



Royal College
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Future Hospital
Programme



Phase 2 Future Hospital development site

North West Paediatric Allergy Network

Integrated care



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Hospital

**Empowering families and healthcare professionals to effectively
diagnose and manage cow's milk protein allergy.**

*A special report from the
North West Paediatric Allergy Network*



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Website: <http://allergynorthwest.nhs.uk/>

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1 Overview

1.1 Executive summary

Founded in 2009, the North West Paediatric Allergy Network (NWPAN) brings together healthcare professionals, families and charities with the aim of streamlining and personalising care for children with allergies.¹

There has been a dramatic increase in food allergies in the Western world over the last two decades. The National Institute for Health and Care Excellence (NICE) 2011² estimated that 6 to 8% of children have proven food allergies, while the level of perceived food allergy is more than double this number. Through the Future Hospital Programme, we aimed to develop a more cost-effective and patient-centred clinical services, specifically for children suffering from cow's milk protein allergy (CMPA). Our aims were in line with the focus of the Five Year Forward View of developing integrated models which span all areas of healthcare.

NWPAN found that the NHS cost of treating children with CMPA in Greater Manchester using replacement milk formulas had doubled over the last five years (£2.4 million in 2016/17). The estimated cost nationally is £58 million. We established that 40% of prescriptions for replacement milk formulas were not required or could have been changed to a cheaper alternative, with a projected national saving of £24 million. Input from community dietitians and medicines optimisation would be vital to instigate this.

Four Patient and public engagement events were held at our Oldham pilot, and the Manchester support group in liaison with the Anaphylaxis Campaign³. From the clinical journeys it became evident that these were often emotional roller coasters with lack of professional and peer support. From this, group dietetic sessions were launched to address negative experiences of families with the concomitant advantage of doubling the throughput of patients. The Patient zone of the NWPAN website is being developed and is being led by, and working with, patient representatives. This ensured patient concerns were being addressed by the website, which is to be launched in autumn 2017.

GPs are on the frontline of delivering care for infants with CMPA. We found that most GPs see few if any children with a food allergy. A survey involving 200 GPs found that only 40% of the GPs surveyed were confident and knowledgeable in managing CMPA and understood the differences between replacement milk formulas. To address this, templates were developed to guide GPs through the diagnosis and management of CMPA. These templates were designed to be automatically triggered when replacement milk formulas are prescribed or when an infant with suspected CMPA presents to their surgery. A new network website providing healthcare professionals with advice and information leaflets has also been launched in 2017.

Key messages from our work for the wider NHS community:

TALK: Understanding the deficiencies in a clinical service cannot be effectively achieved without interacting directly with individual patients, charities and NHS staff delivering the service. Experts often do not fully appreciate the concerns and priorities of those working on the 'shop floor'.

TEST: It is vital for patients and healthcare professionals to have access to knowledge and resources in a form that is simple to understand and use. Good ideas need testing and modifying if they are going to work. Try ideas out on colleagues and patients to make sure they are feasible. Use PDSA cycles.

TEAM-UP WITH YOUR NETWORK: However good your idea is, teaming up with others from different backgrounds and perspectives will make it better. Healthcare may be built on trust, but getting the job done most efficiently often involves a network of multiple healthcare providers, patients and other community stakeholders.

1.2 Alignment with the Future Hospital Programme principles

Our Network vision aligns closely with that of the Royal College of Physicians' (RCP) Future Hospital Programme (Table 1). Our four main objectives of our project are:

Objective 1: To document current deficiencies in diagnosing and managing non-complex CMPA by GPs and other allied health care workers.

Objective 2: To embed templates within the EMIS electronic patient record system used by GPs within the network to providing them with a checklist and clear management plan for children with CMPA.

Objective 3: To promote self-management and shared decision making between patients/carers and health care professionals for CMPA.

Objective 4: To streamline services for infants with CMPA and reduce unnecessary prescribing of replacement milk formulas.

Table 1: Alignment of our objectives with those of the Future Hospital Programme

Future Hospital principles of care	Objective 1	Objective 2	Objective 3	Objective 4
Fundamental standards of care are met.	✓	✓	✓	✓
Patient experience is valued as much as clinical effectiveness.	✓	✓	✓	✓
Care model facilitates self-care & health promotion.	✓	✓	✓	✓
Patients have effective and timely access to care.	✓	✓	✓	✓
All patients have a care plan that reflects their specific needs.	✓	✓	✓	✓
Services also meet needs of vulnerable patients.	✓	✓	✓	✓
Robust transferring of care is in place.	✓	✓	✓	✓
Patients avoid moving wards unless required for their care.	N/A	N/A	N/A	N/A
Good communication regarding patients is the norm.	✓	✓	✓	✓
Responsibility for each patient's care is clearly communicated.	✓	✓	✓	✓
Staff are supported and are committed to improving quality.	✓	✓	✓	✓

2 Impact of project on patient care and patient experience

2.1 Measures used

Table 2 summarises the measures used to assess our project's progress.

Table 2: Summary of our project objectives and measures

Aims	Measure
<ul style="list-style-type: none">• Determine current deficiencies in management of CMPA.• Use EMIS electronic record templates to guide GPs and HVs in their diagnosis and treatment of CMPA.• Promote more effective prescribing of replacement milk formulas.• Deliver group dietetic sessions in order to partner patient families and professionals in delivery of care• Empower patients, families and health care providers	<ul style="list-style-type: none">• Patient journeys/engagement• Patient satisfaction survey• Knowledge and confidence of GPs and HVs• Replacement milk prescribing data: regional, local, individual• Time to dietitian input• Hits to NWPAN website

2.2 Data, findings, key messages

Patient engagement drives and shapes our project's changes to healthcare

Patient representatives have been involved in this project from its inception to help identify key concerns of patients and how to measure outcomes. A range of patient and public engagement activities were pursued. These were led by our patient representatives who developed a patient and public involvement strategy (PPI) (Appendix 1).

Figure 1: Engagement session using emotion-based design principles



We have undertaken three PPI events (July 2016 Manchester [**Front cover**], September 2016 Oldham (our pilot site) and June 2017 Manchester) to shape and mould our programme. We utilised links with Anaphylaxis Campaign and local patient support groups to interact with their members. The findings of these events identified specific areas which we should focus on for maximum benefit. It was clear that CMPA was an area of anxiety and frustration for families. A year on, we returned to the Manchester patient support group to share our progress and identify additional

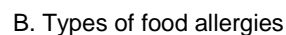
priorities.

"Peer support helps. Health care professionals usually don't sign post peer support groups to patients. There is assurance from parents who have been through it; who have done it. It's quite powerful to hear someone else's story, see photos of allergic reactions and find out how they coped. Allergy support groups help by providing emotional support and practical information, particularly at times where there are changes in the child's life."

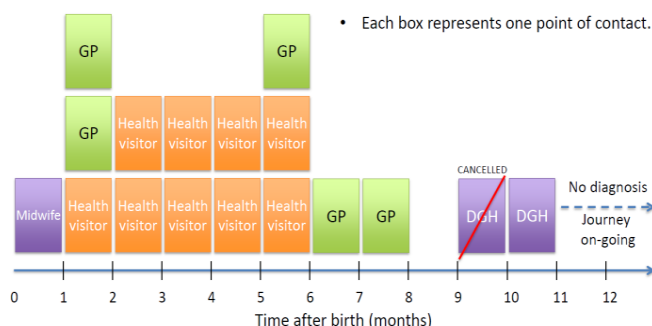
CMPA is a common cause of referral to allergy services

Our Network has an e-forms system into which workload and clinical outcome data are collected.³ Its governance is through a regional data sharing agreement. From these data, we calculated that 60% of referrals to hospital services in the North West were for patients with food allergies and 22%, particularly in infants and young children, were for CMPA (Figure 2).

A. Types of allergies



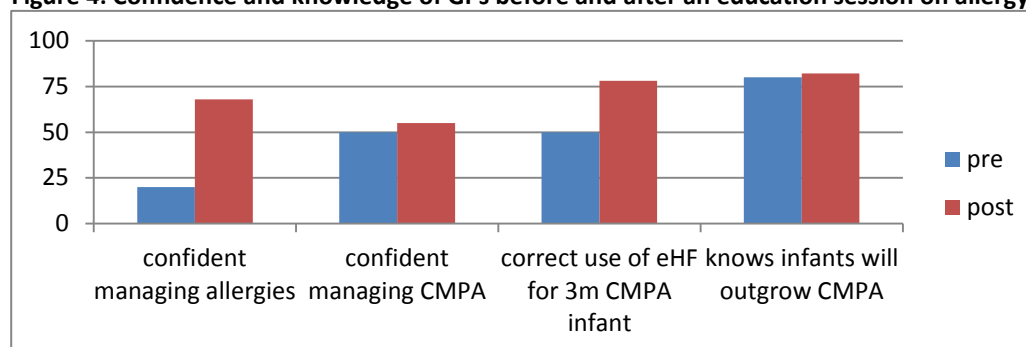
The first port of call for families of infants with CMPA is the health visitor (HV) and GP. Patient pathways were recorded as part of Patient and public engagement events during three engagement events (Manchester (Jul 2016 & Jun 2017) and Oldham (Sep 2016)) (Appendix 2). Feelings engendered by having an infant with CMPA and an example of lack of definitive diagnosis and treatment for infants with CMPA with numerous encounters in the community are illustrated in Figure 3.

[illegible]

To get a broader understanding of the confidence and knowledge GPs have in managing CMPA, between May and September 2016, we conducted four separate surveys (Greater Manchester, Bolton, Oldham, Warrington) and analysed 200 replies with an almost 100% response rate (Appendices 4 & 5). Although 90% of GPs knew that most infants would outgrow their CMPA, only 40% were confident in providing specific advice for infants with CMPA. Only 57% would correctly prescribe an extensively hydrolysed formula (eHF) to a three month with a history of CMPA. The remainder were not sure (20%), or would prescribe amino acid formula (aaF) (15%), soya (7%) or rice milk (1%).

Forty GPs filled out a survey before and after a 60-minute educational session on children's allergies. Although their overall confidence in managing allergies improved, confidence and knowledge on specific areas (confidence managing CMPA; knowledge of the natural history of CMPA) remained unchanged (Figure 4). The current rate of referrals to hospital paediatric services generates long waiting times and prolongs anxiety for families. It is therefore important to empower healthcare workers in the community to more effectively deliver this care.

Figure 4: Confidence and knowledge of GPs before and after an education session on allergy



We conclude that, at present, many primary care clinicians lack the knowledge and experience to allow them to effectively diagnose and manage infants with CMPA.

The findings above suggest that, at present, there is a lack of knowledge and on-going experience by many primary care clinicians which would allow them to effectively diagnose and manage infants with CMPA, which can be partly reversed by direct educational sessions.

As well as studying the confidence and ability of GPs and HVs to manage CMPA, we also looked at potential input from both allied healthcare professions (dietitians, nurse practitioners and HVs) in partnership with the patients' families.

Replacement milk formula prescribing in Greater Manchester and our Oldham CCG Cluster pilot

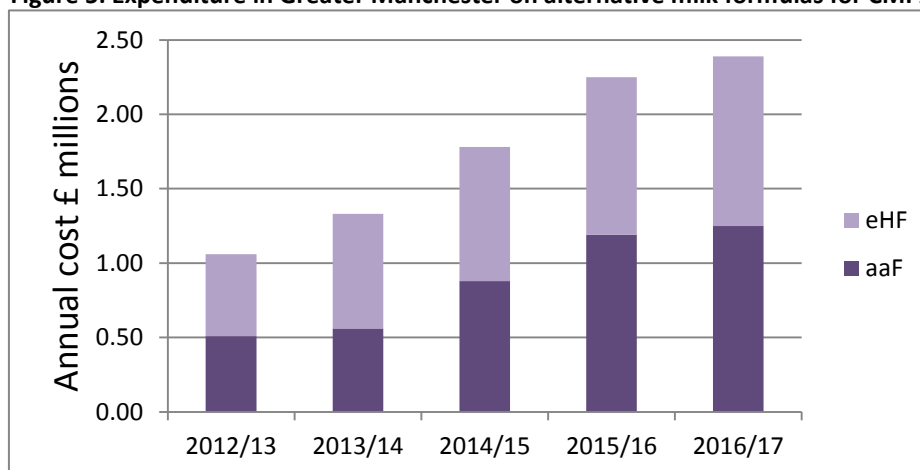
Initial treatment for confirmed CMPA is prescription of a replacement milk formula in which milk proteins have been broken down into smaller fragments. There are two main types: eHF and aaF. AaF costs more than two times that of eHF (Table 3).

Table 3: Two main types of replacement milk formula for use in infants with CMPA

	Extensively Hydrolysed Formulas (eHF)	Amino Acid Formulas (aaF)
Ingredients	Small milk protein fragments (peptides)	Basic amino acids only (highly refined)
Suitability	Tolerated by most (90%) infants	Only required by a small (10%) number (10%) of highly allergic infants
Cost (per year)	£9-11/tin (£1,430 per year per infant)	£23-29/tin (£3,770 per year per infant)

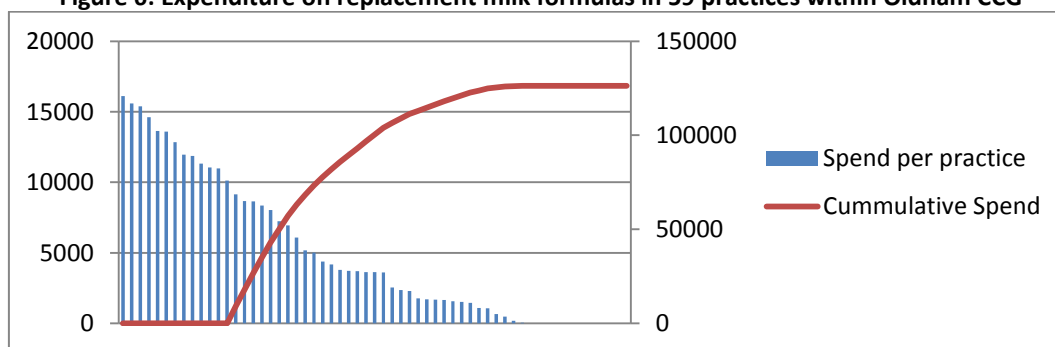
Our data shows that in the last five years there has been a doubling in the cost of prescriptions for both eHF and aaF replacement milk formula by Greater Manchester CCGs (£1.1 million, 2012-13 to £2.4 million, 2016-17) (Figure 5). The ratio of prescribing of the more expensive aaF to eHF is 1:1. As most infants have relatively mild CMPA and tend to outgrow it over the first two years of life, we expect that only 10% of infants should need the more expensive aaF. National milk allergy protein guidelines (MAP) were published in 2013⁴ but have not led to a decrease in replacement formula prescribing in Greater Manchester. It is too early to say if regional guidelines supported by training will reduce this prescribing trend.

Figure 5: Expenditure in Greater Manchester on alternative milk formulas for CMPA



We also obtained a detailed breakdown of replacement milk prescribing within our Oldham CCG pilot for the 12 months of 2016. Prescribing for the 59 GP practices was highly variable. Twelve practices prescribed no replacement milk formulas while 13 practices spent £10,000 to £16,000 pa as illustrated in Figure 6.

Figure 6: Expenditure on replacement milk formulas in 59 practices within Oldham CCG



In view of the variability in GP prescribing, we reviewed clinical records in relation to prescribing of replacement milk formula for 40 infants in high prescribing practices (Table 4). Key findings were:

- 24% of children had no planned follow-up
- 8% of infants were tolerating fresh cow's milk and thus did not need to be on a replacement formula
- 64% children were tolerating some dairy suggesting that they could be changed from an expensive aaF to a cheaper eHF (savings £180 per infant per month)
- 62% of GPs prescribed formulas with no input from paediatricians; 50% had no input from dietitians

Table 4: Characteristics and current status of 40 children on replacement milk formula for CMPA

Demographics	40 children age 3 – 125 months (median 12 months), 44% male 10 GP practices (Oldham, South Manchester, Chorlton)
Presenting symptoms	35% feeding problems/colic 35% vomiting/reflux/diarrhoea 20% rash, 10% acute allergy
Formula	64% on eHF, 36% on aaF time on formula 1 - 43 months (median 6 months)
Onset of symptoms	1 – 10 months (median 2 months)
Prescriber	62% GP 13% GP with input from dietitian 8% Emergency Department

	18% Paediatrician
Shared care	50% none 10% previous dietitian involvement, 40% current dietitian involvement
Current status	8% symptoms completely resolved, still on formula 43% of patients on aaF, tolerating some dairy products 41% not trying any dairy products in diet

For most patients, CMPA resolves in the preschool years and replacement milk formulas are therefore not required for life. **Reviewing the need to continue with a replacement milk formula requires time and understanding by both families and health professionals and is a key unmet need in infants with CMPA.**

2.3 Local impact on patient care

Improved knowledge amongst health professionals in primary care should lead to improved patient experience, with less delay in diagnosis and more rapid treatment. This project is currently too early in the implementation stage to demonstrate any improvement.

Families who attended group dietetic sessions very much appreciated the peer support in partnership with their dietitian and HV. They requested further group sessions and one potential output may be facilitating support groups in these local areas. Sessions will continue in order to refine this novel method of delivering healthcare.

The development of our website providing access to accurate and reliable information is very important and has been designed with the input of our support groups and other families.

3 Impact on workforce/staff/team

Working across organisational boundaries streamlined the delivery of our project outcomes. Having a common vision and values kept the group focused despite numerous challenges. The dogged determination of our members allowed us to achieve the current goals. For a list of key team members see Appendix 6. The support and input from our families and charities was invaluable. Special mention needs to be made of our patient representatives Mr. Nick Stafford and Dr. Michelle Byrne to ensure that the patient voice was central to the project and for inspiring and motivating our team.

Group members shared tools and applications with their colleagues and these have been disseminated to all members of our Network. During the project, there has been an increase in the number of organisations and professionals actively engaging and collaborating with our Network, with increased input from CCGs other than our Oldham pilot, medicines optimisation leads, community and hospital dietitians, HVs and other GPs with an interest in allergies or service delivery.

4 Project progress

4.1 Clinical outcomes and revealed efficiencies

Streamlining replacement milk formula prescribing by GPs via the EMIS patient record system

EMIS Health is the electronic patient record system used by many GPs in England and the predominant system used in the North West. We have created CMPA templates which may help to empower GPs, optimise their management of CMPA and prescribing of replacement milk formulas. We planned to test the

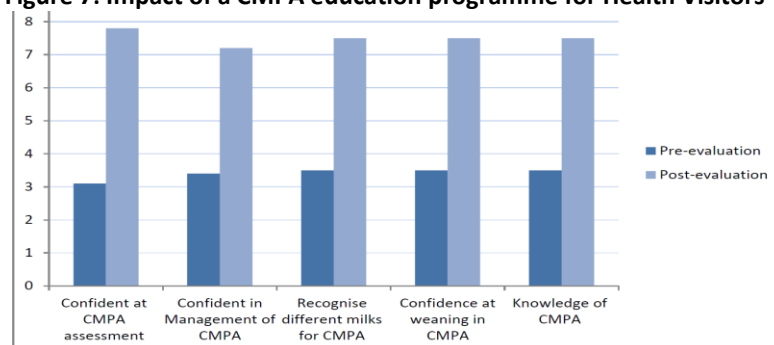
template in our Oldham pilot. The development of the template continues to be a learning path. Table 5 illustrates the stages required to produce a workable product.

Table 5: PDSA summary of development of a workable EMIS template for management of CMPA

Date	Description	Learning
Q4 2015 Version 1	<ul style="list-style-type: none"> • PLAN Concept and Feasibility study: MSc project. • DO Develop first draft of template. EMIS form uploaded onto GP computers and trialled with 9 GPs in 5 North West surgeries 	<ul style="list-style-type: none"> • STUDY Significant improvement in GP confidence after using template 2/10 --> 6/10. • ACT Some GPs do not see children with CMPA. The relevance of the EMIS form to them was questioned - delivery needed more thought/focus
Q1 2016 Version 2	<ul style="list-style-type: none"> • PLAN Decide on triggers for template: "CMPA" or "infant feeding problem" • DO Template refined in line with national MAP guidelines. Supports new and follow-up patients 	<ul style="list-style-type: none"> • STUDY Problem that NWPAN team did not have direct access or experience to EMIS. • ACT Further EMIS form refinements needed to be done with close collaboration with GP partners
Q2-Q3 2016 Version 3	<ul style="list-style-type: none"> • PLAN Further refinement of template • DO Clear pathway developed from time patients were identified as having CMPA 	<ul style="list-style-type: none"> • STUDY Form still too complex for most GPs • ACT Further simplification assuming less knowledge by GPs
Q4 2016 Versions 4a and 4b	<ul style="list-style-type: none"> • PLAN Split template for new and follow-up patients • DO One template for GPs with an interest in allergy: supporting them with diagnosis and management of new patients. Second template for all GPs prescribing replacement milk formula 	<ul style="list-style-type: none"> • STUDY Template now easier to use • ACT Training still needed and template not triggered by specific prescribing of milk formula
Q1 - Q2 2017 Version 5a and 5b (Appendices 7/8: EMIS screen shots)	<ul style="list-style-type: none"> • PLAN Triggering programmes developed alongside EMIS templates • DO Identify additional support regarding how triggers can be added to GP computers 	<ul style="list-style-type: none"> • STUDY Triggering protocol blocked by EMIS central Currently EMIS protocol files need to be uploaded onto each GP computer • ACT Further discussions with EMIS user group and CCG EMIS leads to get round impasse with triggers
Current status	<ul style="list-style-type: none"> • PLAN Focus on overcoming current barriers to automatically uploading latest EMIS triggers EMIS web now available for HVs • DO Test of template in Oldham with both GPs and HVs. Additional interest from North Manchester and Warrington 	<ul style="list-style-type: none"> • STUDY Even with a simple workable EMIS template will need input from regional Medicines Optimisation Team to promote and encourage GPs to use the system 3 additional CCGs are testing template in their practices

We assessed confidence and knowledge of HVs in our pilot Oldham CCG before and after providing a CMPA education session and an accompanying resource pack. The results show a marked improvement in all scores for a health visitor educational programme (Figure 7).

Figure 7: Impact of a CMPA education programme for Health Visitors



The findings above suggest that at present there is a lack of knowledge and on-going experience by many primary care clinicians which would allow them to effectively diagnose and manage infants with CMPA, which can be partly reversed by direct educational sessions.

As well as studying the confidence and ability of GPs and HVs to manage CMPA, we also looked at potential input from both allied healthcare professions (dietitians, nurse practitioners and health visitors) in partnership with the patients' families.

Group dietetic sessions: patients working in partnership with professionals to streamline the service

"Information calms you down. With the right information from the right person an individual can become empowered to take control. It should be practical. It needs to work! It takes time to give. Professionals need to make time to listen to our story. Management plans need to be made in partnership with patients. We don't like to be told what to do." Parent, Manchester PPI event, June 2016

We brainstormed how we might take these comments and ideas forward to better manage infants with CMPA. Traditionally all consultations between the family and the dietitian are one-to-one. We developed a new approach to empower families to work together with each other and their dietitians in order to more effectively manage their infants CMPA and at the same time promote more rapid resolution of the CMPA. Group dietetic sessions were set up for infants with CMPA where 5–10 families came together with a dietitian, and on some occasions also a HV, for both professional and peer support. One-to-one sessions with dietitians typically take 30 – 60 minutes. With group sessions 5 – 10 families could be seen in 90 minutes increasing the throughput from 2 to 5 fold and at the same time improving the quality of the session by allowing participants to benefit from hearing other families' stories. The development of our group dietetic sessions and current status are detailed in Table 6 below.

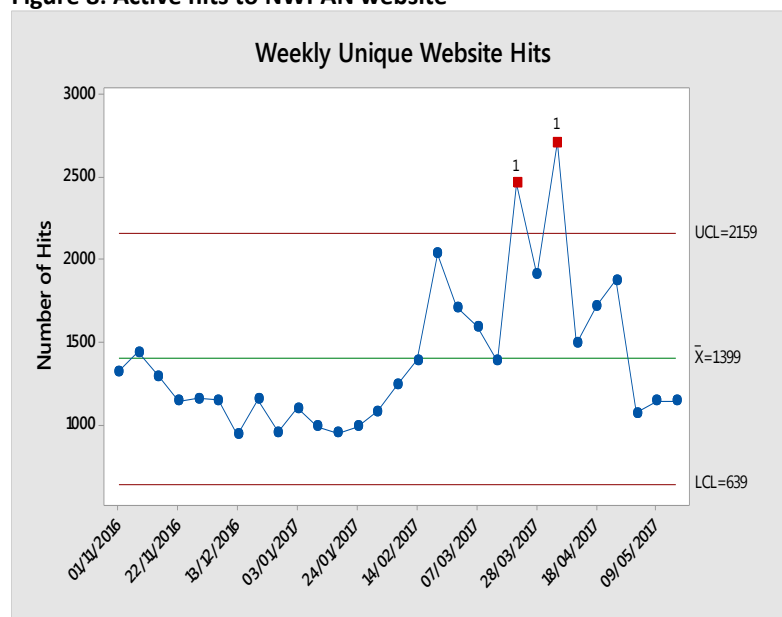
Table 6: PDSA summary of the development of group dietetic sessions

Date	Description	Issues with feasibility
Q4 2015 - Q2 2016	<ul style="list-style-type: none"> PLAN/DO <p>Nine group dietetic sessions conducted for families of infants with CMPA at University of South Manchester NHS Foundation Trust. 69 referrals. 58% (40) attended; 4 per session. 85% extremely satisfied.</p>	<ul style="list-style-type: none"> STUDY <p>Concept presented at allergy network meeting. Interest from a number of regional dietitians.</p> <ul style="list-style-type: none"> ACT <p>Results shared on implementation.</p>
Q1 2017	<ul style="list-style-type: none"> PLAN/DO <p>National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) grant application to roll group dietetic sessions out across the North West</p>	<ul style="list-style-type: none"> STUDY <p>Unsuccessful as application not marketed as 'research' but rather 'service development' and therefore fell outside the remit of the scheme.</p>

Date	Description	Issues with feasibility
Q2 2017	<ul style="list-style-type: none"> • PLAN Group dietetic sessions for families of infants with CMPA, Oldham community. • DO Two group sessions. 16 referrals 	<ul style="list-style-type: none"> • STUDY Running well. Able to cover CMPA demand. Very good patient experience.
Current status	<ul style="list-style-type: none"> • PLAN Meeting planned (February 2018) to drive group dietetic sessions forward through the network. 	<ul style="list-style-type: none"> • STUDY A number of other centres interested in developing their own group sessions.

Web based resources for families and healthcare professionals

Figure 8: Active hits to NWPAN website



Our network launched its new website for professionals in March 2017 containing resources and patient information leaflets. We tracked active interactions with the website. The average number of hits were 1,400 per week, with two peaks linked to educational events (Figure 8). Focus has now turned to developing a Patient zone directed by our patient representatives with input from support groups and families. Launch date: Autumn 2017.

4.2 Progress made against project plan

This initiative is still very much *a programme in development*. Although the initial application aimed to achieve key measurable outcomes within 1 – 2 years, the wisdom and experience of the FHP was that it should be a learning process where ideas are not fully formed at the outset but grow and develop over the period of programme through interaction and discussion with the team, colleagues from other FHP teams, the RCP FHP staff and with new patients and colleagues. This has certainly been our experience as in our PDSA summarised in Tables 5 and 6.

It was hoped that EMIS templates would now be up and running in our Oldham CCG pilot and that we would have collected data to show the effectiveness of this and other initiatives. The EMIS forms are on the verge of being tried by GPs, but the widescale effectiveness or otherwise are still to be determined.

The success of our ambitious programme now relies on the on-going support of colleagues in the north west and nationally. Any success of this programme to date is because of the passion and enthusiasm of all those who we have worked with, from those intimately tied up in driving the project to those who may appear to be on the outskirts but have become very much our partners driving improvement of children's allergy services.

We acknowledge that this programme cannot succeed without challenging dogma and inspiring others. Paradigm shifts in thinking and practice of those yielding with power are needed if the allergy epidemic (perceived and real) is to be defeated.

We would like to thank everyone who has been and continues to be involved - without whose contribution it would not have been possible to reach this stage. Our thanks go to Professor Frank Joseph, Hannah Bristow and improvement analyst Matt Tite from the RCP Future Hospital Programme for their advice, unwavering support and patience.

5. Return on investment

The results from this project suggest that alongside significant improvements to patient experience, cost savings can be made in terms of optimising replacement milk formula prescribing and throughput of patients by dietiticians. This section provides two examples of conservative estimate of these cost savings based on the information presented above. Outcomes would be measured by (1) cost of replacement milk formula per CCG based on type of formula prescribed and time infants were on the formulas, (2) throughput of patients by dietitian, (3) family satisfaction (Appendix 9). Key assumptions are as follows:

1. GPs, HVs and Medicines Optimisation teams would help identify relevant infants with CMPA on replacement milk formula as part of their routine work and refer families for review.
2. The equivalent of 2 hours of band 7 (£30 per hour) has been assumed to be necessary to review each patient. To date this has required input from a dietitian.
3. Recommendations would be in line with CMPA guidelines from the Greater Manchester Medicines Optimisation Group and then implemented.
4. For a 12-month-old infant, the cost of one year of eHF formula is £648, and for aaF £1,656 (VAT excluded).

5.1 Example 1 Single GP practice level

At one practice, 4 infants were receiving aaF replacement milk formulas for CMPA at a cost of £10,274 per annum. If the four infants were reviewed by a community dietitian and **one infant was assessed to no longer require their milk formula, the annual cost saving would be £2,328.**

5.2 Example 2 Multiple GP practice level

As shown in page 7 (Table 4) above, 40 infants with CMPA on replacement milk formula from various GP practices were reviewed. **Cost saving calculated after reviewing the clinical histories of these 40 infants if replacement milk prescribing was optimised through dietetic sessions, in line with the above assumptions would be £17,058 per annum.** Table 7 provides a breakdown of the calculations.

Table 7: Breakdown of cost savings from optimising replacement milk prescribing in a cohort of 40 infants

40 infants with CMPA on replacement milk formulas	Investment	Saving
Band 7 2 hours per patient	£2,400	
4 infants: no change made/did not engage		£0
3 infants on eHF: symptoms had resolved, they no longer required formula		£2,106
17 Infants on aaF: all tolerating some dairy products		
- 3 (20%) stayed on aaF		£0
- 9 infants changed from aaF to eHF		£9,072
- 5 patients no longer required a replacement formula		£8,280
TOTAL	£2,400	£19,458

Extrapolating this to a CCG level - if we assume that the even the smaller CCGs would have 80 patients with similar clinical profiles - this would generate a saving of **£34,116 per annum**. This does not take into account the savings in specialist and dietetic referrals to hospital services, which if taken into account would increase the savings further.

Engagement with families highlighted the fact that many were afraid of changing or withdrawing replacement milks. Accessible dietetic support was important and group sessions would provide further reassurance that this had been successfully done in their infants with CMPA. Information from two group dietetic pilots (Oldham – community based and South Manchester – hospital based) suggests that five families could be seen in a 90-minute session by one dietitian. If a one-to-one session and follow-up normally takes 40 minutes this would double throughput.

6 Future plans

The key recommendations that come from our work are listed in Table 8. The NWPAN will continue to develop and take this forward to regional partners, initially in Greater Manchester and then more widely in the North West. Our network is ideally placed to work with partners and our families to deliver excellence and sustainable allergy services for our children.

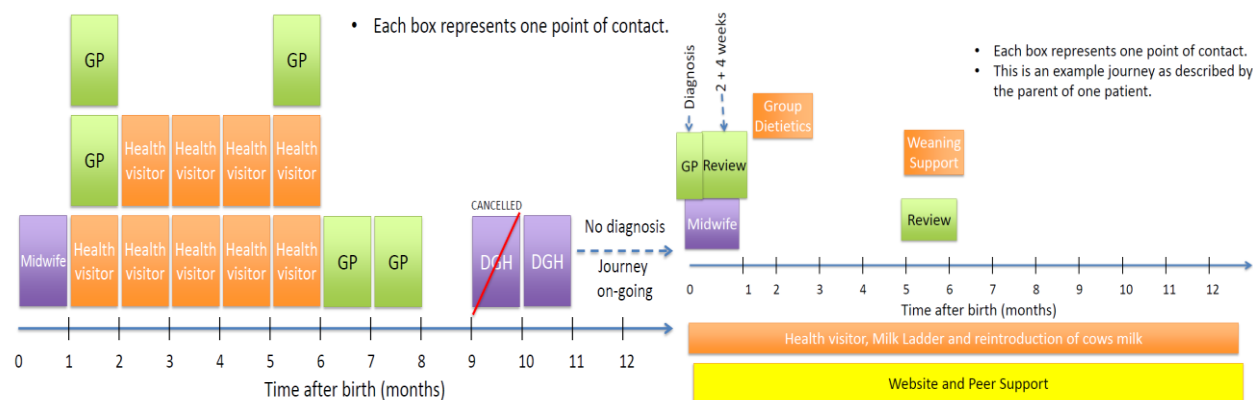
Table 8: Future plans

Problem	Proposed way forward	Expected outcome – Healthcare	Expected outcome – Family
Lack of public knowledge regarding children's allergies, including CMPA.	GPs, HVs to provide more effective advice to families of infants with CMPA with the support via EMIS e-forms and Network website. Development and Promotion of Patient zone on NWPAN website.	Reduction in CMPA by 50% and more rapid resolution of disease. Reduced demand on NHS services. Cost saving of milk formula by at least 50%.	Reduced parental anxiety. Reduced nutritional and growth problems of infants and breast-feeding mothers.
Inappropriate prescribing of costly milk formulas by GPs with little or no knowledge or experience.	EMIS prompt will support GPs. Additional input is required from CCG Pharmacists and dietitians.	Reduction in eHF/aaF prescribing by 50%. More rapid resolution of CMPA. Reduction in referrals to secondary/tertiary care.	More effective management of CMPA. Reduced burden of CMPA in the community. More rapid resolution of disease.
Allergy promoting behaviour by encouraging avoidance of dairy products in infants who are tolerant to these foods.	Promote consumption of dairy products in amount and form that infants tolerate.	Reduced burden of disease. More rapid resolution of CMPA.	Reduced burden of CMPA. Reduced anxiety and restrictions on lifestyle at

Dietetic demand outstripping supply. Despite professional advice, families/carers often not confident enough to engage with advice given.	Develop and streamline group dietetic sessions for selected families to allow peer-support. More effective use of dietitians' time in managing infants with CMPA.	Timely access to specialist knowledge and replacement milk formulas. Reduction in spend on replacement milk formulas. Reduce the need to contact GP for replacement milks.	home and nursery. Greater confidence and ability access support as needed. Resources to ensure children gain sufficient nutrients and confidence in progressing treatment.
Busy clinicians do not have time to have resources at their fingertips when a child presents. Clinicians may see 1-2 children per year.	Replace guidelines with appointments linked to EMIS e-management pathways.	Knowledge and resources easily accessible when required.	Families have confidence in the professionals who they liaise with.

Implementation of the above recommendations will require changes to current practice. Empowering GPs with the help of EMIS will need to be complemented by input from practice HVs, community dietitians and pharmacists. Medicines optimisation teams already have regular review sessions with GPs in their CCG and it should be within their current remit to highlight and explain potential milk formula overspends in relation to CMPA guidelines. An example of how the patient journey may be streamlined with diagnosis within a few weeks and introduction of some dairy by 4 months old and milk by 9 months (Figure 9). Direct patient contact will be complemented with information for both professionals and patients from our website. Envisaged improvements in patient experience are highlighted in the box below. In order to deliver this it needs all parties to work in partnership with the families. Changes to patient practice would need to be implemented by providing the public with more evidence based messages to correct false perceptions of allergies and its management.

Figure 9: Current and new suggested pathways for management of CMPA in infants



- Reduce number of infants labelled with CMPA by one third and halving time to resolution of symptoms
- Improve quality of care and family experience
- Provide primary care of CMPA by empowered GPs and HVs with local and regional e-resources
- Doubling throughput of dietitians seeing infants with CMPA using group sessions, leading to reduced waiting times and improving patient experience
- Halving replacement milk formula prescribing costs with an estimated national saving of £24 million

7 References

1. **Provision of Allergy Services, House of Commons Health Committee's Report, Sixth Report of Session, 2003-2004
2. NICE. *Food allergy in children and young people*. NICE, 2011
3. **Mooney JS, *et al.* How we developed eForms: an electronic form and data capture tool to support assessment in mobile medical education. *Med Teach* 2014;36:1032-7.
4. Venter C, *et al.* Diagnosis and management of non-IgE-mediated cow's milk allergy in infancy – a UK primary care practical guide. *Clin Transl Allergy* 2013;3:23.

***peer-reviewed publications with input from NWPAN team members*

APPENDICES

[Appendix 1: Patient and Public Engagement Strategy](#) (full copy available on request)

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The Anaphylaxis Campaign and the North West Paediatric Allergy Network is looking at the journey that children and their carers take from the point where an allergy is first considered and would like your help

**Monday 4th July
@ 7 – 8.30 pm**

**St John's Church, Irlam Road, Flixton
Manchester, M41 6AP**

Join us to share your experiences in small focus groups and help shape the future of the service. During this session the consultants and managers involved in these services would like to hear about your experiences of the care you received including:

- What has gone well?
- What areas could be improved?
- What are the challenges that children and parents face?
- What is most important to you?

The Anaphylaxis Campaign is helping the North West Paediatric Allergy Network with this project so if you are able to attend please contact debbie@anaphylaxis.org.uk to book a place or for more info. If you are not able to participate in this session but would like to contribute please also get in touch and we will do our best to arrange to speak to you at an alternative time.

Please note this session will be run as a focus group as opposed to the more traditional support group you may have attended in the past. The Manchester support group programme continues in August, full details of upcoming sessions can be found at <http://www.anaphylaxis.org.uk/product/support-group-manchester/>

Registered Charity Number 1085527

Appendix 3: Questionnaire for assessing confidence and knowledge of GPs regarding allergies in children



North West Allergy and Clinical Immunology Network

Questionnaire for health care professionals looking after children with allergies

We are part of a project to help primary care health care workers become more involved in their treatment, and we would be grateful if you would take a couple of minutes to fill out this form to gauge your present level of comfort and knowledge managing allergies.

Postcode of your Practice

Date

YOUR CONFIDENCE IN MANAGING CHILDREN WITH ALLERGIES

As a healthcare provider, how do you feel about the following statements:

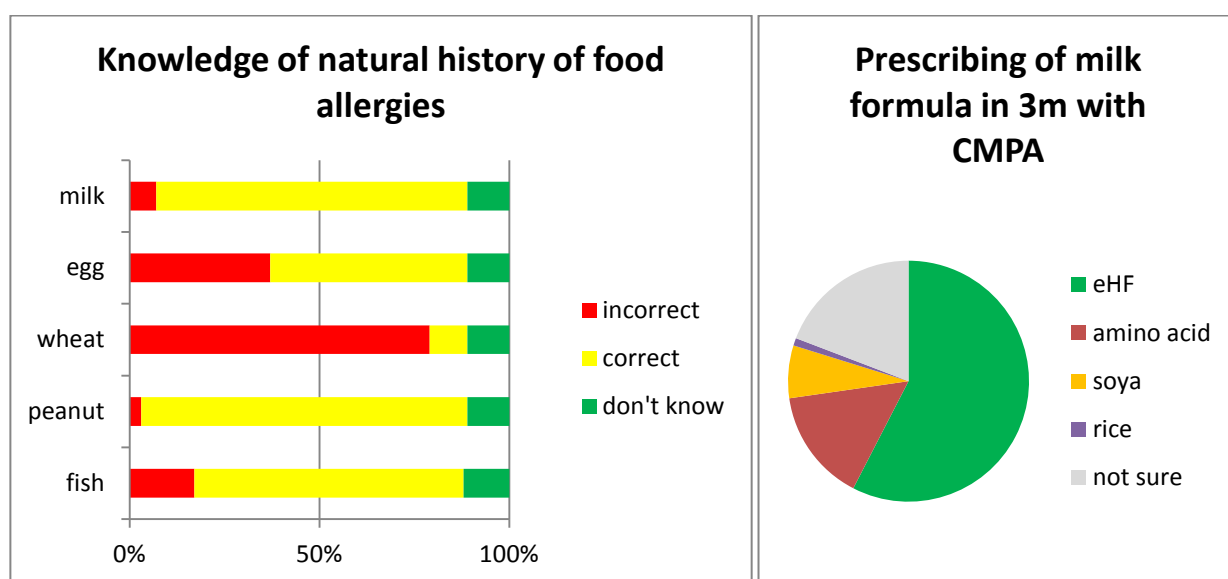
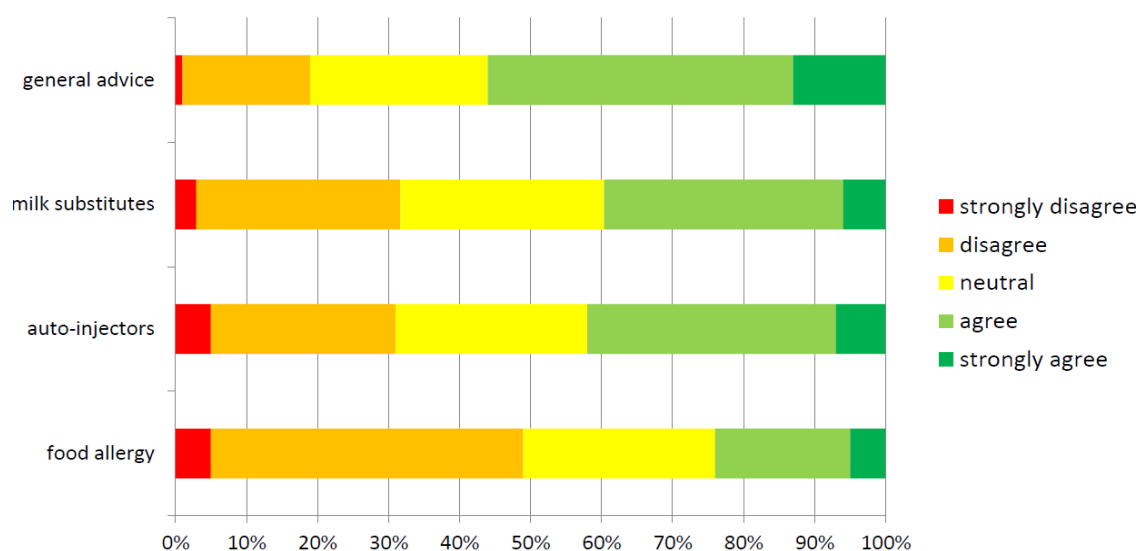
	strongly agree	agree	neutral	disagree	strongly disagree
I feel confident providing general advice to patients presenting with allergies (and their parents)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident providing advice on milk substitutes to parents of children presenting with cow's milk protein allergy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident checking the parents' competence of patients to whom I am providing repeat prescriptions for adrenaline auto-injectors e.g. EpiPens	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel confident providing advice on reintroducing foods to check if patients have outgrown their food allergies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

YOUR KNOWLEDGE OF THE NATURAL HISTORY, ASSESSMENT AND MANAGEMENT OF CHILDREN WITH ALLERGIES

Please tick ALL answers you think are CORRECT

Which of the following food allergies are children likely to outgrow?	Egg <input type="checkbox"/> Fish <input type="checkbox"/> Milk <input type="checkbox"/> Peanuts <input type="checkbox"/> Sesame <input type="checkbox"/> Wheat <input type="checkbox"/> not sure <input type="checkbox"/>
Which of the following are signs of anaphylaxis and would be an indication for adrenaline?	Cough <input type="checkbox"/> Facial swelling <input type="checkbox"/> Faintness <input type="checkbox"/> Urticaria <input type="checkbox"/> Vomiting <input type="checkbox"/> Wheeze <input type="checkbox"/> not sure <input type="checkbox"/>
In treating a patient with anaphylaxis, adrenaline should be administered . . .	Deltoid muscle <input type="checkbox"/> Intravenously <input type="checkbox"/> Subcutaneously <input type="checkbox"/> Thigh muscle <input type="checkbox"/> not sure <input type="checkbox"/>
Which milk formula would you choose in a 3 month old infant presenting with allergy to cow's milk?	Aptamil pepti or another extensively hydrolysed formula <input type="checkbox"/> Goat's or sheep's milk <input type="checkbox"/> rice milk <input type="checkbox"/> Soya milk formula <input type="checkbox"/> Neocate or another amino acid formula <input type="checkbox"/> not sure <input type="checkbox"/>
Which of the following predicts a <u>higher</u> risk of future anaphylaxis to foods?	asthma <input type="checkbox"/> nut allergy <input type="checkbox"/> previous anaphylaxis <input type="checkbox"/> teenager <input type="checkbox"/> use of ACE inhibitors <input type="checkbox"/> not sure <input type="checkbox"/>

Confidence managing children with allergies



Appendix 5: Questionnaire for assessing confidence and knowledge of HVs regarding allergies in children

YOUR CONFIDENCE IN MANAGING CHILDREN WITH ALLERGIES

As a healthcare provider, how do you feel about the following statements:

* 1. I feel confident providing general advice to patients presenting with allergies (and their parents)

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly disagree

* 2. I feel confident in the recognition of common allergic conditions and their presentation

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

* 3. I feel confident providing advice on milk substitutes to parents of children presenting with cow's milk protein allergy

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

* 4. I feel confident giving advice on common triggers in an individual's environment in relation to their allergy

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

* 5. I feel confident recognising the symptoms and features of prophylaxis/acute allergic reaction

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

* 6. I feel confident giving advice on milks/food in relation to allergy

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

* 7. I feel confident providing advice on reintroducing foods to check if patients have outgrown their food allergies

☐ strongly ☐ agree ☐ neutral ☐ disagree ☐ strongly agree

YOUR KNOWLEDGE OF THE NATURAL HISTORY, ASSESSMENT AND MANAGEMENT OF CHILDREN WITH ALLERGIES

Please tick all answers you think are CORRECT

8. Which of the following food allergies are children likely to outgrow?

- ☐ Egg
- ☐ Fish
- ☐ Milk
- ☐ Peanuts
- ☐ Sesame
- ☐ Wheat
- ☐ not sure

9. What are the signs & symptoms of an allergy?

- ☐ Crying & unsettled
- ☐ Raised, itch rash
- ☐ Flare of eczema
- ☐ Loose stools
- ☐ Swelling of lips & eyes

* 10. How soon after eating a food do allergy symptoms present?

- ☐ Within 0-1hr
- ☐ Within 1-2hr
- ☐ Within 2-6hrs
- ☐ Within 6-12hrs
- ☐ Within 12-24hrs

* 11. Which milk formula would you expect an infant presenting with allergy to cow's milk to have been using/prescribed?

- ☐ Extensively hydrolysed formula eg: Nutramigen
- ☐ Goat's or sheep's milk
- ☐ Rice milk
- ☐ Soya milk formula
- ☐ Amino acid formula eg: Neocate
- ☐ not sure

12. Which of the following predicts a higher risk of future anaphylaxis to foods?

- ☐ asthma
- ☐ nut allergy
- ☐ previous anaphylaxis
- ☐ teenager
- ☐ use of ACE inhibitors
- ☐ not sure

Done

Appendix 6: Team Members

Original Application Members

Name	FHP Role: Title and Organisation
Dr Peter Arkwright	Clinical Lead, North West Paediatric Allergy Network & Paediatric Allergist, Royal Manchester Children's Hospital
Dr Michelle Byrne	Patient Representative
Suzanne Dixon	Project Manager, Network Manager, North West Allergy & Infection ODN
Dr Mudiur Gopi	EMIS support & General Paediatrician , East Cheshire NHS Trust
Dr Harpal Hunjan	GP, Special Interest in Allergy, Clinical Director for Children, Oldham CCG
Dr Colin Lumsden	Academic Paediatrician/IT support, University of Manchester
Laurie Niland	Network Administration, North West Paediatric Allergy Network
Nick Stafford	Patient Representative
Dr Vibha Sharma	Paediatric Allergist, Royal Manchester Children's Hospital
Jane Taylor	Specialist Nurse, East Cheshire NHS Foundation Trust
Sue Lunt	Executive Sponsor: Hospital Director, Royal Manchester Children's Hospital

Oldham pilot key contacts (not listed above)

Name	Title, Organisation
Nigel Dunkerley	Locality Medicines Optimisation Lead for Oldham CCG
Siobhan Ebdon	Head of Children's Services ,Oldham Community Health Services
Chloe Hardman	Business Partner, Glodwick Cluster, Oldham CCG
Carly Harper	Oldham CCG Engagement Officer
Dr Prakash Kamath	Clinical Director/ Paediatrician, Pennine Acute Hospitals NHS Trust
Zita Macdonald	Community Paediatric Dietitian, Penine Care NHS Foundation Trust
Ian McKay	Business Development Manager, LLP Oldham
Jeanette Moores	Health Visitor, Bridgewater Community Healthcare NHS Foundation Trust
Anna Pracz	Medicines Optimization Pharmacist, Greater Manchester Shared Services
Pushpa Shaw	Nurse Practitioner
Ashlin Thampy	Prescribing Support Pharmacist, Greater Manchester Shared Services

Charlotte Veitch	Dietitian, Pennine Care NHS Foundation Trust
Jane Wilson	Nutrition and Dietetic Service Manager for Bury and Oldham

Other key contacts

Name	Title, Organisation
Dr Connie Chen	GP, Medicines Optimization and Children's Pathway Lead, Manchester CCG
Dr Tim Franks	GP, Bowland Medical Centre, Wythenshawe
Dr Kavitha Kanakanti	GP, Eastlands MC
Dr Neha Kaushik	Academic GP trainee, Bowland Health Centre
Susan Pavey	Dietitian, Lead for Dietetics, Pennine Care NHS Foundation Trust
Dr Naveen Rao	Paediatric Lead for Allergy, South Manchester NHS Foundation Trust
Lynne Regent/Mandy East	Chief Executive/National Coordinator, Anaphylaxis Campaign
Susan Sumner	111 Clinical Services Manager, North West Ambulance Service NHS Trust
Lee Tomlinson	Dietetic Team Lead, Paediatrics, South Manchester NHS Foundation Trust

Future Hospital Programme, Royal College of Physicians

Name	Title, Organisation
Prof. Frank Joseph	Future Hospitals Officer
Hannah Bristow	Future Hospital Programme Coordinator
Matt Tite	Improvement Analyst

Appendix 7: Version 5 CMPA EMIS Template illustrating prompt on prescribing replacement milk formulas and template for extensively hydrolysed formula (eHF)

The screenshot displays the EMIS interface for a patient named Mickey Mouse. The main window shows a consultation history with a 'Problem' tab selected, indicating an 'Infant feeding problem'. A dialog box prompts the user: 'Do you want to launch the Suspected Milk Allergy Template?'. The right-hand pane shows a 'Summary' section with 'Diary' and 'Problems' tabs, and a 'Medication' list. At the bottom, there is a 'Latest Contacts' section and a 'Summary' button. The interface also shows patient details like 'MOUSE, Mickey (Mr)', 'Born 01-Jan-1950 (67y)', 'Gender Male', and 'NHS No. 111 111 1111'.

Active **MOUSE, Mickey (Mr)** Born **01-Jan-1950 (67y)** Gender **Male** NHS No. **111 111 1111** Usual GP **HODSON, Zoe (Dr)** PDS

Preferred Name **Jimmy**

» **12.4.17 FU template for patient on eHF** «

Follow up template for Cow's milk protein allergy

This template has been developed by the North West Paediatric Allergy Network working across all tiers of the service to help you to decide if the child can come off their milk formula or needs specialist input. For milk allergy patient information leaflet click the link below.

[Cow's milk allergy information leaflet](#)

Extensively Hydrolysed Formulas (eHF): Althera/Aptamil Pepti 1/Aptamil Pepti 2/Nutramigen LGG1/Nutramigen LGG2/Similac Alimentum

Extensively hydrolysed formulas are the first choice for children with Cow's milk protein allergy. If the child is over six months and tolerates soya products, change to soya alternative.

For patients on Extensively Hydrolysed Formulas

☐ Patient is on Extensively Hydrolysed Formula

PLEASE SELECT THE FORMULA THE CHILD IS TAKING

Extensively hydrolysed formula (eHF)

☐ Management advised:

Management for infant/young child on extensively hydrolyzed formula (eHF)

Milk prescribed (if applicable)

[Click for Milk Ladder information leaflet](#)

Latest Contacts

NHS Clinical Practitioner | KAUSHIK, Neha (Dr) | Location: Bowland Medical Practice | In Consultation | Alerts

Appendix 8. Version 5 CMPA EMIS Template illustrating prompt on prescribing replacement milk formula and template for amino acid formula (aaF)

Active **MOUSE, Mickey (Mr)** Born **01-Jan-1950 (67y)** Gender **Male** NHS No. **111 111 1111** Usual GP **HODSON, Zoe (Dr)** PDS

Preferred Name **Jimmy**

View -> My Record « Consultation **1. <No Problem>** » Summary

Yes / No Prompt

Cow's milk protein allergy often resolves as children get older. Specialist milk formulas, particularly amino acid formulas (e.g. neocate), are costly. The 'SPECIALIST MILK FORMULA FOLLOW UP TEMPLATE' will help you to decide whether the child still needs this milk formula. If the child has not been reviewed in the last few months PLEASE ARRANGE REVIEW. Would you like to launch the template now?

External Views

Summary Care Re...
Graphnet Portal

Procedure

- Test Request
- Referral
- Document
- Allergy

08-Jun-2017 GP Surgery (Bowland Medical Practice) KAUSHIK, Neha (Dr)

Problem **Medication requested** (Review)

History Medication review due

Referral Other referral (16-Jun-2017) To: Other

Document Referral Letter (16-Jun-2017) @ (16-Jun-2017) for Other referral

08-Jun-2017 GP Surgery (Bowland Medical Practice) KAUSHIK, Neha (Dr)

Problem **MRC Breathlessness Scale: grade 3** (Review)

Latest Contacts

Summary

MOUSE, Mickey (Mr)

- Signs of infection and prescribed ...
- Mycophenolate monitoring advised
- Methotrexate monitoring advised
- Avoiding Unplanned Admissions R...
- AUA Review Due
- Severely Frail

NHS Clinical Practitioner | KAUSHIK, Neha (Dr) | Location: Bowland Medical Practice

Active

MOUSE, Mickey (Mr)

Born 01-Jan-1950 (67y)

Gender Male

NHS No. 111 111 1111

Usual GP HODSON, Zoe (Dr)

PS

View -> My Record

Consultation

1. <No Problem>

Summary

Yes / No Prompt

Cow's milk protein allergy often resolves as children get older. Specialist milk formulas, particularly amino acid formulas (e.g. neocate), are costly. The 'SPECIALIST MILK FORMULA FOLLOW UP TEMPLATE' will help you to decide whether the child still needs this milk formula. If the child has not been reviewed in the last few months PLEASE ARRANGE REVIEW. Would you like to launch the template now?

Yes

No

External Views

Summary Care Re...

Graphnet Portal

Procedure

Test Request

Referral

Document

Allergy

08-Jun-2017

GP Surgery (Bowland Medical Practice)

KAUSHIK, Neha (Dr)

Problem

Medication requested (Review)

History

Medication review due

Referral

Other referral (16-Jun-2017) To: Other

Document

Referral Letter (16-Jun-2017) (16-Jun-2017) for Other referral

08-Jun-2017

GP Surgery (Bowland Medical Practice)

KAUSHIK, Neha (Dr)

Problem

MRC Breathlessness Scale: grade 3 (Review)

Latest Contacts

Combined oral contra...

Infant feeding problem

Cow's milk allergy

Medication

Acute

Amoxicillin • Aptamil Pepti 1

Aptamil Pepti 1

Aptamil Pepti 1

Aptamil Pepti 1

Aptamil Pepti 1

MOUSE, Mickey (Mr)

Signs of infection and prescribed ...

Mycophenolate monitoring advised

Methotrexate monitoring advised

Avoiding Unplanned Admissions R...

AUA Review Due

Severely Frail

NHS

Clinical Practitioner

KAUSHIK, Neha (Dr)

Location: Bowland Medical Practice



Appendix 9. Family satisfaction survey.





North West Allergy and Clinical Immunology Network

Dear Parents / Carers,

We are currently looking to improve services for children who have allergies. We would be grateful if you would answer the following questions, thinking of when you last met up with your health visitor, doctor or dietitian.

How satisfied are you?		Please circle				
		Very dissatisfied 	Dissatisfied	Unsure (neither)	Satisfied	Very Satisfied 
1	... that as a result of your consultation, you understand your child's allergies?	1	2	3	4	5
2	... that your concerns were met and questions answered?	1	2	3	4	5
3	... that you have a clear written management plan for nursery, school, family and friends?	1	2	3	4	5
4	... that you understand whether or not your child's allergy will improve as they get older?	1	2	3	4	5
5	... that you know where to obtain more information if you have further queries?	1	2	3	4	5

How confident are you?		Please circle				
		Very unconfident 	Not confident	Unsure (Neither confident or not confident)	Confident	Very confident 
1	... that you know how to avoid your child having further allergic reactions?	1	2	3	4	5
2	... that you know how to recognise an allergic reaction?	1	2	3	4	5
3	... that you know how to manage a reaction?	1	2	3	4	5
4	... that you can answer questions about your child's allergies?	1	2	3	4	5

Thank-you. Please place your response in the box provided.

If you have any questions or suggestions on how we could improve our service, or what to get involved please write them overleaf or contact Suzanne Dixon, Suzanne Dixon, Network Manager suzanne.dixon@nwl.nhs.uk



Royal College
of Physicians



Future Hospital
Programme