

PICH PROGRAMME FOR INTEGRATED CHILD HEALTH PROJECT SUMMARIES 2014-2015



PICH Yearbook 2014-15

The Programme for Integrated Child Health (PICH) was developed by the London School of Paediatrics in 2014. Paediatric training has often been focused on hospital rather than out of hospital care, acute rather than long term conditions, and based around organisations, rather than the child. Over recent years it has become clear that this separation, this way of working in a non-joined up way, does not provide the best care for anyone, least of all children, and it is as a response to this that PICH was developed- with a particular focus on integration and joined up working between sectors, be that Primary/Secondary, Education/Health, Social Care/Health.

Participants for the first pilot year were all senior Paediatric trainees. They were allocated a PICH mentor, someone with some expertise in integrated care or working differently, and were required to work through several themes, getting involved or leading on projects that would enable them to get some understanding of those themes. The themes are:

- What is integrated care
- Using data to drive change
- Patient experience and involvement
- Working clinically in an integrated way
- Leading on the development of integrated services

This book contains a summary of much of the work that participants have been involved in over the year. It represents an enormous amount of very varied work, which has been completed alongside trainees' normal clinical posts, on-call shifts, family life etc. Some pieces represent ongoing work, some are reflections on the year, some are completed projects that resulted in wholesale change. They are a reflection indication of the engagement and progress that these trainees have made. We are very impressed by what the participants have achieved this year: watch this space - these are the people who will transform the child health landscape.

For more information on PICH, please see www.pich.org.uk

2014-15 PICH team

PICH Leads	Chloe Macaulay, Mando Watson
Faculty and Development	Holly Boyd, Kate Dharmarajah, Melanie Menden, Francina Cunnington
PICH Mentors	Mitch Blair, Ronny Cheung, Fran Cleugh, Michelle Heys, Ajanta Kamal, Bob Klaber, Monica Lakhanpaul, Claire Lemer, Simon Roth

With Special thanks to Chris Kelly for his input into the website.

Setting up paediatric allergy services in community pharmacies.

Hani Adi, St5, Imperial college healthcare NHS trust.

The itchy sneezy wheezy project is an integrated respiratory and allergy care pathway funded by NW London Collaboration for Leadership in Applied Health Research (CLAHRC) and is led by Imperial College. Its aim is to improve the patient pathway for all children with allergic conditions by earlier recognition, accurate diagnosis and effective management.

As a former pharmacist myself I recognise just how underutilised pharmacists are as a professional body when it comes to the primary healthcare provision and felt that they would be ideally placed to play an active role in the itchy wheezy project. In fact The RCPCH allergy care pathway recognises that pharmacists have a key role in the early recognition of allergic conditions in the non acute healthcare setting.

In support of this, I planned to launch a pilot project with the following aims:

To increase the knowledge of pharmacists about the management of eczema (as well as other allergy conditions particularly food allergies). One of the ways of achieving this is by getting pharmacists to sign up to the itchy wheezy sneezy project where there are various on line learning modules. This will help pharmacists recognise eczema better, learn how to take a focussed allergy history and know which treatments they can instigate

Apart from offering advice on the use of emollients and mild steroid creams such as hydrocortisone, one of the aims of the project is to enable pharmacists through improving their knowledge base to offer more in terms of treatment. e.g. to offer a 6–8 week trial of an extensively hydrolysed protein formula or amino acid formula in place of cow's milk formula for bottle-fed infants aged under 6 months with moderate or severe atopic eczema that has not been controlled by optimal treatment with emollients and mild topical corticosteroids Pharmacists would do this in collaboration with the GP and arrange a review of the patient. If ineffective pharmacists may then refer directly to tertiary allergy services. Pharmacists would also have the opportunity to discuss any clinical queries they may have with an allergy nurse specialist if need be.

If successful the longer term aim would be to expand services further to include conditions other than eczema and food allergies such as asthma.

Needless to say there are significant legal, and financial implications involved in such a project. In addition there are issues related to professional boundaries and whether GP's would be accepting of another professional body carrying out some of their roles. Finally there was the questions of whether pharmacists would be happy to take on extra roles. Even if all of the above barriers were overcome would patients be willing to use the service.

To answer some of these questions I realised that objective data was needed. I then designed a PREM (patient reported experience measure) survey (<https://www.surveymonkey.com/r/LKGX3BM>) and using this survey I interviewed 12 parents/carers in the allergy clinic at St Mary's hospital. Admittedly the number of people interviewed was small but the data obtained was interesting nonetheless. For example not one of the respondents consulted a pharmacist about their child as the first point of call. With regards to their most recent visit to a pharmacy, a quarter of parents had no idea about the job title of the person they spoke to for advice. 42% of parents had not discussed their child's condition (including their medication) with a pharmacist as they did not think it was necessary. Approximately 83% of parents said that they would not discuss their child's condition with a pharmacist because they either did not think they were qualified enough or they thought this was not their role. However on a positive note approximately 67% of respondents stated that they would discuss their child's case more often with a pharmacist if the pharmacist was able to discuss the case with their GP/paediatrician/allergy nurse specialist if needed. 83% of respondents said that they would seek a pharmacist's advice if they knew the pharmacist had completed a training module on allergy related conditions. The results pointed to the conclusion that in order for this project to be successful there would need to be focussed training and that for the moment this should be the first step that is taken. In addition this would be a relatively cheap intervention as the training modules are already in place. I also have designed a survey to ascertain the opinions of GP's regarding such a project and am in the process of designing a survey for pharmacists.

Using Coproduction and a WhatsApp™ group to improve patient experience and engagement with Ealing Hospital Paediatric Diabetes service

Sarah Blackstock, Paediatrics St4, North West London Hospitals NHS Trust.

Children with Type 1 diabetes struggle with multiple daily injections and 'carbohydrate counting'. Self-motivation is crucial to prevent adverse health outcomes. Many adolescents find self-management challenging and can reject conventional healthcare models.

Co-production

Co-production was used to gain insight into user experience. This was a catalyst for a patient WhatsApp™ 'broadcast.' 6 patients and 4 members of staff from the Paediatric Diabetes service at Ealing hospital took part. Graphic facilitation was used to focus the group towards goals and stimulate strategic dialogue. By working in partnership with patients to define problems, patient-led solutions were created. The session took part outside of any clinic area and refreshments were provided.

Participants highlighted improvements to clinic structure using a more adolescent tailored consultation. Other topics included progressing forward a WhatsApp™ group. Discussion also highlighted setting up a clinic in a local school to reduce appointments and a cookery book. Following this session staff undertook additional training in motivational interviewing to further enrich consultations. Qualitative data has highlighted improved patient satisfaction following this coproduction. One patient quoted 'I felt valued and involved in decision-making to improve my care'.

WhatsApp™ Broadcast

All patients aged 11 years or greater were invited to participate in a WhatsApp™ broadcast. Informed consent was obtained from children and parents. Patient confidentiality is maintained as the group is a 'broadcast' rather than an 'open group,' therefore replies are directed to the diabetic team phone, not the whole group, ensuring quality control.

This virtual community allows patients to share information and expertise in self-management; improving motivation, self-care and knowledge by bridging gaps between appointments. Children post questions, videos and messages through the group. Examples include snack advice and 'using new pens'. Twenty six patients are now members. Through the WhatsApp™ network, patients are now collaborated to create a collection of carbohydrate counting recipes to create a cookbook.

Qualitative data of patient and parent feedback has been overwhelmingly positive. One mother quoted 'This is what my son needs, he knows no one with diabetes and often feels he is the only one who has to inject then acts out.' 'Patient user' sent messages now outnumber 'healthcare professional' sent messages to the group indicating good patient engagement. Healthcare has often lagged behind other industries in using social media and technology. This innovative approach highlights how technology can be used to engage patients and improve experience and clinical care.

Summary of project- asthma in children and young people.

Naomi Elson, Paediatrics St5, Croydon University Trust.

INITIAL DATA COLLECTION:

During this project I was working as an ST5 at Croydon University Hospital Trust. The starting point for my project was to carry out some background research and data collection. I started by examining data from the ChiMat (Child and Maternal Health Observatory) website- part of Public Health England. I looked at data collected from 2013-2014. I found that children made up 26.9% of the population in Croydon and the majority were from an ethnic minority group. The hospital admission rate for asthma in the under 19 age group was above the national average during this year and increasing year on year. In 2014 the crude rate per 100 000 children for asthma emergency hospital admissions was 327 compared to the national average of 221 (age 0-18). I found these statistics worrying and it felt like an area of particular need and improvement within the trust. I decided to work on a project about asthma in children and young people in the Croydon area.

INITIAL PLAN FOR PROJECT:

I wanted to target the chronic condition of asthma and my initial aim was to help prevent unnecessary emergency admissions to A and E. I also wanted to improve the quality of life of children and young people with asthma, improve compliance to medication and improve education of the disease. My aims were quite broad but I narrowed them down to focus on the education of asthma.

I collected further local data, provided by the audit department at Croydon, to get a greater understanding of the issues. I reviewed all the discharge summaries and admission notes for all the children that were admitted to the paediatric children's ward for asthma for the previous year. I looked at whether children had asthma action plans, whether they were told to be followed up by their GP and whether they received oral or IV steroids. There were 143 admissions for asthma made up of 118 children. Only 1% of the children had asthma action plans and only 59% were asked to be reviewed by their GP in 48 hours. Following this I set about working on various projects to help try and improve the care of asthmatic children in Croydon.

PROJECTS INVOLVED IN:

- I devised a new asthma discharge bundle for children admitted to the paediatric ward. It encompassed a two page document including education about asthma, a weaning regimen for salbutamol, a reminder to see the GP, a reminder about Asthma Action plans and education on inhaler technique (Previously children were given no information).
- I carried out a teaching presentation to my fellow SHO's, SpR's and consultants. I discussed what integrated care is, the importance of asthma action plans, and gave further education about asthma.
- I sat in on the Croydon CCG steering group for asthma. I meet with this group several times to help in the discussion of the new asthma service being set up at Croydon. I provided additional information to the asthma nurses about the frequent asthma attendees to the ward.
- I have taken on a role as an asthma champion at Croydon working with the asthma nurses to help promote their work and referral to the service.
- I spoke to children attending a GP surgery for their annual asthma review check about their diagnosis and what they understood about the condition. I then gave some education about asthma and gave them an asthma action plan.
- I designed and made a bright and colourful educational board designed for patients and parents on the paediatric ward. It explained what asthma was and advice and tips on the condition.

WHAT I HAVE LEARNT:

- There is a good opportunity still, for improving the care and health of asthmatic children and young people.
- Integrated care and the development of new asthma services for children in the community can help promote better self management, education and overall a better quality of care.
- Despite having good guidelines and recommendation for asthma care, support and promotion of this universal information is still needed with joined up working from each hospital and area in London/ England.
- I have learnt that to get an integrated care project up and running it takes effort, dedication and focus for the project. The local CCG needs to provide both financial commitment and dedication to a project.
- I have learnt that patient engagement and co-production can really help shape and develop a service to make it better.
- I have learnt that integrated care is a new method of health care for children and from a personal perspective I would like to see it develop as an actual speciality within paediatrics.

FUTURE PROJECTS/ LEADERSHIP IN DEVELOPING AN INTEGRATED SERVICE

I am now actively involved with the SW London, Children and Young people's network. I have attended the long term condition work-stream meeting, aiming to develop the ideal SW London asthma pathway. I have learnt that to bring about change to services and the health of children, a multidisciplinary approach is needed. This has helped me develop leadership skills and see how a larger group of people are trying to work clinically in an integrated way to improve asthma services not only in Croydon but across South London.

ALL ABOUT ASTHMA

What happens if you have asthma?

If you have asthma your **airways** don't work so well.

- You cough or sput
- You **wheeze**
- It is hard to breathe.
- Your chest feels tight

You might have all of these symptoms. You might only have some of them.

Asthma is a condition that affects your airways – the small tubes that carry air in and out of the lungs. Managing it well means that asthma will affect your life as little as possible.

Under the rib-cage there are some incredible organs called **LUNGS**. When you breathe in, they fill up with air and when you breathe out the air is pushed out- a bit like when you breathe into a balloon.

PUFFER POWER

The blue one- the reliever- take me only when you need me

The brown one- the preventer- take me every day

STERIODS AND ASTHMA

- Steroids help make it less likely that you will experience symptoms such as coughing, wheezing, chest tightness and shortness of breath.
- They also help to be less likely that your body reacts to asthma triggers, such as pollen or pollution.

TRIGGERS

- Pollen, grass and trees
- Coughs and colds
- Cold weather
- Cigarettes
- Dust
- Air pollution
- Fur and feathers
- Exercise
- Mould and spores

My Asthma Action Plan

The asthma action plan lets everyone know who cares for you about your asthma and the medicines you need. Your asthma nurse will fill it in with you. Take a copy to school.

Cleaning Your Spacer

How to clean a volumetric spacer:

How to clean an aerochamber spacer:

Questions about asthma?

Call our helpline for confidential information and support.
0800 123 62 44
www.asthma.org.uk

Don't forget to take your inhaler!

Don't forget to take your inhaler!

Exercise

Regular exercise can help you breathe better and control your asthma.

Integrated care in Paediatric allergy.

Helen Fitzgerald, Paediatrics St6, Homerton University Hospital NHS Trust.

Increasing AE and primary care attendances linked to Allergy are exacerbating the burden on the NHS. Allergic diseases are amongst the most common in Western society affecting up to 30% of the UK population at some time in their lives. The prevalence of allergic diseases including eczema, asthma, allergic rhinitis and food allergy has risen dramatically over the past 30 years and recent primary care data suggests almost 40% of children have an allergic diagnosis.

The hospital where I work offers a tertiary Allergy Service with choose and book referrals. Last year 528 new patients and 288 follow-up patients were seen. The tariff for paediatric allergy appointments is £251 for 1st appointments and £146 for follow up appointments. I wanted to investigate the scope for moving some of the allergy care into primary care, reducing the emergency attendances and admissions, and improving the accessibility of the service to patients.

My initial approach was to identify the burden of allergy patients in our AE and inpatient departments. Initially, I felt that the electronic discharge summary created for all Paediatric AE patients would be a good source of data. However, it soon became clear that identifying which patients had allergy related attendances within such a large data-set was going to be a massive undertaking which was unlikely to provide sufficient useable data to justify the time required. I refocused my efforts on new Allergy patients attending the allergy Clinic for whom we were the local hospital. I then went on to do a retrospective review of all their AE attendances and identify those which were allergy related.

I chose a 12 week period and there were 39 patients identified, 25 of whom had attended the AE department prior to their allergy appointments (range 1-21) average 4.4 attendances. 9 of those had allergy related AE attendances (range 1-6) average 2.1. 4 patients required inpatient admission on 1 or more occasion. None of the patients had any allergy related AE attendances or admissions in the 3 months after their allergy appointments.

I also wanted to look into whether allergy patients were being seen in general clinics increasing the number of appointments and delaying diagnosis for families as this was felt to be a problem by the consultant body. This created its own challenge as identifying the underlying diagnosis from a clinic letter can be difficult and devising a strategy to review the referral letters in real time was impractical. In the end I reviewed the letters to the GP for all new patients in all of the General Paediatric clinics over a one month period. In a one month period there were 74 new patients who attended their outpatient clinic appointments. Only 4% had allergy related conditions but of those 67% of them required further referral to the allergy clinic.

The next area I wanted to focus on was the actual experience of the patients and families and their perspective on how we could improve the service. The RCPCH recently carried out a patient experience survey on Allergy Services using a Survey designed by the PICKER institute. I modified this survey to better suit my requirements and attempted to get them filled in by those attending the allergy clinic with older children completing their own survey and parent questionnaires for the younger children. Compliance rates for patient experience surveys are notoriously low and this proved to be a problem in my project.

All the patients/families were happy with the overall quality of the care with all rating it in the range of good to excellent. 55% of them were seeking help with their allergy from GP's while only 9% were using AE. Only 20% felt they had been given enough information about Allergy related support groups, while 47% wanted any or more information on allergy support groups. The free text sections of the survey provided the most useful insights. "If there is any new info it would be great to be updated like on an email list with useful links.", " I would like GP to refer quicker at complaint of illness To get this test (allergy) took 7-8 months.". Patients and families are using GPs more than AE to access care for their allergy, they want faster access to diagnosis and more information on support available.

With the increasing prevalence of allergy especially in the paediatric population, the high percentage of patients seeking help from primary care and the desire of patients for a faster and more accessible service I think the next step would be further assessing the viability for introducing a GP special interest clinic to run alongside the hospital with the support of the multidisciplinary team.

GP profiling of A&E attendances.

Andrea Gritz, Paediatrics St4, North West London Hospitals NHS Trust.

My main project for PICH, which I carried out with another PICH fellow Annakshi Sen, looked at GP profiling A&E attendees, aged 0-4 years, over a one year period.

The idea came about after considering patient pathways. My area of interest lies in acute medicine so the discussion progressed to why some patients are more inclined to come to A&E than others, whether the GP Surgery they belong to is a contributing factor and which GP Surgeries have higher rates of attendance to A&E than others. We managed to obtain not only the A&E attendance data but also attendance data from the Urgent Care Centre based within the hospital, therefore capturing all the acute attendances over that one year period. In order to narrow it down, we initially focussed on those patients belonging to GP surgeries within the immediate borough surrounding the hospital, and from this, honed in on the GP Surgery with the highest attendance rate.

As you can imagine, this has been a rather large project yet although our PICH year has sadly ended, we have every intention of continuing on with this! After presenting our project at the July meeting, we received feedback which has enabled us to pinpoint areas to focus on, including refining our data even further. This is something we are now working on and very soon, hope to start looking at the GP Surgery with the highest attendance rate. Our hope is that we can work with the GPs, sharing knowledge in a way which benefits all concerned: paediatricians, GPs and most importantly, the patients.

Patient dialogue: the reasoning and thought process for attending A&E

As part of the 'patient experience and involvement' theme and to compliment the GP profiling project, I spent an afternoon in an A&E department, to explore the thought process and reasoning of parents and carers bringing their children to A&E. Questions asked were simple, quick to answer and included: why did you come? Did you do anything at home? Did you speak to anyone prior to deciding to come? Have you contacted your GP surgery? Answers in this small cohort were revealing and illustrated just how past experiences and current perceptions largely account for the manner in which people access acute healthcare services.

Patient journey

I followed a patient with suspected Autism Spectrum Disorder right through from his first appointment with a local paediatrician (myself) to assessment with other allied health professionals up to the final multi-disciplinary meeting which aimed to establish diagnostic outcome. I chose this patient because he had encountered a rather convoluted path along the way, having been initially investigated rather thoroughly in another city before a diagnosis was established, to London where the whole process started again from the beginning. I strongly felt that his experience could have been made much simpler for him and his family had there been greater integration between services. The one year delay in reaching his diagnosis was rather crucial and affected not only his school placement but also significantly delayed therapy and support from other allied health professionals.

Transition for Sickle Cell Disease at North Middlesex Hospital

Kate Knox, St5, North Middlesex University Hospital NHS Trust.

Transition for Sickle Cell Disease at North Middlesex Hospital: a patient experience and involvement project.

Aims: To use experience-based co-design methodology to review the transition pathway for sickle cell disease at a large district general hospital providing tertiary sickle cell services, with the specific aim of improving patient engagement in transition.

Methods: A baseline assessment of the current pathway was carried out, including gap analysis against peer-reviewed standards and other successful programmes, observation of the service and interviews with clinical staff. All 16- and 17-year-old service users were contacted with details of the project. Filmed interviews were conducted with consenting young people and edited to make a short film structured around key stages of the pathway. A workshop was then held with the aim of identifying key areas for improvement based on the experiences of young people in attendance. The film was used to trigger discussion and facilitate an emotional mapping exercise, which provides a useful visual representation of positive and negative trigger points on the patient journey. Following this areas for improvement were prioritised and initial suggestions for change made. The video and outcomes from the workshop were then fed back to clinical staff and areas to take forward for improvement finalised, with the whole process taking six months in total.

Results: 33 young people were approached to give an interview and be involved in the workshop. 14 young people expressed interest in attending the workshop, with five agreeing to give an interview. All five interviews were carried out, and 85 minutes of video footage edited down to a 19 minute film. Six young people attended the workshop, where the following areas of the pathway were prioritised for improvement: talking to doctors on my own, knowing my medical history, transition information pack, and talking to peers about sickle cell disease. Feedback from those involved in the workshop was overwhelmingly positive with all young people requesting to be involved in further co-design work. After feedback to clinical staff, the following improvements to the programme have been developed: guideline updated with time alone with doctors in clinic for young people from an earlier age, integration of free mobile app containing educational resources and personal medical history, and co-design of an updated information pack with input from service users and uploading of this to the trust website.

Conclusions: Patient experience is invaluable in identifying areas to focus on for service improvement. Involvement in service improvement projects results in young people feeling valued and more engaged, and is extremely satisfying for staff members involved.

Acute Care Experience: improving the patient journey following presentation to A+E

Aims: To use the RCPCH/Picker institute PREM survey to assess the impact on patient experience of a newly introduced patient flow pathway in A+E, and to assess local population's knowledge of alternative acute care providers.

Methods: The PREM survey was translated into common local languages (Turkish, Polish) and adapted to our setting. The survey was given to patients attending A+E during December-January 2014/15, and collected at discharge/admission to ward. Following analysis the team discussed the results and decided on areas for improvement work.

Results: 41 surveys were completed and returned, with results as follows; 1) Waiting times: 44% thought longer than expected. 2) Explanations/safety netting: 59% understood what was wrong with their child, 34% were confident on what to look out for after discharge, 54% reported they were told what to do if worried after discharge. 3) New Paediatric Assessment Unit: 27% found PAU difficult to find. 4) Overall satisfaction: 34% very happy overall. 5) Knowledge of other care providers: 70% had heard of Walk in Centres, 15% of Minor ailments, and 39% of children's centres.

Following these results the team decided to focus on improving information giving within the department. A poster has been designed explaining the different streaming queues and the journey through the department. Patient information leaflets have been developed for minor illnesses and injuries, including NICE-compliant safety netting in a Red-Amber-Green format with instructions for what to do if concerned. The leaflets also contain information about alternative acute care providers, and a discharge summary on the final page with details of diagnosis and advice given. We are conscious of the number of non-English readers in our population and to this end are developing accompanying patient advice videos in English and Turkish that can be accessed online by patients.

Conclusions: Despite adaptations for the local setting, including translation into local languages, it is difficult to achieve survey coverage that reflects the numbers of patients seen in a busy A+E department. However, our results did show us that information giving was not adequate in our department, and that therefore the PREM data was a useful guide to target our service improvement work.

A Paediatric Epilepsy Service: Highlighting the need for integrated care.

PAGONI LADIKOS, PAEDIATRICS ST5, North West London Hospitals NHS Trust.

Background:

In my experience at work, my observation was that children and young people diagnosed with Epilepsy were presenting to the Paediatric A&E department in order to obtain advice for non-acute issues and concerns that did not warrant emergency medical management/review. As the Paediatric A&E is frequently busy, these children and young people were subjected to long waiting times in order to get to Specialist advice, as those in need of emergency management would be seen as a priority. Here an opportunity presented itself for a service delivery improvement i.e. the need to provide care in a more integrated, patient-centred way.

My project incorporated the following:

1. Data review to facilitate change:

The reviewed Paediatric A&E data, confirmed that in almost 50% of cases, children and young people attended the A&E department not for emergency medical review or management but in order to obtain advice.

2. Patient experience:

To get a full picture of what a patient experiences, I met with a mother whose 13 year old daughter has a diagnosis of Epilepsy and Autism as well as co-occurring learning difficulties. She related that the most difficult time for her was around the period that her daughter was diagnosed with Epilepsy. After the diagnosis was made, they were *"waiting for three months"* for the next clinic appointment and there was *"no communication in between"*. She also recalled their journeys to A&E when her daughter had prolonged seizures. She felt that there was a *"lack of awareness"* of her daughter's condition and was of the opinion that had there been a better system of *"improved information sharing"* between the clinicians providing her daughter's care, there would have been less need to repeat her daughter's medical history each time, which she found particularly distressing.

3. Patient involvement, leadership of the development of integrated services & working clinically in an integrated way:

To explore the above-mentioned issues and to identify what is needed to improve the local Paediatric Epilepsy Service, I arranged a co-design event which was attended by a total of 59 individuals. The following groups were represented: Service users i.e. parents of children/young people with Epilepsy and young people (14 years or older) with a diagnosis of Epilepsy, individuals from local clinical commissioning groups and healthcare professionals from the multidisciplinary team from both primary and secondary care.

Group discussions at the co-design event were facilitated by members of an Epilepsy Charity. The following themes for areas of improvement emerged from the discussions: (i) Communication, Support and access, (ii) Education and information (iii) Transitioning from paediatric service to adult service.

This co-design event proved to be a worthwhile venture, as it highlighted and incorporated the experience of healthcare professionals and services users. It provided insight into what is important to service users and therefore which actions and strategies need to be implemented to improve the Paediatric Epilepsy Service. A top priority is to develop the Paediatric Epilepsy Specialist Nurse post which will allow many of the recommendations to be addressed. A report regarding the event is currently in the draft stages, aimed at sending it to the local commissioning groups. Hopefully this work will be translated into an improvement of the Paediatric Epilepsy Service, enabling care to be provided in an integrated and patient-centred manner.

Reflections

Marianne Leach, Clinical Fellow, Great Ormond Street Hospital for Children NHS Foundation Trust.

The integrated care training had significant impact on my work and teaching in quality improvement. I discovered my passion for patient experience and rekindled my pursuit of measuring data and using qualitative data to implement change.

I always felt I had a lot of empathy for patients and having children with special needs myself, I thought I understand patients/carers. But – have I even asked the patient what they think? And how do we find out?

A powerful experience was sitting down with a mother for a couple of hours to go through her medical journey and emotions. She had a 3 year old girl with 'pseudobstruction' (a disorder of the gut which basically stops the gut moving food forward) who required parental nutrition. She was admitted to GOSH because of an acute illness. We went through the girl's 'journey' and what mum has felt during these times. Her little girl was in hospital for the first year of her life till a diagnosis was made and since then has been only at home for few months. During that time mum was not available for her other son, who is one year older. It was moving to see how positive this mother was despite all the heartache the illness had brought to her daughter and wider family. All what they wanted was to be out of hospital and be together with her brother. It highlighted to me that we as professionals perhaps not always taking into account or asking what outcome is important to the patient/carer although medically she was managed well.

Since then in many situations e.g. in clinics I would ask how each patient felt and made sure I listened for the outcome they find important, which has led to make decisions together.

My increasing interest in patient experience led me to invite a chairperson of health watch, patient representative, whom I met at a hospital board meeting, to speak on a quality improvement training day (RCPCH). It added a whole new dimension to outcomes of quality improvement projects. It influenced the delegates to think about asking carers/patients what their needs are and what is important to them, when planning a QI project. On the day we had several discussions as to why and how we can ask the patient/carer as the majority of professionals were not used to ask these.

On another project I experienced some apprehension using feedback from patients/carers when trying to implement patient questionnaire and focus groups to start a QI project regarding quality of ward rounds. One of the challenges was that my strongest co-supporter, the matron, became sick. Another challenge was to get medical staff to see the need for change. Without asking patients/carers and staff it was difficult to make the case. Although the project was not completed partly because of these challenges and time, it taught me a lot about engaging stakeholders and the need to find support/buy-in for a project.

I was able to use the patient experience tools in my latest QI project in a different hospital sampling feedback from staff and patients using the 'Tell me' feedback form and more formalised surveys in order to explore how to run 'baby check' clinics. This influenced the next stage of the project. In this and previous project I learnt how to research and formulate questions developing a survey. It increased my understanding and value of qualitative data and the use of local data when available.

Overall the training in integrated care has given me effective tools to co-design services with patients and incorporate patient experience in QI projects and QI training as well as the vision to work towards connecting the different levels of care in the job I have just started. Thank you team for your support and vision.

Reflections

Eileen Liew, Paediatrics St5, Royal Free London NHS Foundation Trust.

Initially we had planned to focus on A&E attenders for children <5 years of age in the Enfield area as this is one of the areas that Enfield borough is performing lower than the national average from the Chimat data. This evolved into a project exploring patient/parent experience of these under 5 A&E attenders of utilising the health service, their perception of it and how they wanted it to be to fit with their needs. Fortunately we had very pro-active health visitors in the Enfield area who was keen on doing some work along similar lines and hence joined forces with them

The first stage of the project involved us going along to the 2.5 years old developmental checks conducted by health visitors in the Enfield/Edmonton area. We spoke to a number of parents to get an idea of what their perception is of the ease of access to various health care service and of their experience with seeking health care for their child.

In the second stage of the project, we then invited parents into small focus groups to further explore their reasoning for seeking health advice for their <5 years of age children and what influenced their decision of where/when to seek medical advice. There has been some interesting feedback so far such as that a majority of parents did not have difficulty getting to GP appointments for their child. This is initially what we thought could be one of the factors that drove parents to visit A&E. The other interesting feedback is that most parents are unclear of the role of the health visitor and hence tend to bypass them when trying to seek advice. Perhaps this will prompt a rethink of how to best promote the service and utilisation of health visitors in the area.

Currently we are still in the process of collating all the feedback from these sessions and hope to present it to the commissioners in the near future to help shape health care provision to better suit the users in the Enfield/Edmonton areas

Why do under 5 year olds have a high rate of Emergency Department (ED) attendances in Enfield? – Investigating reasons and possible service improvements through qualitative data from parents.

Rosemary Marsh, ST5.

Background

In 2013, Chase Farm Hospital in Enfield closed to acute paediatric admissions. At the time, an increase in community services was proposed in order to cover some of the health needs which were previously being met by the hospital services. There was however no clear structure of how to develop integrated paediatric services within the community. When planning this project, my hope was to identify some areas where there were gaps in current service provision and ideas for an integrated paediatric service which could fill them. However, this was a very large undertaking and so we tried to find a more defined focus for our work: an aspect of care in the area which was demonstrably substandard which we could investigate and use as the base for new service ideas.

Project planning

To try to find a focus we gathered some data from CHIMAT¹ about possible targets for intervention in the area. The high number of ED attendances in under 5s stood out from this data. I had previously spent some time working with health visitors in the area and talking to parents informally in their clinics in order to collect some knowledge of the services and parental opinion. Most of the 2yo children I had seen at these clinics had had ED/walk-in centre attendances and a proportion of parents said they bypassed their GPs because they did not have confidence in their GP services. In contrast, nationally, the majority of patients would prefer to use GP services². These comments reinforced that this was a significant issue for parents and children in the local area.

With the help of the health visitors I had met before, we planned to see some children and their parents attending for routine 2yo developmental checks and record patient stories/journeys from them more formally. We hoped to analyse these to give some idea of patient experience of services when dealing with acute episodes of illness and hoped their reasons for attending ED might emerge from this.

Methods

We used the questionnaire from the first contact care survey² as the base for our parent interviews. We obtained informed consent from each parent and gave them a choice as to whether to participate. Quotes from the parents were collected and themes were identified.

Results and their presentation

Themes identified included:

1. Continuity of care – seeing a known practitioner is important
2. Faith in the service – parents had varied and often unexpected reasons for mistrusting a service
3. Convenience – sometimes parents felt they could not wait until office hours to be seen
4. Communication between services – parents felt let down by failures in referral or communication

We presented these results to the PICH group and disseminated them to the consultants and health visitors locally.

Further action

As a result of interest in our motivation, methodology and themes emerging, the local paediatric consultant and health visitor team decided to continue our work and found funding to:

1. Collect data on all frequent ED attenders in Enfield to flag these to HV services
2. Invite a larger group of parents to a series of focus groups in order to expand the themes and help plan future services
3. Produce a paper to publish our and their results and take these to the local commissioners.

Update

In August 2013 the four focus groups were completed and from there we identified two further themes:

5. Confusion about the ways to access services and pathways through them
6. Uncertainty as to the roles of different healthcare professionals

¹ <http://www.chimat.org.uk/resource/item.aspx?RID=242066>

² <http://www.actionforsickchildren.org.uk/sites/default/files/downloads/ASC-SURVEY.pdf>

We have planned an immediate intervention to address these themes: a poster showing the web of services in the area to be disseminated by local services and social media.

We hope that further ideas for developing services will emerge once our results are fully collated and presented.

Patient experience feedback – parents’ group for parents with children with severe HIE.

Melanie Menden.

Patient experience feedback – parents’ group for parents with children with severe HIE

During my rotation in paediatric palliative care, I looked after five young babies with very similar diagnoses of severe HIE. I sat down with all parents and we talked through the impact this diagnosis had on them as a family and how looking after their children shaped and dominated their daily life.

All mothers feel disconnected from normal life. They feel very isolated. It is a huge undertaking to take their babies out due to the amount of equipment they need, impossible for one person alone. Leaving the house is mainly restricted to taking their babies for hospital appointments. AA's mother can hardly manage with another helper because of the layout of her flat. The husbands of two of the mothers work long hours (one abroad for long stretches), so they do not have any face-to-face contact with anyone other than their babies' carers, as many have families abroad. When they have no carer due to their care package (maximum of five days), they look after their babies >24 hours, hardly sleeping at night. Their babies have three appointments per week outside home on average.

When encouraged to go out with their babies, all mothers were anxious to do so, as they found it very challenging to see other, healthy children of the same age. They are not ready to talk about their children to strangers. For three mothers in particular their experience is still very raw many months after delivery. They have not accepted the diagnosis; all three have sued the Trusts and are waiting for answers that no one has been able to give them yet. They found it difficult to bond with their children, two of them were told their children would not survive the neonatal period, yet here they are. They are in constant fear that their children will die, from an infection, from choking, from something else.

As these mums did not know each other, I was wondering whether I should try to introduce them, so they could share their experiences and potentially support each other. They are all interested in this idea, however there are huge difficulties in bringing them all together because of constant medical commitments and transport difficulties. I therefore decided to try attempting to set up a meeting in collaboration with their local hospice. The manager there was very supportive of the idea, especially as she felt these parents found it hard to engage with their hospice, and this might be a good way of also introducing hospice as a place of respite and extra support. I met up with the hospice's family psychologist to plan this further. The psychologist and the hospice's play therapist already know most of the families well through outreach visits.

We thought about incentives and support to make a parents meeting happening:

- transport for all
- support and therapies (play, sensory-neuro room) for all babies during the session
- pampering for the mums (yoga, foot massage, meal/coffee)

The meeting is planned for October.

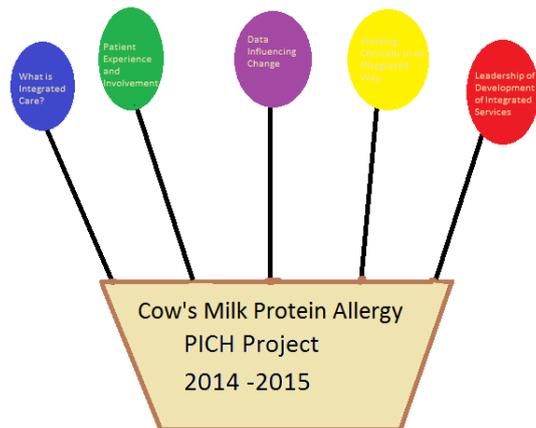
Reflection:

This has been an extremely eye-opening experience for me. It made me understand much better the extend of the emotional, physical and financial impact which living with a child with severe HIE has on these parents.

Reflections

Katherine Murtagh, Lewisham and Greenwich NHS Trust/Guy's and St Thomas' NHS Foundation Trust.

I worked clinically in an integrated way by signing up to GP/ Paediatric Learning Together Clinics. I carried out six clinics with a GP Registrar in a local GP practice near my hospital. We took it turns to see patients – both pre-booked & emergency – with a



range of paediatric/adolescent conditions. We reflected on the cases together and learned from each others' experiences. One particular case struck a chord with both of us. A young infant with severe eczema came with an understandably upset mother who had visited the practice many times. Mother was requesting homeopathic referral. Together, at the clinic, we diagnosed Cow's Milk Protein Allergy. We prescribed an extremely hydrolysed formula, subsequently the baby did very well and her skin improved dramatically. We learned that the practice do not normally prescribe specialist formula without the advice of a paediatrician. This was our "lightbulb moment". Why not? We both thought.

- Prior to this I had thought about carrying out a PICH project on allergy, my PICH local supervisor is an allergist. PICH leaders thankfully pointed out that allergy in itself is a huge topic. I was advised to narrow the scope of my project down. All of this and many more factors gleaned from attending CYP evenings on *what is integrated care* led to my decision to carry out my PICH project on *Integrating Cow's Milk Protein Allergy Management in Primary and Secondary Care* starting at a local level. I felt much more Cow's milk allergy could be managed in the primary care setting - being most convenient for patients and leading to speedier diagnosis and therefore resolution of symptoms.

- To continue the *working together* theme I asked my GP Registrar partner if she would get involved – she agreed and used this project for her GP training too. We recruited our seniors – my local PICH supervisor, the practice GP Partner (who is a local CCG member) and local hospital dietician as well as availing of the skills of my allocated PICH mentor and PICH faculty.
- We decided we would assimilate some *data to influence change* and garner some *patient experience and involvement* for the project. I attended the hospital allergy clinic and spoke to family's first hand. My GP partner identified patients who had been prescribed extremely hydrolysed formulas and sent them a written questionnaire. I got a database of children with cow's milk allergy known locally to the dietician and contacted parents to complete a telephone survey. It was difficult to recruit large numbers for feedback but I learnt from attending PICH/CYP evenings that often in *integrated care* qualitative feedback is as useful as quantitative feedback. Recurrent themes emerged – parents wanted earlier diagnosis of cow's milk allergy by primary care. Many parents felt management in primary care would be more convenient and accessible than attending hospital appointments.
- I took *Leadership of the development of integrated services* for cow's milk protein allergy by meeting with my local PICH supervisor and dietician and formulating a guideline with my GP registrar colleague for use in primary care. The guideline is under the supervision of my PICH local supervisor with input from all my PICH project team members. Universally we feel GPs need ready access to straightforward information. We have been in discussion with our local CCG pharmacist to discuss best formula options for local GPs given finance is a huge issue for primary care. Ultimately we plan to pilot our guidance locally at the "learning together" surgery then present it to our local CCG.
- Being a PICH participant this past year has opened my eyes to the scope of *what is integrated care*. Through my personal project and attendance at PICH/CYP evenings I have learned more about integrated healthcare delivery in its widest setting than I could have imagined at the outset.

Reflections

Swarnlata Saroey, ST7, University College London and Hillingdon Hospital.

My experience

The PICH course has helped me to gain a better understanding of systems, which need to be in place to bridge the gaps between the working of different NHS organizations to meet health care needs for children. I also understood concepts of integration at different levels to achieve better health care and patient experience.

Method

I made contact with the local champion in the organization I was working who was actively involved in the 'Skills sharing service review project' by the Camden CCG.

My project involved gathering retrospective data and studying paediatric A&E attendances to identify the patterns of presentation in frequent attenders between September 2013 and August 2014. The main aim of the project was to identify the episodes of illnesses, which may have been more appropriate for primary care management. The workload of Paediatric A&E during and outside routine working hours was also compared. Background and demographic data was available from the coding department and final diagnosis and outcome was recorded from case notes.

Results

There were 16,152 episodes of A&E attendances in this 1-year time period. Attendees were divided into two cohorts those with 5 or more and those with 10 or more attendances. Any child requiring blood investigations, imaging or admission was considered an appropriate presentation. The presentations were further categorized into injury versus illness episodes, presuming that a child with injury would need to be managed in the hospital setting. There were 402 episodes of children with 5 presentations to A&E and 61 episodes 10 or more attendances. In the 5 episodes/year cohort the proportion of appropriate presentations to A&E were similar irrespective of the time of the day. The data suggested that 60% of the episodes in this cohort may have been manageable in primary care. In contrast, all children in the 10 times/year group were those with complex health needs and close to 40% of these episodes could have been possibly managed outside hospital. The percentage of presentation to AE due to illness was 82% and 92% respectively in the 5/year and 10/year cohorts.

Discussion

During discussion with CCG following presentation of the project, it was highlighted that educating parents to gain confidence in the GP surgeries can be a major factor which can be helpful in changing the parents' perception that AE attendance would provide them quicker access to a paediatric review and investigation. This audit highlighted to the CCG that the major proportion of attenders who are using the services inappropriately are those with common childhood illness' e.g. viral upper respiratory tract infection, gastroenteritis and tonsillitis being the top three. As a result of the project, the CCG have planned take this issue forward and will carry out telephonic interviews of a proportion of the parents of these 2 different cohorts of patients to better understand their reasons for AE attendance as opposed to GP appointments.

Reflections

Allison Ward, Chelsea and Westminster NHS Foundation Trust/Camden and Islington NHS Foundation Trust.

Over the course of the last year I have transitioned from being a final year paediatric trainee to working in a substantive Consultant Community Paediatrician post in Camden, with responsibilities in the Safeguarding, Looked After Children and School Health Services. This period of transition, and the associated new responsibilities that have come with it, have provided me with plenty of opportunities to develop a better understanding of integrated care pathways for children and young people.

What does integrated care mean to me?

Integrated care, in very basic terms, is about providing **the right care, at the right time, in the right place, with the right people present and the right resources available**. It's about putting the child and family's perspective right at the centre of what we do and **ensuring we deliver optimum care through a well coordinated service**. In community paediatrics we need to provide care that is horizontally integrated – for example, health therapists and clinicians working in collaborative and joined-up “teams around the child”. We also need to integrate our work vertically, alongside agencies outside health that form important parts of children and young people's networks, such as education and social care.

Patient experience and involvement

Patient experience has to be at the heart of what we do, and the very foundation that services are built upon, developed and continuously improved. I have focused my PICH patient experience work on **looking at how we ensure “the voice of the child” is considered and recorded in all our statutory looked after children (LAC) health assessments**. Our team has looked at previous health assessment records for evidence of listening to the voice of the child, and we are now developing new health assessment proformas with set prompts to ensure the child's views and opinions are always formally sought and recorded. Future plans include also **using a “voice of the child” prompt in safeguarding medical assessment proformas, and linking this work to promotion of resilience in vulnerable children and young people**. We will also be exploring how additional formal **patient reported outcome and experience measures (PROMs/PREMs) can be incorporated into the Camden Young Inspectors review** of safeguarding and LAC health services.

Data influencing change

I am reminded everyday that **we cannot work effectively as clinicians without data** – data that provides us with the information we need to make routine clinical decisions, and data that can also be used as a tool for driving change and improving services. My PICH data project, which remains ongoing due to its immensity and IT issues (!), has explored the use of RIO (the electronic medical records system used by various health professionals in community paediatrics) **to create a database of all children within the Camden mainstream schooling system with additional health needs** requiring the regular or ad hoc input of a member of the community paediatric team (Paediatrician, school nurse, therapists etc). The vision for this database is that it will allow us to work in a more integrated way – for example by **running coordinated school-based clinics alongside the school nurses, provision of a prompt medical advice service to SENCOS and remote monitoring of health issues**.

Working clinically in an integrated way

The **concept of coordinated multi-professional working is by no means new to field of community paediatrics**. Over the last 6 months I have been involved in many examples of everyday integrated working. I have had the hugely valuable experience of working as a **paediatric representative in the Camden Integrated Children's Service**, a recently established team of clinical assessment and care planning co-coordinators whose role it is to **support families and clinicians to manage children with complex health/developmental needs requiring input from multiple agencies**. Case examples of this work include the integrated management of a school-aged child with complex medical and safeguarding needs, and the coordination of a supportive care package for a child with a life-limiting condition whose family had disengaged with professionals. I have also been involved in **working at the interface between health services and the local educational authority**, ensuring that we work alongside families to meet the specific health needs of children and young people with medical conditions whilst they are at school.

Leading the development of integrated care services

Now that I am settling into my role as a Consultant in Camden I have plenty of ideas about how services can be further developed through more integrated patterns of working. My plans include **further exploration of the role of health professionals within the MASH (multi-agency safeguarding hub)** and also **the use of technology and social media (Twitter, Skype, the “HIP4LAC” blog) to improve access and experience of LAC health services for adolescents**.

Bethany Smith, ST6, Croydon University Trust.

The Healthy, Happy Child in Croydon

A 2 year old boy referred to OPD with constipation and fear using the potty. Mum's going back to work and he needs to be potty trained to start nursery.

A 4 year old girl with T1DM in Diabetes Clinic, lies on the floor and screams until Mum gives her a packet of sweets. Mum struggles with her behaviour and her HbA1c is very high.

Patient experience explored through Family interviews

A one year old boy admitted with his first wheezy episode. His weight is well above the 99th centile. His Grandma says all the family are big and does not feel he is overweight.

An 18mth old South Indian boy brought to ED fitting, found to have hypocalcaemia secondary to vitamin D deficient was not weaned until nearly one parents say he is a fussy eater.

A 2 week old baby girl brought to ED by her young parents. They're not sure about her feeding but she is gaining weight well. Her Mum is a care leaver and Dad was an unaccompanied minor from Afghanistan. They have no family support.

Literature Review

Data Collection

Survey of Paediatric Consultants, Registrars & SHOs; Paediatric ward & ED Nurses; GPs

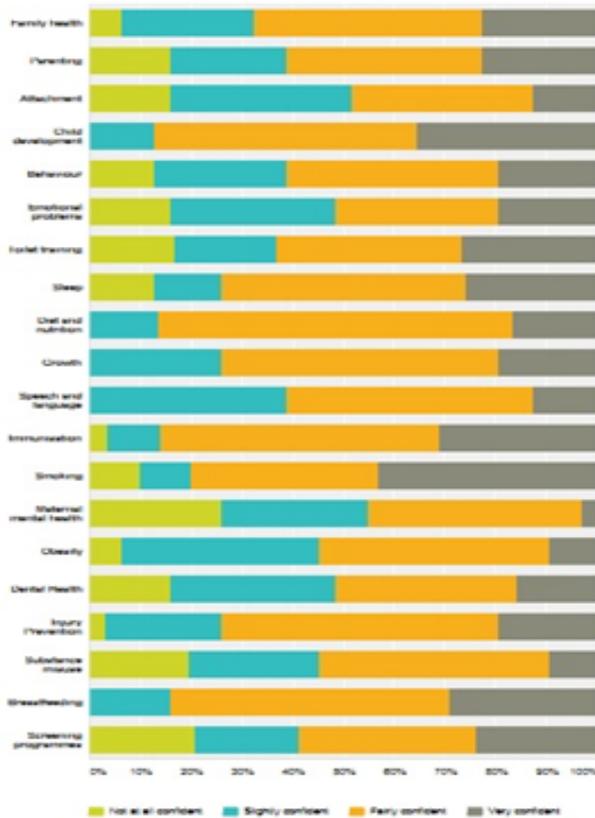
Service Users: Patients Under 5

- 55% of ED attendances
- 50% of Ward admissions
- 50% of OPD referrals

The six High Impact Areas are: **DoH, July 2014**

- Transition to Parenthood and the Early Weeks Maternal Mental Health (Perinatal Depression)
- Breastfeeding (Initiation and Duration)
- Healthy Weight, Healthy Nutrition (to include Physical Activity)
- Managing Minor Illness and Reducing Accidents (Reducing Hospital Attendance/Admissions)
- Health, Wellbeing and Development of the Child Age 2 - Two year old review (integrated review) and support to be 'ready for school'

How confident do you feel speaking with families about...



'In many cases improvement in one early outcome can yield future benefits in many different areas in a child's life'

Rapid Review to Update Evidence for the Health Child Programme 0-5, Public Health England, March 2015



- 60% would like to help health visitors deliver child health to pics at children's centres.
- 100% would like to learn more about child health and wellbeing in the early years
 - 100% would like departmental teaching
 - 92% would like a multi-professional day seminar
 - 66% would like e learning
 - 60% would like evening seminars

