



The Children's Bowel & Bladder Charity



ERIC NURSE PROJECT MAY 2013 TO MAY 2016 EVALUATION REPORT

September 2016

"Lots of parents struggle so much with continence issues in their children and so this help offers a hugely important service to families. If left unaddressed continence issues can have a lasting effect on the parent/child relationship and the child's self-esteem." (School Health Assistant, Participant, ERIC Early Interventions Training)

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1. EXECUTIVE SUMMARY

1.1 Introduction

In May 2013 the ERIC Nurse Early Interventions Project (ERIC Nurse Project) was launched in Bristol and South Gloucestershire working in partnership with The Community Children's Health Partnership. The three-year pilot study was funded by a Department of Health Innovation Grant and concluded in May 2016. The project, delivered by ERIC, the children's bowel and bladder charity, aimed to increase early intervention into childhood continence problems and promote excellence in continence care.

The specific aims of the project were:

1. To increase parents' awareness of what a continence issue is and where to go for support
2. To increase frontline health professionals' (e.g. Health Visitors, School Health Nurses, Family Nurse Partnership teams) and early years workers' (e.g. childminders, children centre staff, nursery nurses) ability to support parents and children around childhood continence
3. To improve the child's journey through continence care in Bristol and South Gloucestershire

The project delivered three main things:

- **Information leaflets** to increase parents' awareness of what a continence issue is and where to go for support.
- **Training for health professionals** to increase their knowledge and skills to better support parents and children around continence.
- Development of a **generic children's continence pathway** to improve the child's journey through continence care.

This evaluation has been conducted to assess the impact and outcomes of the interventions that were delivered and what difference it made to parents and health professionals. The data collection methods included surveys of parents who had received the leaflets and feedback forms, and a survey and qualitative interviews with health professionals who attended training. Existing monitoring data and website statistics were also reviewed.

1.2 Summary of work done and difference made

Increasing parents' awareness

- Two leaflets were developed to help to increase parents' awareness of signs of continence issues, early corrective actions and where to go for further support:
 - 'Thinking about wee and poo now you've reached the age of two' for distribution at the two-year developmental reviews undertaken by the health visitor team.
 - 'Thinking about wee and poo now you're on your way to school' for distribution at school for children in reception year.
- Approximately 110,000 leaflets were distributed during the ERIC Nurse Project.
- Additionally, existing ERIC leaflets were updated and made available to health professionals undertaking training adding value to the ERIC Nurse Project.
- An online survey indicated that more parents knew how much their child should drink after receiving the leaflet than before and to increase fluids as a corrective action if they suspected constipation.
- The online survey showed that significantly more parents would go to ERIC for help after they had read the leaflet than before. The ERIC website statistics reflect this increase in knowledge of and interest in ERIC.

Increasing health professionals' ability to support others

- The ERIC Nurse Project provided training for 1017 frontline health professionals, predominantly health visiting teams and school healthcare professionals, plus early years workers.
- The training included a fundamental 'healthy bladders and bowels' course and follow-up sessions around potty training, night-wetting and working with children with additional needs.
- Those attendees completing our online survey reported that they left the courses with a better understanding of bladders and bowels. 98% out of 49 responding said they knew more about how to recognise a problem and 100% better understood why things go wrong. The most common thing that people learnt about was constipation and the importance of treating it.
- Health professionals who responded to the survey said they came away from the courses knowing more about what to advise parents and children if bladders and bowels aren't

working well. 94% said they understood more about what to advise in terms of fluid intake and 100% said they knew more about where to signpost in terms of medication.

- Since the training, health professionals said they had shared the information they learnt in many settings including clinics, schools, home visits, and teaching sessions.
- 100% of respondents who took part in follow up telephone interviews between 6 and 12 months after training felt more confident to support parents and children around continence since the training. They retained the confidence to recognise an issue and recommend corrective actions.
- The training increased health professionals' knowledge of other agencies to signpost families to for further support. 94% of respondents said they knew more about what to advise in terms of where to go for more information or help. Familiarity with ERIC in particular had increased. The ERIC website statistics reflect this increase in knowledge of and interest in ERIC.

Improving the child's journey through continence care

- The need to improve the child's journey through continence care emerged as a priority during the ERIC Nurse Project and as a result work to develop a children's continence pathway was carried out towards the end of the project.
- Through the ERIC Nurse project, in partnership with other health professionals, a generic integrated children's continence pathway was developed. This evolved as a model of best practice, which could be adapted for use in any area.
- The new pathway will be an online resource hosted on the new ERIC website, available towards the end of 2016.

1.3. Overall success and impact of project

The ERIC Nurse Project was successful in achieving its aims to increase parental awareness and to increase the knowledge of health professionals to support families around childhood continence. The third aim, improving the child's journey through continence care, will be assessed when the new continence pathway has been in use for 6 to 12 months.

Although the longer-term impact of the project has not had time to be fully realised and was not directly assessed in this evaluation, some initial indications of changes to the lives of children and families as a result of early intervention and cost savings in public health care were identified. This gives confidence in the potential of the project to have a significant impact on reducing distress and costs associated with childhood continence issues, relative to the modest size of investment.

1.4. Recommendations and Future Needs

A number of key learning points were identified and the following recommendations made:

- Clear evaluation strategy in place from outset to ensure project outcomes can be effectively assessed. Baselines to be set at the start and appropriate information collected throughout the project.
- At the start of the project a resource distribution strategy to be developed and agreed with methods in place to ensure information reaches communities of interest as well as reaching across geographic communities.
- To review how information is presented and made accessible to all including those whose first language is not English.
- There is a need to find ways of extending teaching and training to teachers and learning care assistants who are in a strong position to provide support and advice on continence issues in young children. Future work needs to identify how this is best achieved
- Future development of family resources should include more input from parents
- The new online children's continence pathway should be widely promoted to parents, HCPs, education staff, early years workers, GPs, paediatricians and commissioners and its use evaluated at 6 and 12 months after launch.

2. Introduction

In the UK an estimated 900,000 children and teenagers have continence problems such as night-time wetting, daytime wetting, soiling, constipation and recurring urinary tract infections¹. The latter two of these issues account for 15,000 hospital admissions in England, and constipation accounts for 18,000 first hospital appointments each year².

Many problems are avoidable or treatable yet it is estimated that only 11% of those affected seek treatment. With improved early intervention including information, education and training of health and early years professionals and parent/carer education it is estimated that 80% of admissions could be avoided³. This would potentially reduce distress among children, teenagers and families as well as saving vital health service funds.

In May 2013 a three-year project, funded by a Department of Health Innovation Grant, was launched in Bristol and the South Gloucestershire area. The aim of the project was to increase early intervention into childhood continence issues and promote excellence in continence care. The project was delivered by ERIC, the children's bowel and bladder charity.

ERIC Nurse Project overall aim:

To increase early intervention into childhood continence issues in the Bristol and South Gloucestershire (South Glos) pilot study area

Over the three years, the project secured funding to support a specialist continence nurse for 26 hours per week, with part-time admin support. The balance of funding was used broadly to develop and deliver training to healthcare and early years professionals and develop resources for health professionals, early years professionals, parents and carers.

The early months of the project were spent:

- Consulting with local health care and child care professionals about the issues and to identify needs.
- Raising awareness of ERIC and the services it provides.
- Mapping existing continence services, learning from current provision.

¹ NHS Modernisation Agency (2003). Good Practice in Paediatric Continence Services – Benchmarking in Action

² NICE (2014). Helping children with constipation avoid A&E. www.nice.org.uk/news/press-and-media/helping-children-with-constipation-avoid-accident-and-emergency

³ NICE (2010). Guideline: Constipation in children and young people - diagnosis and management (CG99) www.nice.org.uk/guidance/cg99

- Gaining 'buy-in' to working towards the proposed aim.

The specific aims, which express the areas in which the project planned to make a difference, then emerged.

Specific aims (planned areas of change)
1. To increase parents' awareness of what a continence issue is and where to go for support
2. To increase frontline health professionals' and early years workers' ability to support parents and children around childhood continence
3. To improve the child's journey through continence care in Bristol and South Gloucestershire

To achieve the specific aims of the project work was divided into three categories:

1. The development and production of information **leaflets** for distribution to the parents of every child turning two from September 2014 onwards, and every child starting Reception class in September 2014 and September 2015.
2. The devising and implementation of a **training programme** providing free, easy to access training sessions to health professionals and also staff working in Early Years settings such as nurseries and Children's Centres.
3. The devising of a **generic children's continence pathway**. This aspect of the work evolved significantly as the project progressed. The original plan was to update the existing Bristol Children's Continence Care Pathway; after much consultation it was decided that a generic pathway was a much better outcome as it could be adapted for use not just in the pilot study area but in other areas around the UK.

The evaluation report that follows the work undertaken and the immediate difference it has made against each of the three project aims.

3. ABOUT THE EVALUATION

This evaluation was conducted by ERIC with support from NCVO Charities Evaluation Services. It covers the period of the ERIC Nurse Project, from May 2013 to March 2016.

The purpose of the evaluation was to:

- Summarise and assess the work carried out under the project and the products and services that were produced.
- Find out what difference the work made (outcomes and impact) in line with the project aims.
- Gather and reflect on learning points for future work in this area.

Data collection was undertaken throughout the ERIC Nurse project to monitor work delivered and establish baseline levels of awareness and knowledge in parents and immediate feedback from health professionals.

Work was undertaken with NCVO Charities Evaluation Services in August 2015 to define specific intended outcomes of the project, expand the monitoring and evaluation framework, and identify any gaps in data collection. Further and follow-up data was then collected between September and December 2015.

3.1 Evaluation methods

Data was collected for the evaluation from five sources:

- A survey of parents who received the leaflets.
- Feedback forms and survey of health professionals who attended training.
- Telephone interviews with health professionals who attended training.
- ERIC monitoring records.
- Google analytics for the ERIC website.

A survey of parents who received the leaflets

Parents of two-year-olds and school starters were asked to complete a paper questionnaire to assess their baseline awareness and knowledge before receiving one of two the ERIC Nurse project leaflets. 270 responses were collected from parents of two-year-olds and 253 responses from parents of school starters.

In November 2015 a follow-up online survey was sent to 177 of the parents of two-year-olds, the total number of those who had provided their contact details on the baseline questionnaire. 21 parents completed the follow-up. In December 2015 a follow-up online survey was sent to 107 parents of school starters, those who provided their contact details. 57 parents completed the follow-up.

In order to try to increase response rate, methods such as incentives and reminders were used. The higher response rate from parents of school starters is presumed to be because the parents had received the leaflet much more recently (two months previously) than the 2-year leaflet (distributed over the previous 14 months). Only the information from the data set from parents of school starters is used in this evaluation report as the return for the 2 year olds was deemed to be insufficient.

	2 year olds	Pre school
Baseline awareness questionnaire completed	270	250
Follow up requests sent	177	107
Follow up questionnaire returned	22	57

Feedback forms and online survey of health professionals who attended training

Paper feedback forms were used after all of the 44 training sessions to gather health professionals' immediate thoughts on what they had learnt and any suggestions for improvement.

In October 2015 an online survey was sent to 127 health professionals who attended training between January and June 2015 to assess change in knowledge as a result of the training and whether and how they were applying the learning in their work. A total of 49 health professionals completed the survey.

Telephone interviews

Ten semi-structured qualitative interviews were carried out with a cohort of the health professionals who had attended a range of ERIC Nurse Project training. Of the 49 healthcare professionals who took part in the initial survey, 27 indicated they would be willing to participate in a telephone interview and 10 interviews subsequently took place with available respondents.

The interviews all lasted around 15 to 30 minutes. The questions explored in more detail whether and how the health professionals felt more able to support parents and children around continence, to what extent this was down to the ERIC Nurse Project and asked about any impact on parents or children. The interviewees were also given the opportunity to share any thoughts on the child's journey through continence care in Bristol and South Glos.

ERIC monitoring records

The ERIC records include information on the number of leaflets produced, training sessions delivered and who attended.

Google analytics for the ERIC website

Analytics information was gathered for visits to the ERIC website homepage both before and after the leaflet distribution period and the health professionals' training.

3.2 Data that could not be collected

Other potential sources of data were explored for this evaluation. For varying reasons, it was not possible to source the following information that had been identified as potentially useful in assessing the contribution of the ERIC Nurse Project:

- **The number of interactions that frontline health professionals are having with parents and children around continence.**
This is not currently recorded in a consistent way that could be collated across the pilot area and analysed by ERIC.
- **The number of cases presenting to GPs, continence clinics and A&E around continence.**
The codes that are applied to these admissions and appointments are not consistent with the information that ERIC would need to gather to interpret the data for their needs.
- **The number of ERIC helpline calls relating to early stage or chronic continence issues within the Bristol and South Glos area.**
The system used to record helpline data during the period that the project was delivering did not capture the exact information that would be most useful to this evaluation.
- **Number of incontinence products provided to children on the NHS in the pilot area.**
It was not possible for ERIC to access this information.

Assessing any reduction in NHS and local authority continence care costs requires methods that are beyond the budget of this evaluation.

3.3 Scope of Evaluation

As an end-of-project evaluation, only the difference that has been made by the ERIC Nurse Project *within the project timescales* could be assessed. Some of the changes that the project makes are likely to be realised in the longer term, beyond the life of the project. In particular, the work to develop a generic children's continence pathway was carried out at the end of the ERIC Nurse Project. Therefore, there has not been sufficient time for outcomes to be realised or the work evaluated. For the children's continence pathway, this report focuses on explanation of the need for this work, the difference it intends to make and plans for assessment of this in future (see 4.3).

This evaluation focuses on whether the immediate changes that were planned as a result of the ERIC Nurse Project have been achieved. In parts there will be reflection on any initial indications of longer term change, such as change in the lives of families and children, but this was not a priority focus for the evaluation.

4. THE WORK AND THE DIFFERENCE IT MADE

4.1 Increasing parents' awareness

Work Undertaken

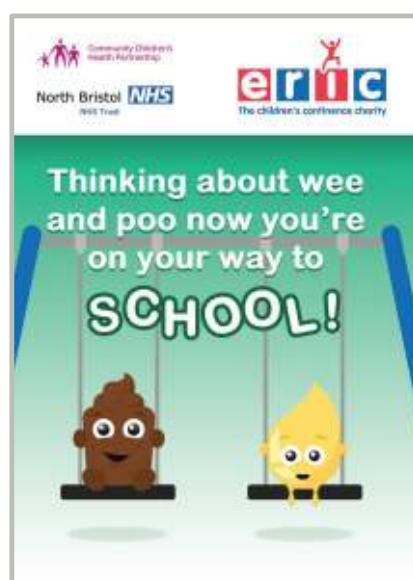
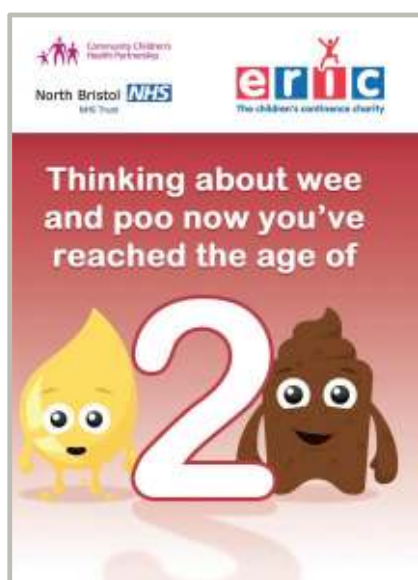
In order to achieve its overall aim to improve early intervention the ERIC Nurse Project needed to try to reach all families in the pilot area, not just those who were aware of continence issues. We know from calls to the ERIC Helpline and experiences shared at training sessions that many parents do not understand childhood soiling, for example; most believe children who soil do so because they are naughty, lazy or preoccupied by playing. They do not therefore seek the help of a healthcare professional. However, the vast majority of childhood soiling is caused by constipation, a medical condition requiring treatment with prescribed laxatives. Information about healthy bowel management therefore needs to be disseminated to all parents.

The project needed to reach as many families as possible in a cost-effective and resource appropriate way. Two key target ages of children were therefore chosen:

- i) At two years old, when the Health visiting teams had face-to-face contact to perform two year developmental reviews.
- ii) At school entry, when the School Nursing service distributed information packs to the parents of every child as part of the National Child Measurement Programme.

A leaflet format was chosen for the dissemination of the information as it is something tangible which can be given to parents to look at straight away and for consideration later. It is an accessible resource for health professionals and others to utilise during discussions and for families to take home. It also provides a resource for families that do not have access to the internet and is low cost to produce. For some years ERIC has offered leaflets; these added value to the existing range.

Two leaflets were designed to be eye-catching and clearly recognisable as information about bladder and bowels; the inclusion of the 'wee and poo' characters from the Kid's Pages on the ERIC website facilitated this.



The content was written in plain English in an informal and engaging style. Rather than including large amounts of text (which could be off putting) the leaflets signpost the reader to further sources of information. These sources include:

- Topic-specific ERIC information leaflets such as *ERIC's Guide to Potty training*
- The ERIC website and helpline
- The child's Health Visitor or School Health Nurse
- GPs

ERIC already had an existing range of topic-specific information leaflets. These needed to be revised to include the most up to date information and reflect the style of the two project leaflets. This was particularly important as readers were signposted from the project leaflets to these further resources for more detailed information. Crucially these leaflets can also be used effectively as stand-alone resources. Four leaflets were re-written as part of the project:

- ERIC's Guide to Children's Bowel problems
- ERIC'S Guide to Potty Training
- ERIC's Guide to Night Time Wetting
- ERIC's Guide to Childhood Daytime Wetting

Before embarking on the re-writing, ERIC sought advice from a number of different professionals who worked with families about how to make the resources accessible to as wide an audience as possible. We are aware that they are not ideally suited to:

- Parents who find reading English difficult
- Parents with Learning Disabilities
- Parents who prefer to receive information aurally rather than in a written format

Overall, the leaflets were well received and it was still felt that this was the best and most cost effective solution for achieving a wide reach amongst families.

Distribution of Leaflets

Since the two project leaflets were printed in summer 2014, over 110,000 have been distributed. The breakdown is as follows:

Thinking about wee and poo now you've reached the age of 2

Since March 2014, 55,000 have been distributed to:

- Health Visiting Teams - the majority have been distributed in the pilot study area in this way. They are given out routinely at each child's two-year development reviews. It is estimated that during an 18-month period teams across Bristol and South Gloucestershire distributed 15,660 leaflets.
- Children's Centres, Local Authority Nurseries and Private Nurseries – supplies have been made available in the pilot study area which have been given out informally to parents and carers.
- Exhibitions, Conferences and Training seminars – distributed at events across the UK as opportunities have arisen.

Thinking about wee and poo now you're on your way to school

Since this leaflet was first printed in August 2014, 55,000 have been distributed to:

- All reception pupils starting school in the pilot study area – at the beginning of 2014/15 and 2015/16 academic years:
 - Leaflets were included with information already being sent out
 - Distributed in Bristol by the School Health Nursing Service via the schools– approximately 6,000 each year.
 - Distributed in South Glos by the local authority – information sent direct to families. Average of 4,300 per year.
- Children’s Centres, Local Authority Nurseries and Private Nurseries – supplies have been made available in the pilot study area which have been given out informally to parents and carers.
- Exhibitions, Conferences and Training seminars – distributed at events across the UK as opportunities have arisen.

The four topic-related leaflets were re-written and printed between February 2014 and December 2015. Distribution numbers since re-print are as follows:

Leaflet	Print Date	Number Distributed
ERIC’s Guide to Children’s Bowel Problems	Feb 2014	50,000
ERIC’s Guide to Potty Training	July 2014	57,600
ERIC’s Guide to Night Time Wetting	June 2015	32,000
ERIC’s Guide to Childhood Daytime Wetting	Dec 2015	9,200
		148,800

Looking at historical information, the same number of old-style leaflets would have lasted more than 3 years rather than the 22 months since the new leaflets have been available. This indicates a significant increase in leaflet distribution during the ERIC Nurse Project.

Difference made (outcomes)

The ERIC Nurse Project leaflets are intended to help parents to recognise the signs of continence issues in their children at an early stage and take action to mitigate them. It was hoped that they would also help parents to know the most appropriate place to go for further information about bladders and bowels or for help if they identified an issue.

When 57 parents of school starters were followed up between two and 14 months after receiving the leaflet:

- 98% remembered receiving
- 69% reported reading it all and
- 27% said they skimmed or read parts of it.

The responses from this group of parents indicating what they said they learnt from the leaflet and any changes they made as a result are explored throughout this section.

Ability to recognise issues

Outcome 1: More parents are able to recognise the early signs of continence issues

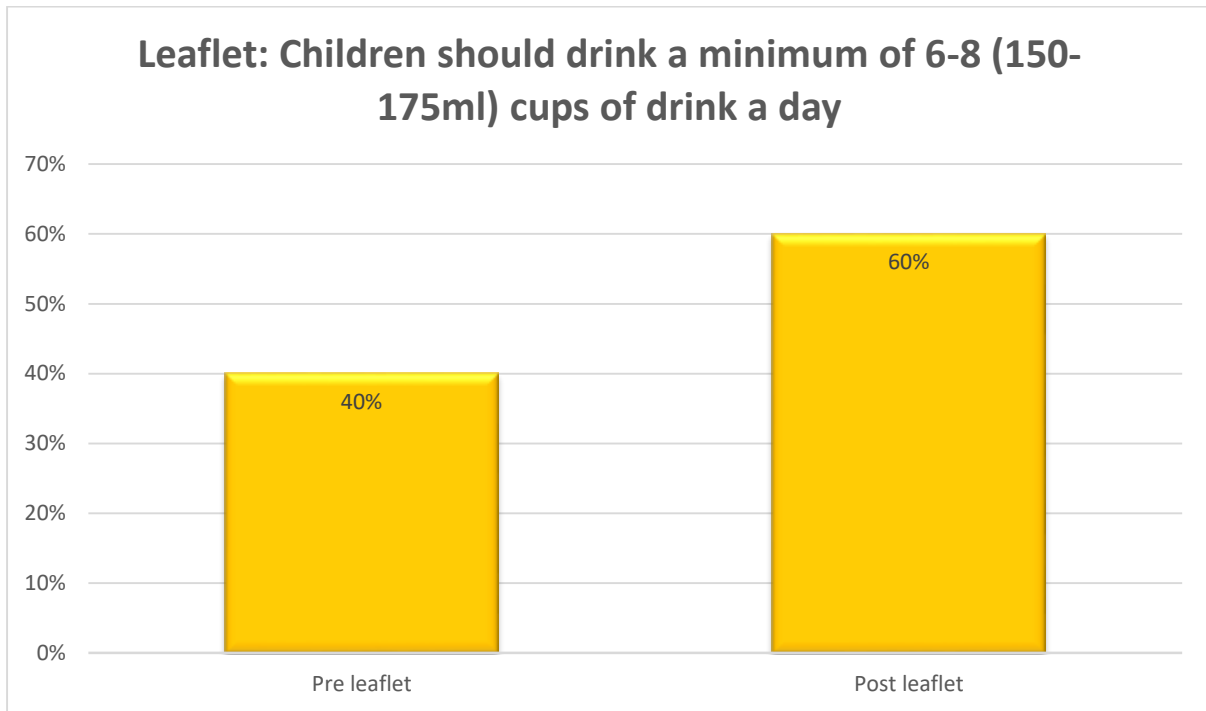
Based on the responses of 57 parents of school starters, the leaflet was successful in increasing their ability to recognise some signs of continence issues. The most common things that people said they learnt from the leaflet were:

- What healthy poo looks like
- How much a child should drink
- What is normal for a child of that age

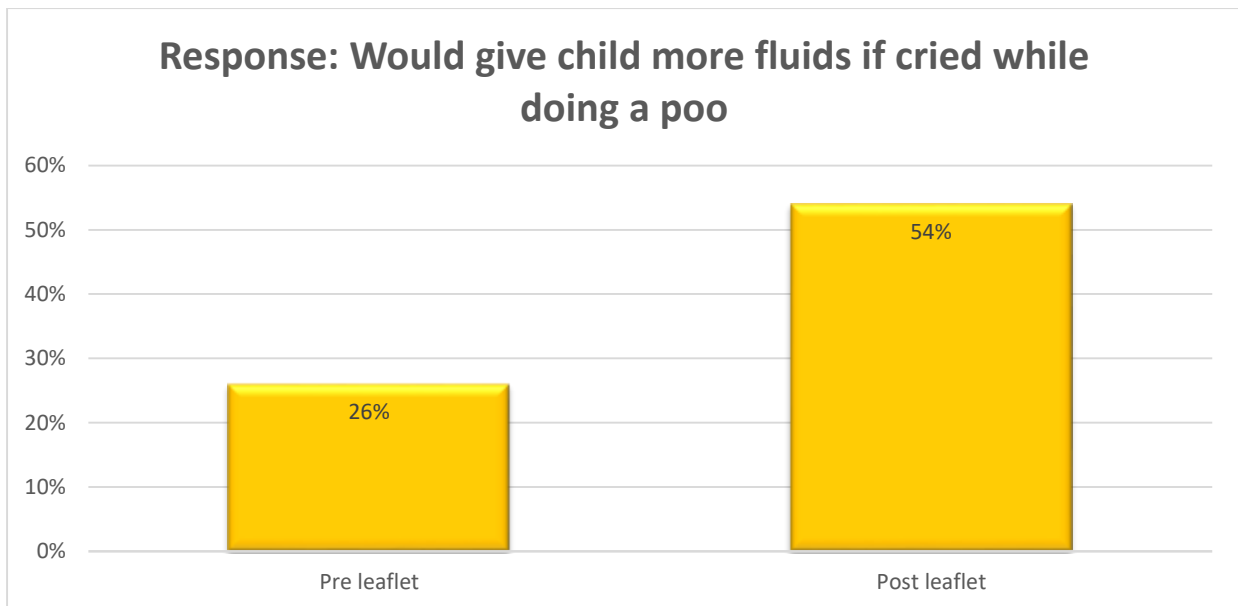
I found the leaflet extremely useful; especially the section telling us about what does a healthy poo look like. I also found very useful the information about how many drinks your child should have. (Parent of school starter, online survey)

[I specifically learnt about] normal bowel habits and expectations for school age children. (Parent of school starter, online survey)

The leaflets state that children should drink a minimum of 6 to 8 (150-175ml) cups of drink a day. When asked how many cups of drink they think a four/five year-old should have a day 40% of parents answered correctly in the baseline measure, before reading the leaflet. In the follow-up survey, 60% of parents answered correctly. The average number of cups of drink that parents believe a child should shifted upwards between baseline and follow up. This indicates that parents had increased their expectations of how many cups of drink their child should have for good bladder and bowel health after reading the leaflet.



When asked what they would do if their child cried when they did a poo, at baseline 26% said they would give more fluids and at follow-up 54% of parents said they would give more fluids.



Taken together, these results indicate that more parents are able to recognise that drinking enough is important for good bladder and bowel health, that crying while pooing is a sign of a continence issue and they would increase fluids as an early action.

Parents were also asked at what age they think children should be dry at night, as this could be a sign of a continence issue. The leaflet tells them that their child could well still be wet at night and that this is quite normal at school starting age so not to worry. The mean age that parents felt a child should be dry at night at baseline was 3.8 and at follow-up was age 4.4. This indicates a slight shift upwards, but as the most common (modal) age cited was age 4 at both baseline and follow-up, we cannot draw conclusions from the evidence.

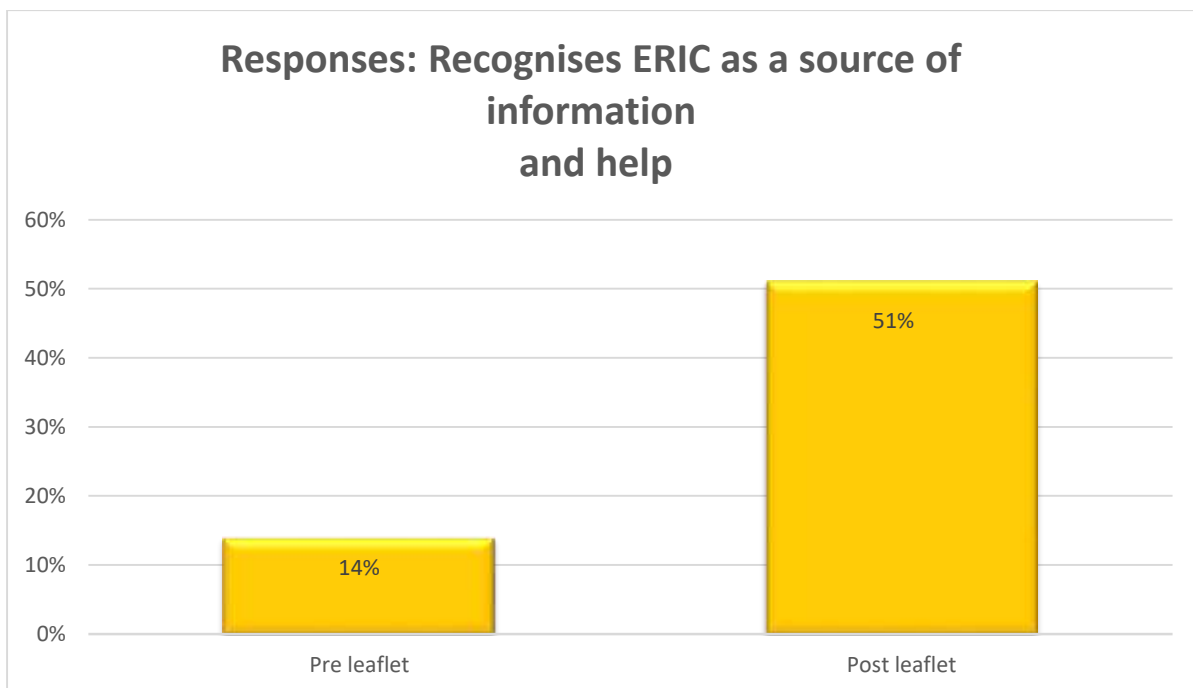
Knowledge of support

Outcome 2: More parents know where to go for information about continence

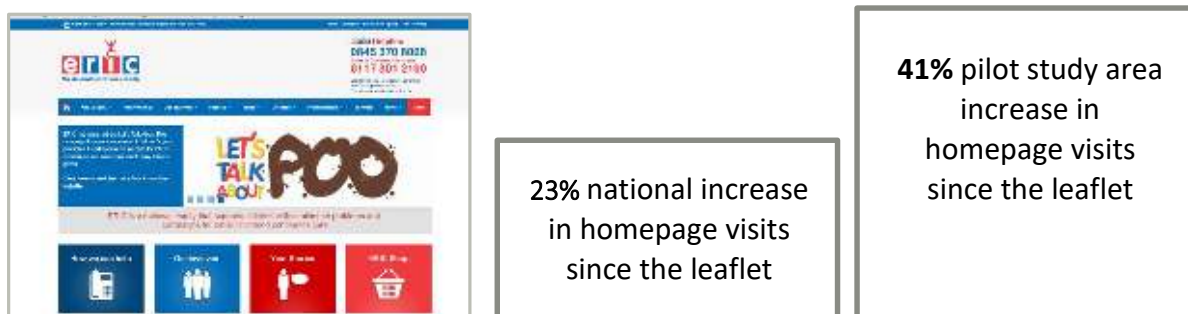
Outcome 3: More parents know where to go if they identify a continence issue and need help

Based on the responses of 57 parents of school starters, the leaflet was successful in increasing knowledge of ERIC as a source of help and information. There are indications that it also increased intention to consult a GP if an issue is identified, but this needs further exploration.

When asked at follow-up where they would go for information, help or advice on their child's weeing or pooing if they needed it in future, 51% of the respondents said they would go to ERIC. This compares to 14% of respondents citing ERIC as a possible source of help in the baseline questionnaire.



Although it could be considered that the online survey itself raised awareness of ERIC, the same could be said of the baseline questionnaire. Therefore, it is presumed that the leaflet raised awareness of ERIC as an early source of help, support and information for parents. It has also been considered that those parents who were aware of ERIC were more likely to complete the online survey. But our confidence in the increased awareness is supported by the translation of that awareness into action in increased visits to the ERIC website. Visits to the ERIC website homepage increased significantly in Bristol and South Gloucestershire in the year following the start of the widespread distribution of the ERIC Nurse Project leaflets (Oct 2014 – Sept 2015), compared to the previous year (Oct 2013 – Sept 2014). The increase is nearly double the increase seen nationally.



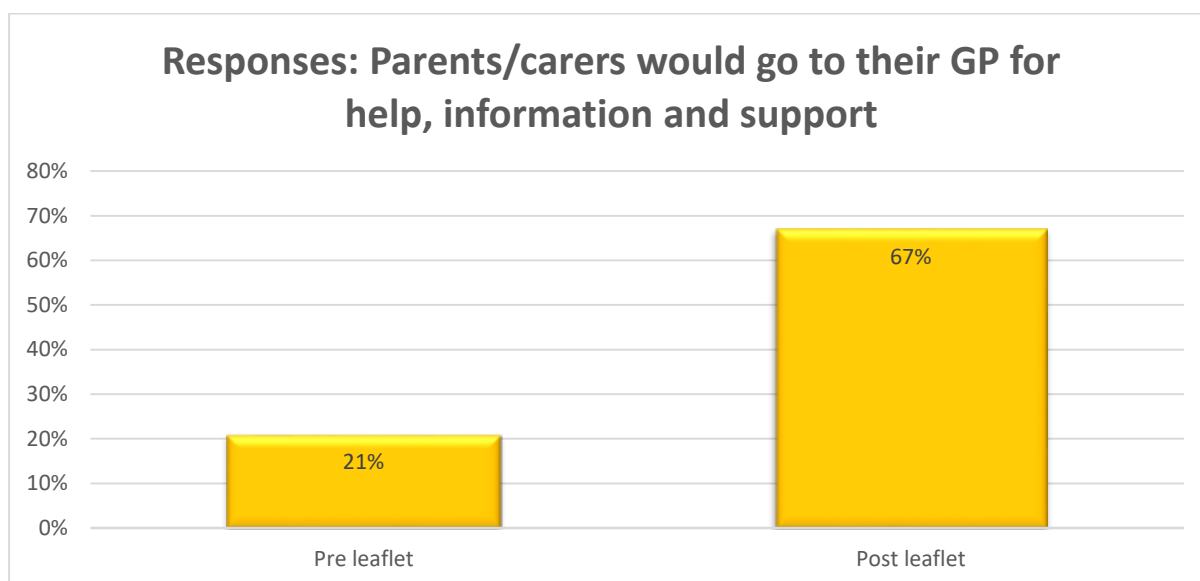
The fact that the increase in visits was significantly larger from the Bristol and South Glos area than nationally indicates that activity in that area was having an effect on the increase in website visits, over and above any effect of website improvements or search engine optimisation. Given the timing of the leaflet distribution and the increased web activity, we believe this to be due to more people accessing ERIC information and help as a result of the leaflets and advice from health professionals trained through the ERIC Nurse Project.

Six people gave details in the survey of further information, help or advice on potty training that they had actually received since they had read the leaflet when their child started school, three of which had come from ERIC. This included:

GP prescribed laxatives again. Got more information about constipation from ERIC website. (Parent of school starter, online survey)

My nearly 5 year old is still wet at night, most helpful was ERIC helpline. Gave us loads of ideas of things to try that we had not thought of and reassured us that it is quite normal. (Parent of school starter, online survey)

When asked where they would go for information, help or advice in future most respondents also identified frontline health professionals including health visitors, community nursery nurses, school nurses or GPs. Overall the percentage mentioning frontline health professionals as a source of support stayed relatively stable between baseline and follow-up. However, the type of health professional changed, with 67% in the follow-up saying that they would go to their GP, compared to 21% in the baseline.



This could indicate that more people are able to recognise a continence issue as a medical issue needing support at an early stage, rather than as a behavioural issue. The ERIC Nurse Project leaflet advises: “If you’re worried see your GP – your child may need some medicine to help them poo. The sooner the better – don’t let it become a long-term problem.” Further exploration with those parents around the reason for the increased potential to visit GPs is recommended.

Summary

- Two leaflets were created to help increase parents’ awareness of signs of continence issues, early corrective actions and where to go for further support:
 - ‘Thinking about wee and poo now you’ve reached the age of two’ for distribution at the two-year developmental checks run by health visitors.
 - ‘Thinking about wee and poo now you’re on your way to school’ for distribution at school starting time.
- Around 55,000 of each type of leaflet were distributed during the ERIC Nurse Project, 110,000 leaflets in total.
- Four standard ERIC leaflets have been re-developed as part of the ERIC Nurse Project and their uptake increased throughout the project timescale, compared to pre-project uptake.
- An online survey showed that more parents knew how much their child should drink after receiving the leaflet and to increase fluids as a corrective action if they suspected constipation.
- The online survey showed that significantly more parents would go to ERIC for help after they had read the leaflet than before. The ERIC website statistics reflect this increase in knowledge of and interest in ERIC.

4.2 Increasing health professionals' ability to support others

Work Undertaken

The two principal ERIC Nurse project leaflets were distributed via health professionals and early years workers in the pilot area. Before the ERIC Nurse project, the majority of these professionals would have received either very little or absolutely no specific continence training. It was clear that everyone involved in disseminating the leaflets needed to provide a clear and consistent message regarding a basic understanding of bladder and bowel health so they would be equipped to answer any questions arising, and so that they could promote the tools with integrity.

A fundamental healthy bladder and bowels training programme was devised, explaining:

- how bowels normally work
- how to recognise constipation
- how constipation is treated (in line with NICE Guideline CG99)
- how the bladder normally works
- acquisition of bladder control
- healthy fluid intake
- how to prepare for potty training
- how to structure a toilet training programme

Initially training was targeted at specific health professional groups such as health visitors and school health nurses. However, it soon became evident that it was important that all professionals in the team were trained. Additional sessions were targeted at community nursery nurses (CNNs) and school health assistants (SHAs). This was important as in many cases it is these latter groups that engage regularly with parents.

Training was also offered to early years workers and attended by a broad cross section of staff including child minders, children's centre staff and staff from day nurseries and pre-schools.

Reflective of the spread of attendee roles overall, those responding to the survey were predominantly part of health visiting teams or worked as school healthcare professionals. However, there were no responses from early years workers as no early years specific training sessions were run in the first half of 2015.

Around half of the respondents had attended the fundamental healthy bladders and bowels training only. The other half had attended that training and follow-up training on potty training or toilet training children with additional needs.



The table below provides a breakdown of the numbers and types of health and early years professionals who attended training:

Table 1 – Training attendees

Job Role	Numbers	Percentage of attendees
Health visiting teams	398	39%
School healthcare professionals	323	32%
Early years workers	184	18%
GPs and Practice nurses	49	5%
Nurses working with children with learning disabilities or special needs	30	3%
Others such as portage, inclusion, support workers, teachers	33	3%
Total	1017	

Initially training was offered in bases around Bristol to encourage take up and make it easy for people to attend. A range of times were offered including twilight sessions.

The same fundamental programme was offered at each session, though tailored to meet the learning needs of each particular audience. The fundamental healthy bladder and bowel sessions continued to run on a regular basis throughout the project with an open invitation to any health care workers, with a similar programme for early years workers.

As the needs of each audience became clearer over time the training programmes evolved and a range of specific topic based training seminars were developed as follow-up training. These were available for those who had attended fundamental healthy bladder and bowel training and needed more in-depth knowledge. Follow-up seminars were developed for Potty Training Trouble Shooting, Night time Wetting, Children with Additional Needs and management of Complex Bladder and Bowel Problems.

A breakdown of the number of training sessions delivered is detailed in the table below:

Table 2 – Training sessions delivered

Project Year	Fundamental	Follow-up	Combined	Total Sessions
Year 1	9	0	0	9
Year 2	15	4	1	20
Year 3	10	5	0	15
Totals	34	9	1	44

Location of sessions – 33 training sessions were held at ERIC offices in Kingswood, Bristol. 11 training sessions were held elsewhere (e.g. community settings).

Length of sessions – 3 of the training sessions were a full-day long, 36 of the sessions were half-day or evening courses and 5 sessions were 1-2 hours long.

Feedback on training

The intention of the ERIC Nurse Project training was to increase frontline health professionals’ and early years workers’ ability to support parents and children around continence, thus increasing early intervention. To do this, the training aimed to give health professionals a better understanding of how bladders and bowels work and to be better able to advise or signpost parents. The online survey sent to a sample of those who had attended ERIC training was designed to test the success of the training in achieving these things.

In October 2015, an online survey was sent to 127 health professionals who attended training between January and June 2015. The survey was designed to find out what they thought about the training, what they had learnt and how they had applied that learning to support parents and children. 49 health professionals responded.

100% rated the training as ‘good’ or ‘excellent’*

98% rated the relevance of content to their role as ‘good’ or ‘excellent’

Survey respondents were given the opportunity to add any further comments. Many made general positive comments about the training and the trainer:

All training put on by ERIC is fantastic. Brenda is a god send and so enthusiastic about her role. The leaflets are simple to understand and I use them all the time. (Training participant, online survey)

Really good and informative course, good pace and kept interest throughout. All information given will be really useful in my setting and I will be sharing this information with other childminders over the next week. (Training participant, evaluation form)

Very informative course. Very engaging and practical. Brenda was amazing at explaining things and also keeping all conversations on track. (Training participant, evaluation form)

ERIC and Brenda's role has been invaluable in my role as a nursery nurse in educating parents to prevent future problems around childhood continence. The leaflets are excellent resources that I use daily. Thank you. (Training participant, evaluation form)

Difference made (outcomes)

Evaluation forms were distributed straight after every training session asking participants to give feedback on the key things they had learnt and suggested improvements for future.

Additionally, a cohort of those completing the initial evaluation forms said they were happy to be contacted again. At the time of contacting them, 10 health professionals from a range of disciplines were available to take part in follow up interviews which took place between six and 12 months after they had attended training. The information gathered enabled us to see what learning had been retained and how they were applying it in their role. The difference made is highlighted below:

Understanding of bladders and bowels

Outcome 4: HPs and EYWs have a better understanding of how bladders and bowels work

Those responding to the survey told us that, as a result of the training:

<p>98% know more about how to recognise a bladder or bowel problem (e.g. missing developmental milestones, frequency of weeing or pooing or consistency).</p> <p>2% (n=1) said they already knew about this.</p>	<p>100% better understand why things go wrong with bladders and bowels (e.g. why children soil)</p>	<p>96% better understand the relationship between bladder and bowels.</p> <p>2% (n=1) said they already understood this before the training.</p>
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The majority of respondents said they had learnt ‘a lot’, rather than ‘a little’ in all of these areas.

When asked to write down something particular they had learnt from the training at the end of the day, the most common increase in understanding was around constipation:

Constipation is the biggest cause of 'wee' infections. Get constipation treated early. More than 95% of soiling is caused by constipation. (Training participant, evaluation form)

Constipation, constipation, constipation! Was very unaware how much a problem it is and the other causes it has. (Training participant, evaluation form)

I learned so much about constipation, didn't know how it worked or that it causes 95% of children's issues with toileting. (Training participant, evaluation form)

Knowledge of what to advise

Outcome 5: HPs and EYWs know more about what to advise if bladders and bowels aren't working well

The training aimed to equip the health professionals with information and knowledge so that they could better advise parents and children. As a result of the training:

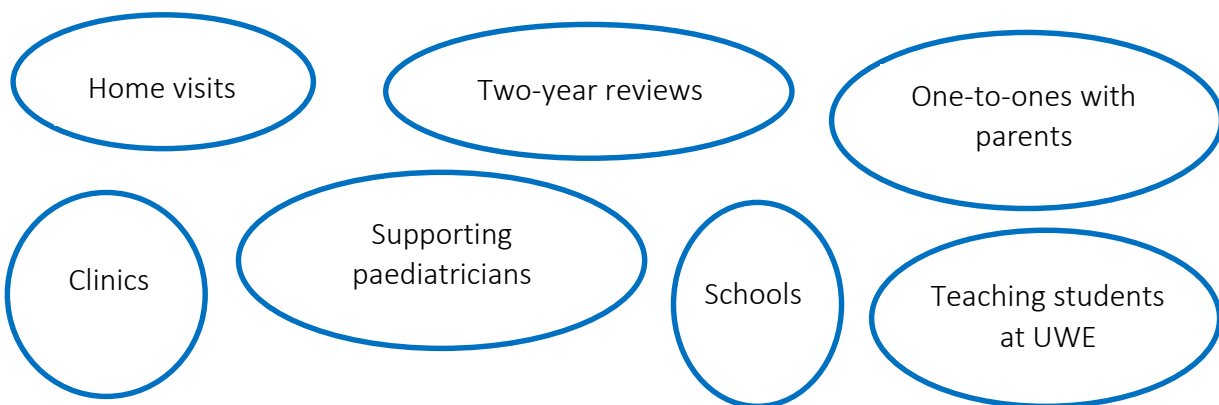
<p>94% know more about what to advise in terms of recommended fluid intake.</p>	<p>100% know more about what to advise in terms of appropriate medication and how to use it.</p>	<p>90% know more about what to advise in terms of a scheduled toileting programme.</p>
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<i>6% felt they already knew about this.</i>	<i>8% said they did already and 2% (n= 1) didn't feel they learnt this in the session.</i>
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Without the training by Brenda I would not be able to help parents with their child's potty training and continence. Training, leaflets and support is invaluable. (Training participant, evaluation form)

Health professionals were asked in the online survey whether or not they had already **shared** the information they learnt in the training with parents or children. 96% said they already had and the remaining four percent had not done so yet but said they intended to in future. Nobody said they had not and did not intend to share the information.

In a supplementary question 28 Health professionals went on to give examples of where they shared the information they had gained in the session, which include:



I am more confident about teaching parents the biology of weeing and pooing in a way they will understand. I feel more able to explain about how the medication works. I have used this information to teach students at UWE who are students in learning disability nursing. Overall I feel much more competent and use the leaflets regularly with parents and young people. (Training participant, survey)

The most common **types or topics** of information shared were:

Around constipation and impaction. 13 people talked about sharing information around how to recognise constipation, the link between bladders and bowels and in particular impaction as a result of a constipation problem:

I spoke to a parent in clinic who thought that because their child had runny poo they weren't constipated. I was able to offer advice and recommended they see a GP for

medication. They have been given Movicol and as a result seem to be eating better as well as going regularly. (Training participant, survey)

Advice to go to GP and/or to try Movicol. 12 people gave examples of advising parents and children to visit their GP for more help around constipation and specifically to discuss Movicol (or macrogol), or simply advised them to try Movicol.

This reflects the finding from the parents of school starters' survey where more people said they would go to their GP around continence issues at follow-up than baseline.

Toilet training. Seven people said they had used the information from the ERIC Nurse Project training to advise parents and children on toilet training and to support the discussion around when a child is ready.

As a result of ERIC training I have begun monthly potty training sessions to offer advice to parents. (Training participant, survey)

Signpost to ERIC. Six people mentioned not only sharing ERIC Nurse Project information with parents but also directing them to ERIC to receive further support or information.

I have regularly discussed information at 2yr reviews and backed this up by giving ERIC leaflets and signposting them to the website. As a HV, parents often ask about older siblings and night time wetting and ERIC's leaflet and advice have been very helpful. (Training participant, survey)

Increasing fluids. Four people talked about sharing information around children drinking an appropriate amount to encourage healthy bladders and bowels.

[I] explained about drinking to parent of year 1 child with history of soiling. Advised mum to work at increasing drinks during forthcoming school summer holiday which she did and episodes of soiling reduced according to mum. (Training participant, survey)

Further, an example of how this new advice helped to change a distressing situation for a child and family was shared in the online survey:

I've got a different perspective on the issue now which I can pass on to parents. I've recently been working with a family who I recommended Movicol to and the parents have already seen a huge change in their child and things have moved on for them. Having waited until bedtime to poo in their nappy, they are now pooing in the potty and toilet for the first time. Before I only really knew about lactulose. (Training participant, survey)

Further unsolicited examples of impact that health professionals had on children and families, using the ERIC Nurse Project information were received. Although this feedback

falls outside the scope of the evaluation they are nevertheless important and have been included as additional evidence of impact in appendix 1.

Confidence to support

Outcome 6: HPs and EYWs have more confidence to advise and support parents and children

By increasing the knowledge and skills of health professionals through training it will improve their confidence and further support their work with parents and children.

100% of respondents to the online survey said they now felt more confident to support parents or children around continence than they did before the training. (88% said they definitely did and 12% partly/a bit).

The cohort of 10 health professionals who took part in follow up interviews between 6 and 12 months after they had attended training said their increase in confidence had been retained.

Interviewees were asked how **confident** they now felt **to recognise** a continence issue in the children they see or work with and how far the training had affected this. All 10 people interviewed reported that they felt 'quite' to 'very' confident and it was overwhelmingly felt that this increase in confidence could be attributed to the training:

[I feel] a lot more confident than I did. It's definitely down to the training. (Training participant, Interview)

This training means I feel much more confident in terms of recognition of symptoms and helping children to manage their situation. (Training participant, Interview)

A training participant wrote on her evaluation form of a second training, how the first training session had helped her to recognise a continence issue:

After the last training session, I recognized a child having constipation rather than night terrors as the referral suggested. (Training participant, evaluation form)

Interviewees also reported increased **confidence to recommend corrective actions** when things aren't working well with bladders and bowels. All interviewees talked of a retained confidence and feeling of being more able and being more supported themselves in taking forward their work:

[I feel] really confident. We've got the leaflets and I feel really aware of what's on there and I talk through them with parents. I'm also more confident to talk about the NICE guidance and to tell parents to go to the GP. I sometimes contact ERIC for them

or I let them ring on my phone. I guess I just feel more supported, which makes me feel more confident in helping parents with it. (Training participant, Interview)

I feel more able to deal to with more complicated things myself now. (Training participant, Interview)

I do feel more confident when it comes to fluid intake, healthy diet, access to toilets for little one, routines and ERIC website for products for older children. (Training participant, Interview)

Two interviewees said they already knew about some corrective actions, but the training provided an update and refresher for them:

Quite confident now. A good refresh. (Training participant, Interview)

I gained much reassurance in being more confident in my prior knowledge and having that consolidated by Brenda at my training day. This has enabled me to practise more confidently and empower parents to manage their children's bowel/toileting concerns. Thank you. (Training participant, Interview)

Knowledge of where to signpost

Outcome 7: HPs and EYWs have a greater knowledge of relevant support and products that can help

If health professionals aren't able to resolve a continence issue with initial advice, then it is hoped that the training will help them to know where to signpost parents and children and what products are out there to help them.

The results of the survey told us that, as a result of the training:

94% know more about what to advise in terms of where to go for more information or help.

6% said they knew this already.

94% know more about what to advise in terms of...continence products.

2% knew this already and **4%** didn't learn anything about this.

[Without the training] I wouldn't have known about Movicol and CosmoCol or how the system works. (Training participant, survey)

The interviews conducted with a sample of training participants 6 to 12 months later showed that the training helped to familiarise them with ERIC as a source of support for them and

for parents. All interviewees said they were now familiar with ERIC services, products and resources and many said they weren't before the training. Several interviewees gave examples of how they were using ERIC support and referring parents there:

[I'm] really familiar now. I use the helpline and the leaflets and the website. We've all got the app on our phone. We talk about ERIC with families regularly now, like in the clinics, and refer parents to use them. (Training participant, Interview)

I'm familiar with ERIC from the training and from when we were shown around. If I had any questions I would look on the website or call the helpline. (Training participant, Interview)

Delivering many of the training sessions at the ERIC offices, including facilitating introductions to ERIC staff, seems to have helped to increase this familiarisation.

[I] enjoyed coming out of the office for local training at ERIC, like being shown around the ERIC offices and having a chance to chat to the Helpline Team. (Training participant, Interview)

When asked where they would refer a child with a continence issue if they weren't able to help, **all** interviewees mentioned ERIC, unprompted:

I'd ring ERIC. I probably wouldn't have done the same before the training as I wasn't as aware of ERIC as I am now. (Training participant, Interview)

We believe that this new familiarity with ERIC and the services available has led to increased access to the ERIC website by health professionals and the parents that they are supporting. This is evidenced by a significant increase in visits to the ERIC homepage in the eight-month period since the training started (January – July 2014) from the pilot area, compared to the first eight months of the previous year (January – July 2013). Visits for the later period increased by 59% in the Bristol & South Gloucestershire area which is nearly three times the national increase of 21%.

Another key place that those health professionals who were interviewed since the training said they would refer a child was to their GP. Most said they wouldn't necessarily have done this before the training:

I now have a better idea of when to refer to a GP. (Training participant, Interview)

I now know more about where to direct people such as to GPs for Movicol. (Training participant, Interview)

This finding supports that of the parent survey that more parents mentioned that they would contact their GP for help around continence in the follow-up survey than the baseline.

These results suggest that the health professionals left the training with a better idea of where to appropriately refer children that they couldn't help around continence.

[I learnt] how to contact others, who to contact and when to contact. (Training participant, evaluation form)

Suggestions for future

Respondents to the survey were asked whether they had any suggestions for the future. Four people said that they would like to receive regular update sessions from ERIC:

For Brenda to keep teaching her very informative and enjoyable training possibly a 2-hour update once a year. (Training participant, survey)

In addition, several of the interviewees also requested update training in future:

Update training is great. It refreshes the memory and is good for new colleagues. (Training participant, interview)

As many updates as possible as things seem to change. (Training participant, interview)

Other ideas for future support included training for schools, flow charts for health professionals and for the leaflets to be available in different languages:

Training for Schools to have a better understanding of toileting – they feel young people with complex needs are being naughty and miss the need for support and how it may impact on their education. Lack of understanding causes barriers. (Training participant, interview)

Two people reflected as part of their comment on the training that there is a lot of confusing or contradictory advice out there for parents and children:

The training and the resources have been an incredible tool for me in my job role. Being able to explain things to parents confidently has been really good and showing diagrams in the leaflets. I think it's a shame that not everybody gives the same advice, often when parents have spoken to a GP or another health professional they get a slight mix up of advice. (Training participant, survey)

Finally, a couple of interviewees gave reflections on how the partnership between ERIC and frontline health professionals has worked:

As CNNs we've really got on board with it all, we have a link contact and Brenda comes to our CNN meetings sometimes. I feel like we could contact her and she'd come straight out and do anything. (Training participant, survey)

It's a great partnership situation and if it can continue that would be fantastic! (Training participant, survey)

Summary of Key Findings

- The ERIC Nurse Project provided training for frontline health professionals who would be disseminating the leaflets and act as the first line of contact for continence issues and advice.
- The training included a fundamental 'healthy bladders and bowels' course and follow-up sessions around potty training, night-wetting and working with children with additional needs.
- 44 training sessions were run in total, attended by 1017 health professionals. These health professionals were predominantly part of Health Visiting Teams, School healthcare professionals and early years workers.
- 100% of training participants completing a survey rated the training as good or excellent.
- Those attendees completing our online survey reported that they left the courses with a better understanding of bladders and bowels. 98% said they knew more about how to recognise a problem and 100% better understood why things go wrong. The most common thing that people learnt about was constipation.
- Health professionals who responded to the survey said they came away from the courses knowing how to advise parents and children if bladders and bowels aren't working well. 94% said they knew more about what to advise in terms of fluid intake and 100% knew more about what to advise in terms of medication and who can prescribe it.
- Since the training, health professionals stated they had had shared the information they learnt in numerous settings including clinics, schools, home visits, and teaching sessions.
- 100% of respondents said they felt more confident to support parents and children around continence since the training. The confidence to recognise an issue and recommend corrective actions had been retained at six to 12 months after training.
- The training increased health professionals' knowledge of other organisations to signpost families to for support. 94% of survey respondents knew more about how to advise in terms of where to go for more information or support. Familiarity with ERIC in particular had increased. The ERIC website statistics reflect this increase in knowledge of and interest in ERIC.

Training participants suggested that they would like update training in future.

4.3 Improving the child's journey through continence care

Work Undertaken

Early in the project the ERIC Nurse attended a continence meeting hosted by the Children's Commissioning Manager, South Glos Clinical Commissioning Group (CCG) in partnership with the Programme Manager, Children and Maternity Commissioning, Bristol CCG. The meeting was called in response to the South Glos Adult Continence Service discontinuing their inclusion of children in the continence pad provision service. Interim measures were put in place but the opportunity was taken to review the local children's continence service. An overall need to appoint a Children's Continence Nurse was identified. A similar situation developed in Bristol and it was agreed that a Children's Continence Nurse for Bristol and South Glos would be employed. The ERIC Nurse offered advice and information including signposting to the Paediatric Continence Forum's draft Commissioning Guide, and contributed to developing the job description for this role.

During the review of children's continence services, it became apparent that the existing *Bristol Children's Continence Care Pathway* required updating to meet current service requirements and this provided an opportunity to develop it to meet local needs.

Initially the ERIC Nurse, a paediatrician with continence expertise and a GP with a special interest in children worked together to develop flowcharts for the pathway. Progress was reviewed regularly at multi-disciplinary Continence Meetings hosted by the CCGs.

Reviewing the local pathway highlighted that flowcharts formed only part of the overall picture and there were different viewpoints on who should deliver each aspect of care. The model developed for Bristol and South Gloucestershire would be unique to that area and the pathway and delivery of services was likely to differ across the country depending how services were commissioned.

Although it was not intended at the project outset, the aims of the ERIC Nurse project evolved and as result it was agreed that an integrated care pathway focussing on the needs of the child, rather than the way local services were delivered exclusively in Bristol and South Glos was required as the third aim. If it was to be useful outside of the pilot area, it had to recognise that there are many different service configurations and so it evolved as a generic pathway with the facility to be adapted for use in any area.

The ERIC Nurse continued developing the integrated pathway on that basis, taking account of suggestions at every point as to who and how the service may be delivered.

During telephone interviews health professionals were asked if they had any thoughts on a child's current journey through continence care in Bristol and South Glos. Some of the comments are illustrated below:

“In the past completely useless for disabled children – no flexibility – little understanding of children with special needs. Now we have a Paediatric continence advisor things have changed for complex needs. Pathway did not match our children. Early intervention needed before the age of 5.”

The fundamental work on flowcharts developed by the original continence group provided the framework for the pathway and ERIC’s existing resources provided the ideal tools, such as informative fact sheets and charts to support the care. Draft documents have been peer reviewed by North Bristol Trust Community Children’s Health Partnership as well as members of the Paediatric Continence Forum. The draft pathway was also the main focus of a North Bristol Trust Continence Study Day on 22 April 2015 attended by approximately 50 health professionals.

The new pathway will be an online resource. The advantages of this are:

- It can be kept up to date with national guidance and policy
- Printing costs are reduced
- It will be easy to navigate using the website search function
- Individual sections can be used in isolation if appropriate

The pathway will be hosted on the new ERIC website and will be available from late 2016.

Intended Outcomes of Continence Pathway

Because of the evolution of the Children’s Continence Pathway, it will only become available after the very end of the ERIC Nurse project. It will not therefore be possible to evaluate it within the life of the project. However, ERIC is committed to evaluating the success of the pathway after 6 and 12 months beyond the end of the project, particularly as this is a pilot.

The intended outcomes for the Children’s Continence Care Pathway are:

Outcome 8: More parents that need further continence care for their children know what to expect

Outcome 9: Gaps in paediatric continence care services are more easily identified, based on the needs of the child

Outcome 10: Primary care providers work more effectively together to address different aspects of a child’s continence needs. (longer term)

The plan for evaluating both the uptake of the Children's Continence Pathway and the difference it makes includes:

- Monitoring the number of downloads of the online pathway at 6 months and 12 months after launch.
- Monitoring which parts of the pathway are most and least frequently accessed online at 6 months and 12 months after launch.
- Conducting telephone interviews with a sample of health professionals and commissioners that are using the pathway 12 months after launch to explore:
 - How they are using the pathway to guide their work and/or how the pathway is being used in their local area
 - Whether or not the pathway has helped them to address any gaps in local continence care provision
 - Whether or not the pathway has helped them to work more effectively with other health professionals to address children's continence needs
 - To what extent they feel the pathway has or hasn't affected parents' knowledge of what continence care their child is entitled to or they should expect.

5. OVERALL SUCCESS AND IMPACT OF PROJECT

The ERIC Nurse Project has been successful in achieving its first two specific aims:

1. To increase parents' awareness of what a continence issue is and where to go for support
2. To increase frontline health professionals' and early years workers' ability to support parents and children around childhood continence

This achievement is significant and it is intended that the ERIC Nurse Project will have the following impact in the longer term:

Impact: More children in Bristol and South Glos with a continence issue receive intervention at an early stage.

This will contribute to improved lives of children and families and reduced NHS and local authority continence care costs.

At this early stage it is not possible to measure whether there is a sustainable impact on the lives of children and families as well as long-term cost savings for the NHS and local authorities.

However, during the process of this evaluation, some indications of longer term improvements to the lives of children and families and a reduced public care cost have been identified.

Improvement to the lives of children and families

Our evaluation showed that health professionals have gone on to share their learning from the ERIC Nurse Project with parents and children. We collected qualitative information from an interview, an email and two unsolicited examples from attendees of the healthy bladder and bowels and potty training sessions that illustrated the longer term impact of the ERIC Nurse Project information they had shared on the lives of children and families. As the unsolicited feedback fell outside the scope of the evaluation they are included in appendix 1

Reduced cost

The ERIC Nurse is a paediatric continence specialist. Working in the pilot area her expertise was recognised and she was invited to contribute to defining the role of the appointment of a children's continence nurse for Bristol and South Glos. Once appointed the children's continence nurse set about reviewing the continence products allocated to families and children. This resulted in a forecast saving for the year of £15.5K. She was supported in this exercise by the ERIC Nurse. There is a strong correlation between early intervention and

assessment of need for continence product, however as this is outside the scope of the evaluation the results of this exercise are included in appendix 1.

Longer term impact

There is anecdotal evidence which may show the positive longer term impact of the ERIC Nurse project and indicates confidence in the potential of the project to make a difference to the lives of children and families and reduce the public health care costs associated with childhood continence issues.

The long-term success of the project will really become apparent as the children who have received targeted leaflets and the care of trained professionals in the last two years grow up.

The third project aim, to improve the child's journey through continence care in Bristol and South Glos, was developed later in the project in response to a need that emerged. The evolution of the solution to a generic online resource rather than a specific local tool, and the buy-in achieved to that solution, is in itself a success for the project. The difference made by this tool will be evaluated 6 to 12 months after its 2016 launch.

6. KEY LEARNING AND RECOMMENDATIONS

Learning happened both through the delivery of the project and through this evaluation. Some immediate changes were implemented during the project, particularly around the children's continence pathway. Further learning points and associated recommendations that could be applied to future work in this area are considered below.

6.1. The Evaluation Process

Proper consideration was not given to formal project evaluation until two years into the project, although some feedback was being collected. This was due to changes in staff and the lack of a project management board at the outset. With hindsight, a full evaluation framework should have been built in from the outset, taking the opportunity to establish baselines and gain clarity over what could and could not be measured. Although initial questionnaires were completed earlier on in the project not all the information collected could be used.

Recommendation: Clear evaluation strategy in place from outset to ensure project outcomes can be effectively assessed. Baselines to be set at the start and appropriate information collected throughout the project.

6.2. Reach to Parents

To check the reach of the ERIC Nurse Project leaflets into different groups in the pilot area, parents were asked in a follow-up survey to identify their ethnic background. 98% of the parents who completed the survey following receipt of the school starters' leaflet identified themselves as 'white' and 2% as 'other'. No parents completing the follow-up identified themselves as 'Asian/Asian British', 'Black/Black British' or 'Mixed Ethnic Group'. This may have been because we had no control over which schools the Questionnaires were sent to.

Recommendation: At the start of the project a resource distribution strategy to be developed and agreed with methods in place to ensure information reaches communities of interest as well as reaching across geographic communities.

6.3. Appropriateness of Resources

ERIC has previously had some of its leaflets translated into languages commonly spoken in the UK, but this is very costly and not necessarily the best use of our limited resources. To produce Accessible leaflets for learning disabled parents and children would also incur significant cost. It was decided to focus on one leaflet format, using every day English and plenty of illustration. It was acknowledged that English would be the language used in any clinic consultation; perhaps there is a role for ERIC literature to equip users with useful terminology/vocabulary.

Recommendation: To review how information is presented and made accessible to all including those whose first language is not English.

6.4. Reach to Education Based Staff

The ERIC Nurse project was successful in reaching a broad range of health professionals and early years workers from a variety of settings. It did not replicate this training specifically for non-health professional staff working with school age children, another important group who may be able to support children with early stage continence issues. A few teachers and teaching assistants attended the early years sessions and found it beneficial. The principle obstacle was contacting them as a group; in the early years area we liaised with the Early Years Officer who ensured that training sessions were advertised in the Bristol Early Years Bulletin and the Bristol Early Years CPD Programme. We did not find a similar central communication network for those working with school age children; schools operate independently. Suggestions to contact Family liaison/link workers and/or offer INSET day training to Cluster schools have not yet been followed up due to time constraints.

Recommendation: Access to more school staff needs to be found for any future training delivery. Since there appears to be no single contact, time needs to be allocated to contact individuals or small groups, in the hope that they will be able to cascade information.

6.5. Review by parents

All the leaflets produced were widely circulated amongst health professionals for their feedback and were subsequently amended prior to publication. However, the project would have benefitted from direct contact with parents for their advice and insight. ERIC did not have any ongoing relationship with any of its beneficiaries when the project started; ways of working have changed and contacts to the Helpline are now offered follow up, resulting in a register of available contacts. ERIC also now has a 'Parents Panel' – an online group with whom resources can be shared.

Recommendation: Resources should be reviewed by the intended target audience. Parent information leaflets should therefore be shared with Helpline contacts and the Parents panel. Early years workers who have attended training can be asked to identify groups of parents for similar feedback.

6.6. Need for systemic change and the pathway

The field of paediatric continence has undergone many changes in the last decade. The work of ERIC, PromoCon and the Paediatric Continence Forum has done much to raise the profile of children's continence, and the NICE Guidelines for Commissioning a Paediatric Continence Service published in 2010 provided compelling evidence for the need for a children's continence service in every area. The number of nurses working in the speciality has risen. In recent years however, the way services are commissioned in England has divided what were previously integrated services; generic HCPs have found that fundamental bladder and bowel care is not part of their remit. Access to care has become complicated and differs hugely from area to area. In the current climate of care, the generic ERIC children's continence pathway is vital, as the focus is on what the child needs.

Recommendation: Once the pathway becomes an online resource it should be widely promoted to parents, HCPs, education staff, early years workers, GPs, paediatricians and

commissioners. Its use should be evaluated at 6 and 12 months after launch. It should be regularly reviewed to ensure it remains fit for purpose.

7. The future

As presented in this report, some significant changes have been achieved through the ERIC Nurse Project in terms of parental awareness and health professionals' ability to support parents and children around childhood continence in the pilot area. It is hoped and expected that these initial changes will translate into long term changes in the lives of children and families who receive earlier intervention into continence issues, as indicated by the case examples collected.

It is also sincerely hoped that the successful resources and the learning that have come out of the investment into the ERIC Nurse Project can be rolled out beyond the pilot study area to increase early intervention into childhood continence issues around the country.

I would like all my new staff to attend the healthy bladder session, and feel the training should be county-wide. (Training participant, Interview)

Appendix 1 – Impacts outside the scope of the evaluation

Reduced Costs to NHS

As summarised in the box below, the newly appointed children's continence nurse for Bristol and South Glos put in place a process to regularly assess needs. This resulted in a number of children no longer being assessed as in need of continence products which has subsequently led to a forecast saving for the 2016/17 financial year of over £15.5K. This figure is a useful baseline and future reductions in product use are likely to be related to improved continence management, of which early intervention plays a big part.

Box 1 – Summary of continence product review by children's continence nurse

The number of children who are on the Hartmann system allocated products has reduced from 516 on 1/7/15 to 388 on 18/3/16. This is a reduction of 128 children, however not all of these families were activating their products or the system had placed them on hold so they were unable to activate any products anyway. I have basically tidied up the system and removed any children who hadn't been in contact for more than 6 months. I have also put in place annual assessments so all children are gradually being assessed to ensure they are receiving the correct products and only as many as needed.

There has been a £15,714 reduction in the forecast for the cost of products for this financial year, dated 1/3/16.

Improvement to the lives of children and families

The evaluation showed that health professionals have gone on to share their learning from the ERIC Nurse Project with parents and children. In addition, we received two unsolicited examples from attendees of the healthy bladder and bowels and potty training sessions that illustrated the longer term impact of the ERIC Nurse Project information they had shared on the lives of children and families.

Box 2 – Intervention by a community nursery nurse and changes for family (unsolicited feedback)

I just wanted to share my experiences of a family I have been working with recently and how helpful ERIC has been.

Mum contacted the Health Visiting Team wanting support with her 3-year-old who would only poo in his pants, standing up in another room. This was also proving a problem at nursery and causing Mum some anxiety. Mum was also becoming reluctant to take him out because of the difficulties she was experiencing.

Over several visits we identified an earlier, brief episode of constipation. Mum had seen the GP and was given Movicol but felt the constipation had resolved. We looked at ways of encouraging him into the bathroom. Our first step was just to encourage him to just go into the bathroom. Mum started to use a toy to coax him closer to the bathroom each time, she put toys in the bathroom to keep him occupied, she used a reward chart that we made with lots of praise and appropriate rewards.

At our visit today we were so pleased to hear that he has been using the toilet and has used it at nursery too! I gave Mum lots of Eric information, which she read through and she also used the website. She said she found reading other parents' experiences really helpful.

The support I was able to offer the family was mostly from the brilliant ERIC training that I have been on, and I feel much more confident in this now. So, a big Thank you to ERIC and you.

Box 3 – Intervention by a community nursery nurse and changes for family (unsolicited feedback)

I had a phone call from one of my clients saying she was having problems with her son soiling himself and it was becoming very stressful for her and him. I visited them at home and listened to the family's concerns. I could identify that the child was constipated and now that had led to him soiling himself frequently. It had also moved into behavioural issues and the mum was reacting in ways she didn't want to, like shouting.

I gave lots of advice and contained mum. Mum was highly stressed and felt depressed at the time and the little boy was very shameful about it on my visit and didn't want to talk about it. They already had some Movicol from the Doctor but they didn't really tell her how to use it properly, so she was confused.

The tips I gave were from the potty training session: to try a marble jar, to put toys in the bathroom, for mum to clean her little boy up in silence and praise lots when he had success, to get him to drink more and to put him on the toilet 20-30 minutes after eating, to get him to the toilet even if it is to soil in his pants, for parents to relax about the situation. I also showed mum the ERIC leaflet and website which she went onto use and her little boy really liked the poo story app.

I revisited for a follow up visit and it was like a different family. Mum looked brighter and so did the little boy. Mum had put all of my tips in place and now they were having lots of success. He is now mainly pooing on the toilet and loves his marble jar. He was happy to talk to me on the visit and was keen to tell me about his pooing. Mum said she feels so uplifted that it has changed so much for her and it has empowered her to make other changes such as give up smoking and encourage healthy eating for the rest of the family.

I feel that it's so nice to see that with just that bit of advice, encouragement and support how much it can change families."