



Phase 2: Integrated care

North West Paediatric Allergy Network

Aim

To deliver healthcare responsive to the needs of families with children who have an allergy to cow's milk protein or one requiring an adrenaline auto injector.

Objectives

There has been a dramatic increase in allergies in the developing world and it is estimated that 6–8% of children have a proven food allergy, while levels of perceived food allergy in communities are more than twice this number (NICE clinical guideline CG116: *Food allergy in under 19s: assessment and diagnosis*, 2011). The team set out to:

- 1 document current deficiencies and work to improve knowledge and confidence of GPs and other healthcare workers in diagnosing and managing non-complex milk allergies and children needing adrenaline auto-injectors
- 2 embed allergy templates within the electronic patient record system routinely used by GPs within the region, providing them with a checklist and clear management plan for children with these allergies
- 3 promote self-management and shared decision making between parents/carers and healthcare professionals for common food allergies
- 4 improve the public's knowledge and confidence of children's allergies and reduce their reliance on healthcare professionals for ongoing care.

Key messages

- Having a **common vision** and values has kept the group focused on delivering change through whatever challenges they faced.
- The support and input from our **families and charities** has been invaluable.
- Secondary care allergy activity is bundled into general paediatrics and hard to extract. The ability to **collect activity and clinical** detail was very challenging but vital.
- Increasing capacity in hospitals for when an infant first presents would not address the key areas needed for a **sustainable, family-centric approach** to managing allergy.
- **NHS 111** is a great support for families with children suffering from allergic symptoms out of hours.
- Using links with the Anaphylaxis Campaign and their local support groups to develop an approach to involve patients and learn from their experiences was vital.

Methods

1. Knowledge and confidence of GPs and health visitors in Oldham

The knowledge and confidence in both GPs and health visitors needed to be addressed. Educational packages and resources were developed to meet these needs, including:

- how to manage milk allergy
- the differences between replacement milk formulas.

2. Access to dietetic support for families, as outlined in NICE guidance

Access to dietitians was reported by families as a vital requirement, and is outlined in NICE guidance. The North West Paediatric Allergy Network (NWPAN) team developed group dietetic sessions to provide information and a forum for peer support.

3. Group dietetic sessions: peer support and reducing time to dietitian

Group dietetic sessions for infants with cow's milk protein allergy (CMPA) were developed. Five to ten families could come together with a dietitian with the support of a health visitor for both professional and peer support. This empowered families/carers to work to not only manage their infants CMPA, but also promoted tolerance and thus resolution of the disease in the quickest time, improving the family's overall quality of life, and reducing the workload of the dietitian and cost of replacement milk formulas to the NHS.

4. Patient records

The team developed electronic patient record templates to be embedded into EMIS (a leading electronic patient record system used in primary care). These are triggered when a milk formula or adrenaline auto-injector is prescribed, and when infants present with a potential milk allergy, for example infant feeding problem.

5. NHS 111

The team worked with NHS 111 (North West) to understand and support how children with allergies could be managed. Collaborations continue for managing the 85% of calls for rashes, which are currently directed to primary care.

Milestones

- Jan 2016: Appointed as a FHP development site.
- Feb 2016: GP competencies set. Baseline spend on milk products established.
- Apr 2016: Develop a decision tool that would be used by parents after consultation.
- May 2016: Decision tool used at educational event for 100 GPs.
- Jul 2016: Patient involvement event hosted in collaboration with Anaphylaxis Campaign Manchester Support Group.
- Sept 2016: Meeting with NHS 111 (North West) to discuss allergy pathway.
- Sept 2016: Patient engagement group meeting.
- Feb 2017: Hosts of phase 2 learning event.
- Mar 2017: Wythenshawe hospital: dietitians seeing more patients.

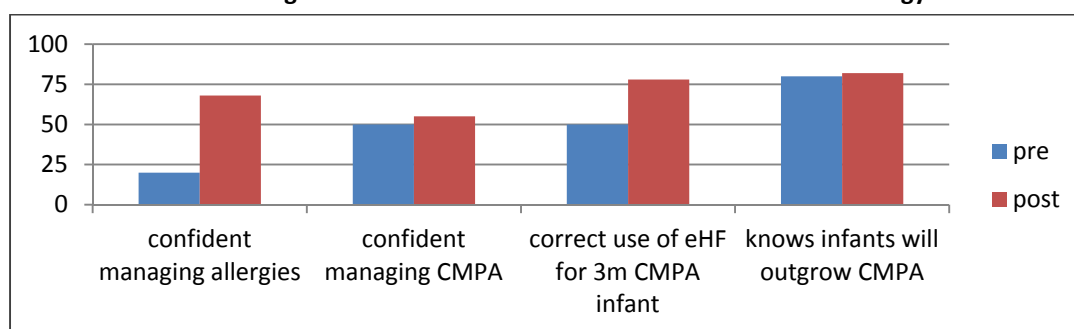
Outcomes

1. Experience and confidence of healthcare professionals in managing CMPA

GPs

Although 90% of GPs knew that most infants outgrew CMPA and 56% were confident in providing a general allergy advice, **only 40% were confident in providing specific advice on milk allergy**. Forty GPs filled out the survey before and after a 60-minute educational session on children's allergies.

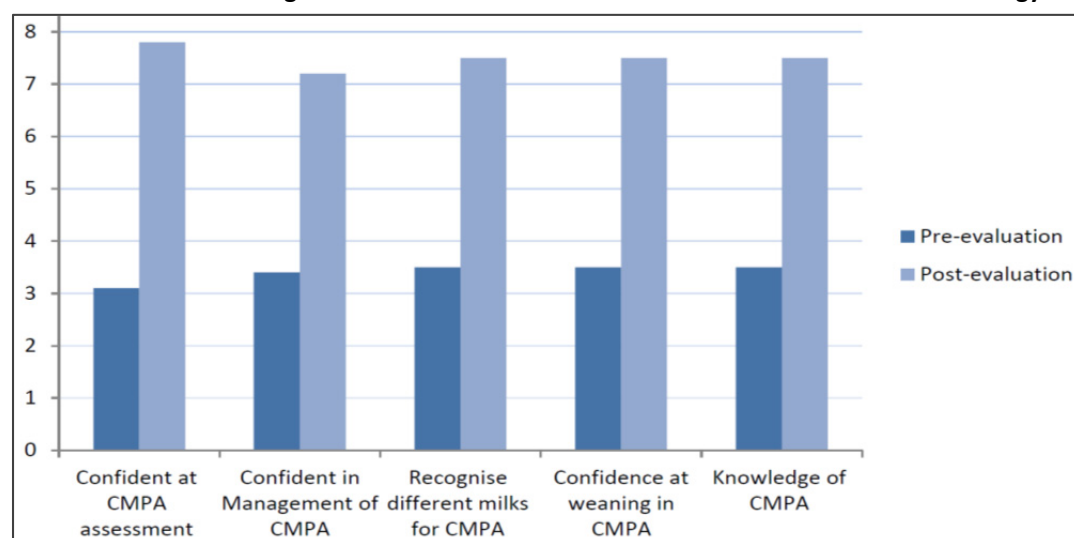
Confidence and knowledge of GPs before and after an education session on allergy



Health visitors

To provide knowledge and confidence to our health visitors, a 90-minute CMPA education session and an accompanying **resource pack** were developed and delivered.

Confidence and knowledge of health visitors before and after an education session on allergy



2. Prescribing of milk allergy formula

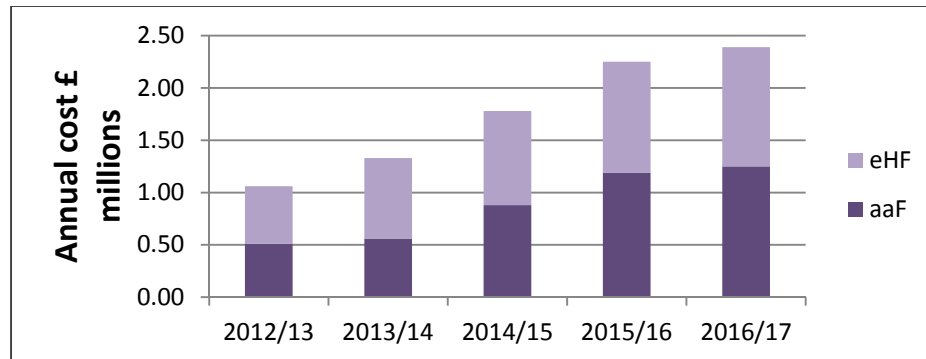
In view of the variability in GP prescribing, clinical records were reviewed in relation to prescribing of replacement milk formula for 40 infants in high prescribing practices. Key findings were:

- 62% of GPs prescribed formulas with no input from paediatricians; 50% had no input from dietitians
- 24% of children had no planned follow-up

- 64% of children were tolerating some dairy, suggesting that they could be on an extensively hydrolysed formula (eHF) rather than an amino acid formula (aaF) (saving £180 per infant per month)
- 8% of infants were tolerating fresh cow's milk and thus did not need to be on a replacement formula.

Our data shows that in the last 5 years there has been a doubling in the cost of prescriptions for both eHF and aaF by Greater Manchester CCGs (£1.1 million in 2012–13 to £2.4 million in 2016–17).

Expenditure in Greater Manchester on alternative milk formulas for CMPA



3. Web-based resources

The network launched its new website (www.allergynorthwest.nhs.uk) for professionals in March 2017, containing resources and patient information leaflets. Active interactions with the website were tracked and the average number of hits was 1,400 per week, with two peaks linked to educational events. Publicity will be vital to ensure that families are aware of this resource.

Successes and challenges

Successes

- ✓ Through strong teamwork, the network has maintained determination to deliver its aims.
- ✓ Widening of network: over time, there has been an increase in the number of organisations and professionals actively engaging and driving the network.
- ✓ Support of collaborators: the input, advice and support from families and charities have been invaluable.
- ✓ Strength of patient representation: the work and commitment of the patient and carer representatives has been exceptional.

Challenges

- Publication of national milk allergy protein (MAP) guidelines in 2013 has not been associated with a noticeable decrease in specialist milk formula prescribing in Greater Manchester; rather the opposite trend has occurred.
- The current level of referrals is not sustainable; referrals to secondary or tertiary services generate long waits for families, creating anxieties.

Read the full report from the North West Paediatric Allergy Network development site team at www.rcplondon.ac.uk/delivering-the-future-hospital

Contact: Dr Peter Arkwright, peter.arkwright@nhs.net