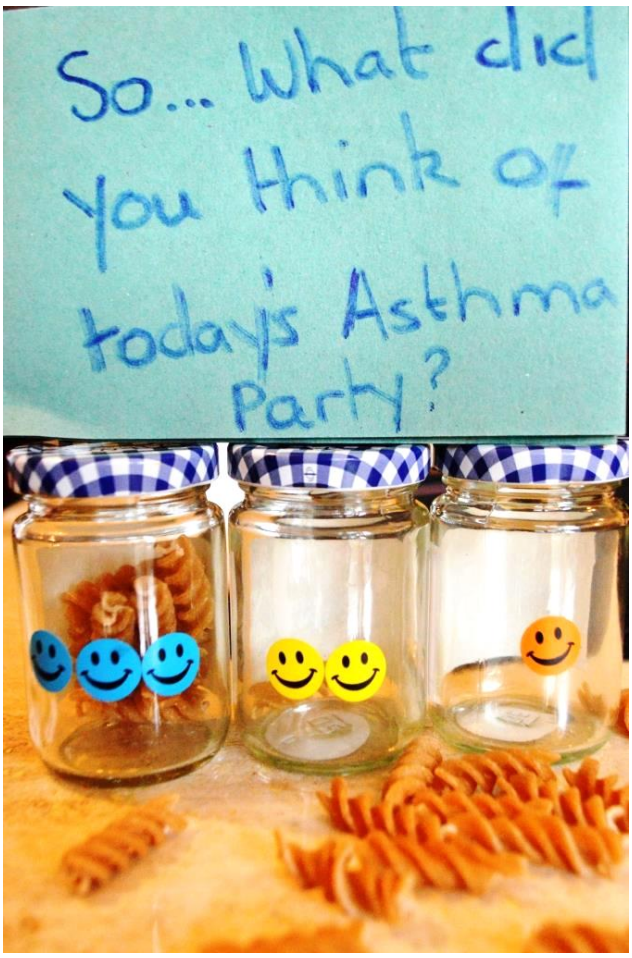
Reported Measurable Impacts
No episodes of requiring time off school or additional visits to the GP were reported, but the parents who reported to the researchers explained that there had been none in a similar period before joining the choir. Again, this aspect of change is likely to be a long-term measure and beyond this project (though it could be applied again in future versions).

Unintended consequences (positive or negative), such as the knowledge, understanding and support (or not) of family members and the wider community

The Choir as a Positive Experience
Detail from the postcards, supplemented by testament during interviews, evidenced that children (with and without asthma) and their parents all found participation in the choir to be a positive and enjoyable experience. The perspective from professional musicians was that the benefits often seen by music interventions - increased concentration and enhanced confidence - were to be seen in the children who joined the choir. Both mothers who were interviewed confirmed this independently, one adding further personal detail of the change in her child. They also spoke of better general behaviour linked to raised mood. This they attributed to a general improvement in self-esteem, and the ability to join in both this and other activities with other children (which had previously seemed impossible).

Perceptions on Games and Activities

An integral part of the intervention was exercises and activities, presented as games, that help with lung expansion and control of breathing, or which addressed psychological issues of lack of self-esteem and confidence. Despite explicit explanations during the weekly sessions, the children who were interviewed denied any therapeutic link with the games and activities. They reported these to be simply "fun games". One child who was not asthmatic wished for fewer games and more singing instead. This child would probably not have experienced any physiological effects from the breathing exercises, so these activities would have meant no more than games. One mother had a different take on this for children who were affected directly by asthma. She described them as being carried away with the singing and activities, and forgetting about the focus on their asthma. They seemed to have moved beyond undertaking the activities for an explicit therapeutic reason to simply enjoying *being able* to take part in them. This is a positive outcome as the impact could be achieved without medicalisation of the games and activities. These would leave parents with additional strategies to use to help with regaining control of breathing, and especially the forced expiration that is necessary to counter trapping of air in the lungs during episodes of exacerbation of asthma.



Crucial Factors in Acceptance of the Intervention

Speaking of both the singing and the activities, a different mother emphasised the importance of this being a non-medical intervention, a community activity that was not linked to statutory or formal services. In discussion, she suggested that this was what members of this community would usually prefer, and that they were generally service-resistant. This nature was emphasised by the community location, the emphasis on enjoyment, and the camaraderie of the mothers. A once-in-a-lifetime trip to Bridgewater Hall was offered by The Hallé as an example of this bonding between families and the potential for ongoing peer support.

Importance of the Family-Centred Approach

The choir had been organised on the basis of siblings, parents and friends of children with asthma being encouraged to join in both the singing and the activities. Both adults and children who were interviewed held this to be an important factor in the success of the choir. Unaffected siblings both enjoyed the experience but came to understand better what their affected sibling was experiencing and how they might respond more positively and helpfully in future. Parents saw this change in unaffected siblings, remarking on increased tolerance of both their sibling and other children with long-term conditions. One of the children thought that it was good for children of any age to be included, and this was echoed by a volunteer who remarked on the readiness of very young children (of 3-4 years) to learn from the intervention.

Potential for Wider Impact

The potential for generational change was also pondered by a volunteer who had joined in the choir. She saw the possibility of wider change through this and similar initiatives, as children gained confidence and aspiration, perhaps to consider alternative employment, careers and perspectives on life. This requires further investigation, but has clear links to the Salford City Council's Fuelling

Ambitions Creatively Together (FACT) project, designed to promote exactly these attributes in young people.

Community Benefit

A volunteer and her daughter indicated that there could be wider benefits for the community and society at large. They spoke of helping other children (and parents) to understand asthma better, and one child reported having helped other children at school to take their inhalers more effectively (despite not having asthma personally). An entry in the postcards by a parent also showed that they were thinking about the potential for children to "learn how to help themselves and others with asthma". This effect would be similar to that sought by campaigns for all adults (and latterly children and young people) to be competent in basic first aid, hands-only resuscitation, or recognition of someone struggling with a mental health issue. If the initiative were to be rolled out wider, and if this effect were to be evidenced again, it might need to be reviewed as a public health intervention as well as a local primary health intervention.

Conclusions

Problems with recruitment (and retention) of families had knock-on effects for the potential musical achievement in performing as a choir. However, those who participated found it to be a pleasant and fulfilling experience.

What made it a positive experience was the joy of singing, learning new songs, joining in with other children and adults, and the incorporation of games and activities. These must have been understood to be therapeutic for those with asthma, but this knowledge faded and was replaced by empowerment in those with asthma and enjoyment by all.

The context in which this was achieved was the establishment of the group in the locality, the informal atmosphere (with parents bringing in food to share, for example), and the family focus.

Improvement in asthmatic control was reported by children, siblings and parents, notably reduction in the need for inhalers, less coughing, and less disturbance during the night. These changes were not sufficient to be identified by the CACT instrument or the wall poster.

The improvements in asthmatic control were part of wider changes, and were seen in the context of greater confidence, improved behaviour, and raised mood and self-esteem.

Clearly, both psychological and physiological impacts must be considered when selecting outcomes, in addition to the link between these.

Despite the adoption of strategies to encourage compliance, serial completion of the instruments was patchy, and consequently the data was less useful than had been hoped for. It was clear that parent-completed data was more reliable than that by children (wall posters).

This response must be interpreted against the background of parents with busy lives, often with several children, who were seen to be rushing off to the next commitment as the session ended. While their devotion to the singing and activities (indeed to the group generally) was unquestionable, the pressures on those who remained in the group may serve as an insight into reasons for others not managing to include the choir in their diary.

Parents seemed a little surprised to realise some of the impacts on their child that they had observed but not registered consciously previously. Making these impacts explicit might serve to boost retention in the group. Similarly, the benefits gained by asthmatic children from the activities might also need to be made explicit (and repeatedly).

Wider community impacts were reported - for example, the ability and willingness to help other children with asthma following the gaining of new knowledge and understanding through participating in the choir. This was the case for siblings, too.

This was reported both by those with asthma and those without. It indicates an internalisation of the learning, perhaps through the enjoyment that it brought and, for some, the (perhaps unconscious) discovery of new ability and confidence.

Understanding of the new knowledge, and appreciation of the corresponding ability to improve both one's own asthmatic control and that of others was essential to this wider impact.

Long T, Bowden L (2018)
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