

Cow's Milk Protein Allergy Infant Feeds

Analysis of Public and Health Professional Engagement

March 2018

Purpose

The six CCGs wanted to capture as wide a range of views, concerns, support and information as possible, relating to the proposal to introduce a voucher scheme to part subsidise infant formula milk for those infants up to the age of 13 months who have cow's milk protein allergy (CMPA). This included views of health and social care professionals as well as affected families and the general public.

Executive Summary

More than 85% of the health professionals and over 70% of the public who completed the survey, thought that the CCGs should replace the free prescription CMPA infant formula milk with a voucher scheme to cover part of the cost so that it cost a similar amount to standard infant formula milk.

Of the 80 public respondents who had either at present, or had in the past, had a child or family member with Cow's Milk Protein Allergy, 62% were in favour of the voucher scheme, with 30% wanting the process to remain as present, with families not contributing at all to the cost.

There were a number of key issues which both the public and the health professionals thought that the CCGs should take into consideration, including:

- the administrative burden of a voucher process on GPs and pharmacies
- concerns about changing feeds and the 13 month cut off
- the affordability for low income families
- breastfeeding issues
- CMPA as a medical condition which needs to be treated
- the inconvenience for families
- effective communications with families about the voucher scheme.

Background

At the moment across the whole of Staffordshire, CCGs spend around £1 million each year on funding alternative infant feed products for babies and children who have cow's milk protein allergy (CMPA). This means that parents and carers of those infants pay nothing for these alternative products but are eligible to claim them via free prescriptions.

To help the CCGs to make things fairer for everyone, and to save money, we are considering replacing free prescription CMPA infant formula milk with a voucher scheme.

This would involve GPs issuing a voucher for part of the cost of each 800g of CMPA formula milk for infants with the allergy. The parents/carers would use the voucher to buy the CMPA formula milk from a pharmacy, contributing a similar amount to the cost as those people buying standard infant

formula. The average cost of 800g of standard infant formula is £10.00. That would mean, whether or not babies had CMPA, their families would all pay around the same for the infant formula milk their babies needed.

This scheme would apply to infants up to the age of 13 months.

There are approximately 1,000 infants across Staffordshire who have CMPA and whose families would be affected by this proposal.

Engagement Methodology

A simple survey was developed for both health professionals and for the public. Both surveys ran from 22 January to 4 March 2018.

Information and survey links for health professionals were sent out in GP newsletters throughout the period by the Communications & Engagement Teams in the north, east and south of the county and shared by the Medicines Optimisation teams with pharmacists and dieticians.

For the public, there was an online survey which was publicised through press releases, website information, social media messaging, newsletter articles and publicity via Healthwatch and other partners. Paper copies were provided to dieticians at UHNM and Burton Hospitals, for families attending CMPA/Allergy clinics to complete and return by freepost, and surveys were shared with some children's' centres / nurseries. Information about the engagement and links to the survey were shared with Allergy UK and posts added on Mumsnet.

Survey Results - Health Professionals

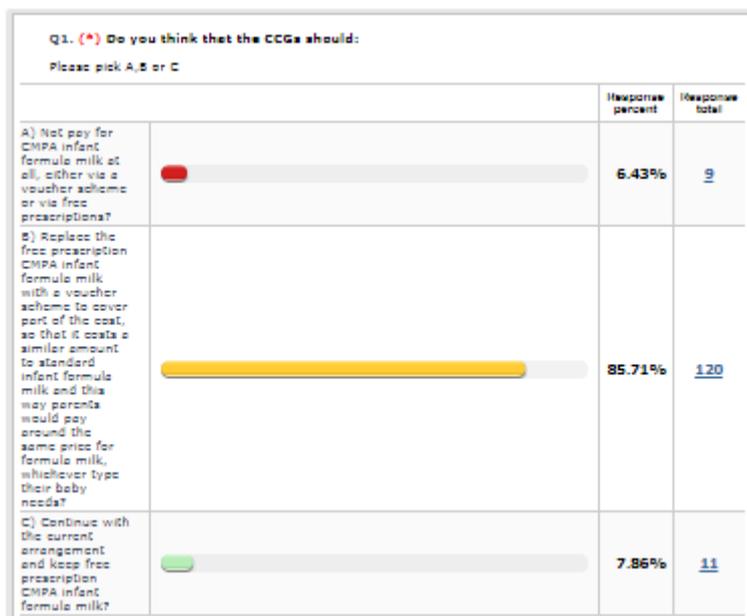
A total of **140** health professionals took part in the survey and the results are set out below.

Question 1

More than 85% of the health professionals thought that the CCGs should replace the free prescription CMPA infant formula milk with a voucher scheme to cover part of the cost so that it cost a similar amount to standard infant formula milk.

7% felt that the current arrangements should be kept in place, with the free prescriptions for CMPA milk.

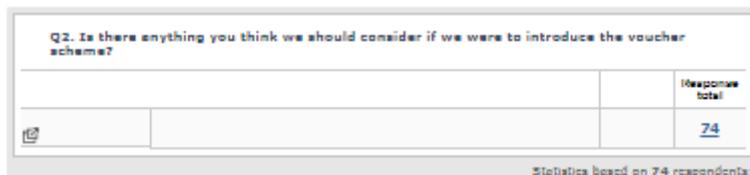
6% thought that CMPA infant feed should not be paid for either by a voucher scheme or a free prescription.



Question 2

Is there anything you think we should consider if we were to introduce the voucher scheme?

74 health professionals noted issues that the CCGs should consider. Many of the respondents listed more than one issue.



The screenshot shows a survey question: "Q2. Is there anything you think we should consider if we were to introduce the voucher scheme?". Below the question is a table with two columns: one for responses and one for the response total. The response total is 74. At the bottom of the screenshot, it says "Statistics based on 74 respondents".

	Response total
	74

Statistics based on 74 respondents.

The full set of health professionals' comments can be found at Appendix 1.

The main themes of the comments are listed below, illustrated by some examples of the sort of comments made.

1 Administrative burden of a voucher scheme on GPs and Pharmacies

Most concerns (16) were raised about the administrative burden of the scheme, both on GPs and Pharmacies.

Please consider the complexity of how you ask pharmacies to provide the service. Often there is too much paperwork which takes time to complete.

You cannot assume pharmacies will do this for free. There should be a admin fee at least to cover time spent processing and claiming vouchers, and of course, agreement that they are happy to add a further burden to their increasing workload.

Remove GPs from the process, or at the very least minimise any involvement (e.g. signature onto a simple form might be acceptable)

Make it as admin light as possible so that this workload doesn't keep coming back into general practice

As it is recommended by dietitians the voucher should be issued by them not the GP. If GP is issuing then we need to see and discuss and that is an unnecessary appointment or use of practice staff.

2 Feed queries

There were 7 queries about the trial period for a formula and 5 queries relating to the process if feeds were changed.

Will the GP give a trial prescription initially to ensure tolerance etc before giving the whole 6 months of feed on voucher? Will parents be allowed to go back and swap their remaining vouchers for another brand of feed without problems if this is the case?

To make any returns of the vouchers or change brands of formula will the parents / carers have to make an appointment with the GP or will another system be put in place to reduce unnecessary delays in changing formulas etc?

Would the feed allowance be at the upper end of fluid recommendations for the age range to ensure adequate feed is provided? How will the scheme cover the additional requirements for babies who are on concentrated feeds and therefore will use more powder than a standard feed?

How will the voucher scheme work for babies on a CMPA free formula but having it via tube? Will the GP still complete a prescription to send to the home delivery company? Or will the option of delivery be removed from the family and they will have to get their feed and ancills separately?

3 Communications with families

There were 8 comments about how families would be made aware of the voucher scheme and how it would work.

Can a guide be put on the voucher or a separate written leaflet advising the parents how many tins per week you would expect them to use so they can ensure they are not going to run out of formula - what provision will be in place if they do run out?

The patients need to be made aware that the Pharmacy aren't going to have for example 13 tins in stock and that they will need to communicate in advance of coming in to pick up that they are going to need to be ordered.

Provide a support line for mothers to help and deal with enquiries otherwise all the complaints will come to General Practice and Pharmacist

4 Low income families

7 expressed concerns about the ability for some families to pay the £10.

The issuing of a prescription for CMPA is due to a clinical assessment by a GP/Consultant/Nurse is done so as the child can develop with the correct nutritional balance. In certain areas of Stoke and Staffordshire parents will not be able to afford a £10 levy on a tin of milk for their child - this needs to be addressed, the current issuing of a FP10 counteracts this.

Perhaps make it slightly cheaper than £10 as many mums in more deprived areas would opt for a cheaper formula.

5 13 month age limit

There were 4 comments about the 13 months cut off.

Although most CMPA disappears by the age of 13 months, there are a few of our patients who have failed to reintroduced cows milk at that age and therefore have continued on the formula until 2 years of age. what would be the recommendations for these patients.

6 Less convenient for families

There were a few concerns about different aspects of the inconvenience for families

Think about urgent supply, if chosen pharmacy is closed how could a family get a supply.

At the moment they will have 6 to 10 tins prescribed. With this scheme they will only be able to afford one tin at a time

Ensure there is a way that patients cannot 'lose' the voucher.

7 GP contractual obligations

There were a couple of comments about GPs' contractual obligations.

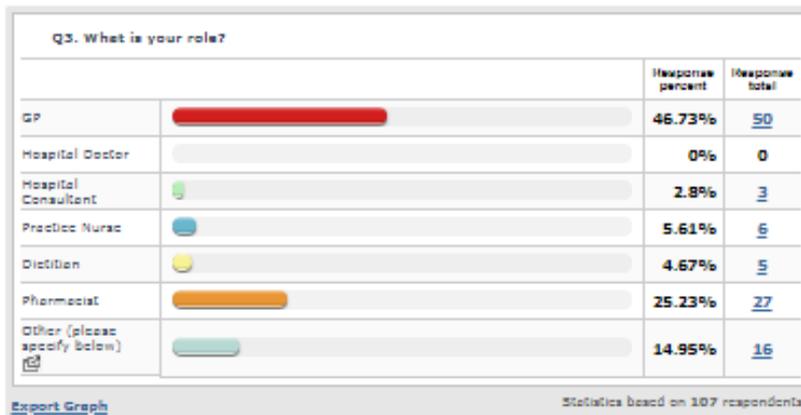
GP under GMS regulations have to offer on request medication they recommend on an FP!) or face being in breach of contract

Question 3

What is your role?

Of the health professionals who completed the survey, almost **47%** were GPs and **25%** were pharmacists and **5%** were dieticians.

Those who considered themselves as 'other' included pharmacy technicians, dispensers in GP practices, practice managers and practice admin staff.

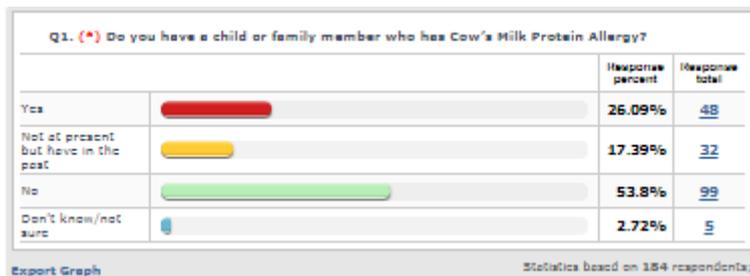


Survey Results - Public

180 members of the public completed the survey.

Question 1

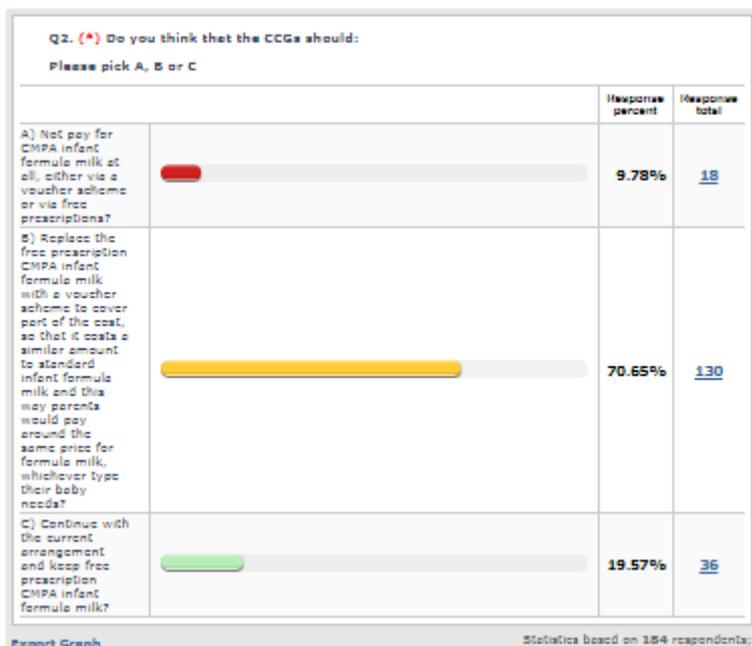
Of the 184 public respondents, 80 had either at present, or had in the past, had a child or family member with Cow's Milk Protein Allergy. 5 people weren't sure, and 99 people did not have a child or family member with CMPA.



Question 2

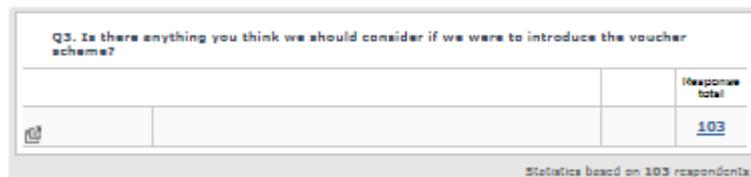
Over 70% of the public who completed survey felt that thought that the CCGs should replace the free prescription CMPA infant formula milk with a voucher scheme to cover part of the cost so that it cost a similar amount to standard infant formula milk, with 20% in favour of retaining the current system, and 10% stating that CMPA feed should not be funded at all.

Of the 80 public respondents who had either at present, or had in the past, had a child or family member with Cow's Milk Protein Allergy, 62% were in favour of the voucher scheme, with 30% wanting the process to remain as present, with families not contributing at all to the cost.



Question 3

103 members of the public added comments about what the CCGs should consider if they were to introduce the voucher scheme. Some people included more than one issue for consideration.



Q3. Is there anything you think we should consider if we were to introduce the voucher scheme?		Response total
		103

Statistics based on 103 respondents.

The full set of comments are available at Appendix 2

The main themes from the comments are below.

1 Affordability

Most comments (19) were about the cost.

Young families are already struggling financially if they cannot afford the more expensive milks it is ultimately the child that will suffer. This sort of prescription is largely for the under 1's anyway they should be entitled to it free.

Failure to invest in the well being of infants will lead to less healthy children and therefore prove to be more expensive in the long run. The voucher scheme would hit the less well off and reduce life chances for their children.

2 Breast Feeding

There were 18 comments relating to breast feeding.

Perhaps the voucher scheme should be introduced in conjunction with a drive to encourage mothers with babies/infants with milk protein allergy to breast feed.

More support for breastfeeding mothers with going dairy free, if there was more support less mothers might turn to formula, it took me 8 months to get a dietitian appointment, during that time I found everything out myself.

That for Mum's who are breastfeeding, there is support to continue rather than just recommending they put their baby onto formula. This would be even more cost effective and I think this new way would help with the over diagnoses of CMPA.

How do you plan on compensating those who breastfeed babies with cmpa as it costs extra to buy dairy free? The nhs should be encouraging breast feeding not supplementing formula

3 Voucher scheme process

Concerns (17) were raised around how the voucher scheme would work.

Try and keep the admin costs as low as possible by giving one ticket which will allow an adequate number of feeds to cover the whole 13 months for the baby

Where parents will get the vouchers from? Getting prescriptions from a GP is sometimes difficult then to have to get a voucher at the same time. Will GP's provide the vouchers? They

will not cover costs!!

It needs to be accepted at all chemists because I have found with a few of the other schemes there are only certain ones that participate

4 In favour of voucher scheme

There were 15 comments in favour of the scheme.

There will be those who suggest that any payment is penalising their child because of a medical condition. However, all mothers have financial support for their child by way of child benefit and therefore their receipt of free milk would disadvantage others who do not have a child with this condition. Part payment would make a level playing field and provide the child with the milk essential for their health.

Treat everybody fairly regardless of whether baby has allergies or not and regardless of whether parents work or not. Everybody should be treated equally.

5 Inconvenience for families

There were 12 comments about how the scheme would be inconvenient for families.

Firstly, it is so difficult to manage the ordering and collection of CMPA milk, incurring extra cost to the parent who can't simply collect from a local supermarket or order online with their shopping, but who has to go out of their way several times a month to go to a pharmacy. In my case, my choice to breastfeed was taken by CMPA, I would never have chosen to formula feed and I hate having to do so. Lastly, our tins cost over £80 for 8 tins of just 400g. Each tin lasts just over 2 days. The reduced quantity and extra expense of these formulas need to be factored in when consider the change of these milks, especially when low income families can use their milk vouchers in a much more accessible way.

Along with this how would vouchers be obtained as if have to be through and appointment it's hard enough to get in the drs when there's an emergency let alone to get milk. Along with this would thickener be the same too as I know I can't afford to buy both! I personally feel it's a disgrace how poor children who suffer daily with cmpa and cannot help it are being penalised for there conditions when a child for example with a different long term condition gets the prescriptions they need

6 CMPA as a medical condition

There were 10 comments about CMPA needing to be treated as a medical condition.

Cows milk protein allergy is a disabling medical condition and there should be no obstacle to getting the sort of milk the baby needs. Complicated arrangements with vouchers just make life difficult for mums who have quite enough to cope with. Poorer mums could do with a break because they will probably have to buy more expensive foods etc during the weaning process and we want to be sure all babies have the best chance and do what we can to support mums. The voucher scheme should not be introduced..what happened to free at the point of need

This voucher scheme won't eork as the milk is a vital life line for babies who are in so much pain and more importantly the parents that have to deal with this. Please don't double whammy them. They have had to deal with so much in the run up to a diagnosis to then be issued with this a cost

for the specialist milk that will vitally save their baby and help it grow and develop. Parents will pay the cost via this voucher scheme as it's their baby and they will do anything to see it happy calm and more importantly not in pain. But is this fair no. At present it's free and it's proved to be a god send in supporting the patent and highlighting the support of the system as milk protein allergy is not the parents fault however they blame themselves for this so to add more pressure on the parents could have more of a adverse affect on the mental health of the people you are trying to add more burden on to.

7 13 month age limit

There were 5 comments about the 13 month cut off.

The scheme needs to run past 13 months. We had our prescriptions stopped at 13 months for a child who had a limited diet having not been weaned till 6 months due to allergies and was still somewhat reliant on CMPA formula. It needs to be done on an individual basis not just issuing a cut off age and there's little available to replace unlike standard infant formula.

My first child had to have formula up to two years for multiple allergies, how would this affect him?

8 Communications

There were 4 comments on the importance of communicating to families about the scheme.

Communicate the scheme to every mother when they are in hospital and advertise in doctor's surgeries - so they know about it - sometimes allergies aren't recognised until a later age but at least the parent may retain this information.

Demographic information

Public participants' responses to questions about ethnicity, background, age etc can be found in **Appendix 3** of this document.

13 March 2018

Appendices overleaf

Appendix 1 – Health Professionals – Full listing of comments grouped by themes

Health Professionals - Q2. What else should be considered?

Administrative burden on GPs and Pharmacies

GP issues

GP under GMS regulations have to offer on request medication they recommend on an FP! or face being in breach of contract. Are the proposals consistent with this. Is there any input on the appropriateness of the milk in the first place?

Nhs eligibility criteria and GPs responsibility as it relates to GMC and contractual requirements

As it is recommended by dietitians the voucher should be issued by them not the GP. If GP is issuing then we need to see and discuss and that is an unnecessary appointment or use of practice staff.

Better engagement with HVs and dieticians. I don't see why GPs need to be very involved with this at all its a very good idea but wether the voucher can be given through health visitor/dietician to save Gp time workload on GPs and effective communication between specialties

Ensure a robust process to ensure accurate diagnosis and a clear review pathway to allow prescribing only for as long as clinically mandated.

GPs should have no involvement in voucher scheme

I like the voucher scheme so gps not issuing prescriptions every month. Also think it's fair to request contribution same price as normal milk. Can you look at similar scheme for gluten free food (and I request this as a GP and mother if coeliac child!!!)

Remove GPs from the process, or at the very least minimise any involvement (e.g. signature onto a simple form might be acceptable)

Make it as admin light as possible so that this workload doesn't keep coming back into general practice

make sure it does not create more work for practices

would need to be simple and not increase workload on general practice

Dispensing doctors

Ease and speed of diagnosing suspected cases Simple process of administration for GPs

Pharmacy issues

from pharmacy point of view we had a debate with my colleague whether the voucher should be kept in pharmacy or whether they should have a booklet of vouchers to use for individual supplies, the issues being possible problems of obtaining stock from one pharmacy, lack of freedom of using different pharmacies, on the other hand possible expectations from the pharmacy to keep stock of any milk at any time (freedom to choose the pharmacy)

Please consider the complexity of how you ask pharmacies to provide the service. Often there is too much paperwork which takes time to complete.

You cannot assume pharmacies will do this for free. There should be a admin fee at least to cover time spent processing and claiming vouchers, and of course, agreement that they are happy to add a further burden to their increasing workload.

Can this not be done straight from the pharmacy (Like minor ailments scheme) or Health visitors?

Some kind of quantity check at the time of dispensing to avoid stock piling

If some of these formulas aren't stocked by our suppliers, Alliance or AAH and they had to be obtained through other channels how would the covering of the out of pocket expenses / wholesale fee be worked out.

General workload issues

Make the voucher scheme as easy as possible for everyone involved - no long or complicated paperwork to complete.

The workload for GPs and Pharmacy staff in administering the process and ensuring that guidelines are adhered to. would need a clear line of referral for any complaints or issues

Try to keep admin simple and easily workable in terms in terms of GP /dispensary time.

Administration of voucher scheme

Why are vouchers needed? Can't it just be that parents are prescribed the milk and they just pay £10 per 800-900g of milk issued, as there are many different formulas all at different prices. I worry about the logistics of getting vouchers to parents, what if they lose them etc etc

ACTIONS IN EVENT OF LOSS OF VOUCHER ? MAX LIMIT SET FOR ISSUING VOUCHERS

To put it on a parent or baby named basis so the vouchers can not be sold on or the system abused. Perhaps look at a maximum quantity that should be prescribed so that parents do not use the milk for their other children or family/friends children and therefore abuse the system. Maybe look at something similar with gluten free items. I know many families that use the gf products to feed the whole family not just the celiac in the family ie make a lasagne for everyone to eat.

Ensure there is a way that patients cannot 'lose' the voucher.

Ensure that the voucher scheme is designed specifically for the Milk rather than as a Food voucher. Parity around the patients on the scheme.

The range of products covered and what would happen if a patient is swapped onto a different baby milk formula mid-cycle. Would the voucher be claimed for and a new one issued or does the voucher have to be complete in order to claim.

It is a good idea to make patient partially pay for the milk as it might improve the availability of the CMPA milk and pharmacy/patient doesn't have to wait for the prescription to order the correct product

Feed queries

Would the feed allowance be at the upper end of fluid recommendations for the age range to ensure adequate feed is provided? How will the scheme cover the additional requirements for babies who are on concentrated feeds and therefore will use more powder than a standard feed? What happens if a 6 month voucher is given for an EHF and then this needs to change to a AA formula? Will the GP's be happy to exchange the remaining vouchers for the new feed?

How will the voucher scheme work for babies on a CMPA free formula but having it via tube? Will the GP still complete a prescription to send to the home delivery company? Or will the option of delivery be removed from the family and they will have to get their feed and ancills separately?

breast feeding is free- if the baby is so allergic it cant tolerate this it seems unfair administration costs and pharmacy time will increase and the number of affected babies is small. in addition we currently order milk in for scripts- do not keep in stock as find end up with lots of out of date stock as babies change formulation.

What happens if the formula requested changes?

what would happen if a patient is swapped onto a different baby milk formula mid-cycle. Would the voucher be claimed for and a new one issued or does the voucher have to be complete in order to claim.

To make any returns of the vouchers or change brands of formula will the parents / carers have to make an appointment with the GP or will another system be put in place to reduce unnecessary delays in changing formulas etc?

Think about urgent supply, if chosen pharmacy is closed how could a family get a supply. There will be a lot of resistance to this scheme from the families involved, but on the whole I feel it will be fairer and ultimately reduce waste that results when 16x400g tins of milk are given on one prescription as happens now. Less waste if a child changes on to something else.

Trial periods

sometimes products are prescribed on a trial basis, ie. to establish diagnosis by exclusion -- this would be complicated with a voucher also -- who would need to make the diagnosis to qualify, GP or specialist? in many cases this is a slow process and with an age limit of 13 months, not many would be able to use the full 6 month supply

Will the GP give a trial prescription initially to ensure tolerance etc before giving the whole 6 months of feed on voucher? Will parents be allowed to go back and swap their remaining vouchers for another brand of feed without problems if this is the case?

How long is the intended `trial period` I suspect there may be opposition from parents. They don't pay for antibiotics or eczema creams etc. Labelling will be the issue.

How many tins would be prescribed as a trial before issuing the vouchers - i.e. at what point would the GPs input end? Would this apply to AA as well as EHF? If the GP's input would not be needed until 13mths, who would give advice re weaning or arrange dietician input if not confident re the milk ladder?

How would a trial of treatment work? There is no primary care test for CMPA or lactose intolerance and sometimes a trial of treatment is used to assess benefit. If the voucher covers 6 months, I haven't followed how an initial trial would be accommodated.

It needs to be clarified what happens for those on a trial of formula for cmpa in order to help make the diagnosis. do parents get a prescription for the milk? for how long? guidance needs to be clear, so that we can communicate this to parents.

Communicating about voucher scheme

There would have to be careful discussions with a family about giving a pharmacy notice to reorder a milk and not just expect the pharmacy to keep it in stock.

Can a guide be put on the voucher or a separate written leaflet advising the parents how many tins per week you would expect them to use so they can ensure they are not going to run out of formula - what provision will be in place if they do run out?

That pharmacies often need to order special formulas as due to short expirys we cannot keep all in stock. So ensure parents are told this.

The patients need to be made aware that the Pharmacy aren't going to have for example 13 tins in stock and that they will need to communicate in advance of coming in to pick up that they are going to need to be ordered.

Provide a support line for mothers to help and deal with enquiries otherwise all the complaints will come to General Practice and Pharmacist.

information sheet/ guidance to educate the infants parents on the different types of milk and what is best for the infant in terms of their needs and how to ensure they get enough nutrients to grow. Also explaining the differences between allergy/ intolerance to cow milk and how parents can help their infants.

educate health visitors and public well

Ensure that the parents know that may need to order the milk in advance rather than expecting the Pharmacy to have it on the shelf. These milks are expensive so are normally only ordered once there is a Prescription for the items rather than keeping them as a stock item.

I think this is an excellent idea. Charging the "normal" supermarket price for the formula is more than fair. Speaking as a Practice Nurse and mother of a CMPA baby (mine breastfed), I do think the awareness of CMPA through primary care staff needs increasing and also encouraging/supporting mums with information to try to continue breastfeeding on a modified/elimination diet.

It would need to be widely publicised to reduce the backlash towards primary care - I suspect a lot of my patients would not be happy to contribute anything to the cost of their baby's milk

Effects on low income families

The issuing of a prescription for CMPA is due to a clinical assessment by a GP/Consultant/Nurse is done so as the child can develop with the correct nutritional balance. In certain areas of Stoke and Staffordshire parents will not be able to afford a £10 levy on a tin of milk for their child - this needs to be addressed, the current issuing of a FP10 counteracts this.

What we would do if parents stated they could not pay the £10 What about the extra cost to breast feeding mums who have to go dairy free while feeding

That some patients might struggle to cover the £10 cost.

The implications of families unwilling to contribute to the costs

Families in poverty would claim they should still get it free. pressure on GP s to prescribe, paucity of health visitors, lack of paediatric dietician appointments, further training for health professionals on infant feeding formulae, better promotion of breast feeding.

Families on lower incomes should still pay the same, as they already get additional monies.

Perhaps make it slightly cheaper than £10 as many mums in more deprived areas would opt for a cheaper formula.

low income families patients who are being tube fed or those who rely on specialist formula for their total nutrition. This will include those who can not:- be weaned on to solid foods due to swallowing difficulties meet their nutritional requirements from oral diet due to multiple food allergies/feeding difficulties/metabolic patients

some way to alleviate the effects on low income families?

Age limit of 13 months

Although most CMPA disappears by the age of 13 months, there are a few of our patients who have failed to reintroduced cows milk at that age and therefore have continued on the formula until 2 years of age. what would be the recommendations for these patients.

What about infants over 13months?? Would the amount be limited per voucher or just cover a set period?

Sensible assessment of baby intake of milk and tapered system /dietician review required from weaning onto a milk ladder guided diet. You cannot buy CMPA over the counter and we cannot leave parents short of provision

Will the voucher scheme be available if the child needs a longer term prescription beyond 6 or 12 months on the advice of a Dietitian / Consultant?

Not so convenient for families

patient convenience, at the moment they will have 6 to 10 tins prescribed. With this scheme they will only be able to afford one tin at a time make sure that parents have a good supply of vouchers to ensure they don't run out

Infants already getting full free feeds

Existing patients on formula - will they remain on previous free script scheme?

Partial funding

I think a voucher scheme would be fairest. BUT would anticipate a public backlash if local CCGs applied this on their own. Postcode lottery would then apply. Much better if this were a national initiative. Similar concept applies to gluten free prescribing or oral nutritional supplements. It seems inherently unfair that some individuals can effectively be fed for free by NHS prescription whilst others who don't have a qualifying health condition aren't. Equally, having a health condition shouldn't penalise individuals by substantially increasing their food bills as this disproportionately affects the least well off. A voucher scheme that effectively reduces cost of expensive items to average cost seems sensible. It should be patient specific though.

It should be an all or nothing scheme (i.e. no milk is available AT ALL from the NHS or it is fully funded). This is a scheme which sets a precedent for other items to be partly funded by the NHS and partly by patients and could be seen as being the "thin end of the edge"

Gluten free

I would suggest considering something similar for gluten free products

Appendix 2 – Public – Full listing of comments grouped by themes

Q3. Is there anything you think we should consider if we were to introduce the voucher scheme?

Affordability

My son has cmpa and on prescription milk and thickener if I were to buy currently it would cost a fortune which due to not working I could simply not afford. even if there were vouchers

I can't see how it would be affordable unless it was guaranteed that per grams the cost was the same rather than tins as they have considerably less than the average tin of milk. Along with this my son has reflux which is common with cmpa and has thickener In his milk however due to acid he struggles sometimes with bottles meaning we are having to offer them even if he drinks it or not and with the thickener once made up don't last as long as normal bottles which does cause a lot of waste which cannot be helped. So therefore for a condition which my son cannot help I would be out of pocket compared to a parent who's child didn't have it as we would get through more milk. However if this was to come in and vouchers were issues like mentioned previously they would need to consider the grams of cmpa milk compared to those sold in an average tin and Make sure that they issued enough vouchers at a time to make a pharmacy trip visit worth while and take into consideration that currently pharmacy's can take days to get the milk in. Along with this how would vouchers be obtained as if have to be through and appointment it's hard enough to get in the drs when there's an emergency let alone to get milk. Along with this would thickener be the same too as I know I can't afford to buy both! I personally feel it's a disgrace how poor children who suffer daily with cmpa and cannot help it are being penalised for there conditions when a child for example with a different long term condition gets the prescriptions they need

Failure to invest in the well being of infants will lead to less healthy children and therefore prove to be more expensive in the long run. The voucher scheme would hit the less well off and reduce life chances for their children.

Consider families who are unable to contribute the £10.

I think that this would increase the likelihood of infants actually getting the treatment that is required due to the reduced cost on the GPs budget as i really struggled for 2 years to get medics to listen to me as a parent when my son was an infant. I ended up purchasing nutramigen myself, however, had to stop after a few months due to the cost. It improved his symptoms but because he was no better on soya milk my GP refused to prescribe it saying he couldnt be allergic to cows milk otherwise he would have been better on soya milk. Anyway after a 2 year battle turns out he was allergic to both. But the GP refused point blank all the way through to prescribe nutramigen or pepti junior due to the cost implications, and I myself was unable to fund it due to having to have alot of time off work with a very sick child. So I agree that a voucher system may imprive children actually getting the treatment they need and deserve. I would have quite happily contributed towards it, had this have been an option.

If it is the case that those on low incomes do not pay less for standard infant formula milk, then they would not be unfairly disadvantaged by having to pay the same for CMPA, and therefore there is no need to offer a further discount. It appears that the only people who are disadvantaged by the current scheme are those with babies who are breastfeeding and/or on standard formula milk

It should be means tested. So it is fair for people who are on benefits. Also consider for those parents on a higher pay should have to pay for the formula milk out right.

Healthy Start vouchers for parents on low incomes would be fair and help to ensure that babies are fed appropriately, regardless of their parents financial status

Consideration to parents who are on low income in ensuring they are able to afford the milk in view of some families having to seek help from a food bank.

Some families not be able to contribute if low income families.

I think low income families should still get free on prescription.

Young families are already struggling financially if they cannot afford the more expensive milks it is ultimately the child that will suffer. This sort of prescription is largely for the under 1's anyway they should be entitled to it free.

The CMPA milk is very expensive and some parents would struggle to pay for it and therefore babies could suffer. More research should be undertaken to find out why so many babies suffer from this allergy.

I think you should consider that not just low income families will struggle to pay everyone will be affected because CMPA formula is very very expensive. CMPA is a medical problem therefore prescriptions should be free.

More assistance for families who are disadvantaged.

Whether parents can pay

A food suitable for allergic children increases the cost, so a free formula milk is a great help for parents, especially having more children.

Whether the family receive child tax credits and / or child benefit for child. Some families won't be able to afford formula and dairy free/ soya free diet is also expensive. Danger of child being fed incorrectly as option to breastfeed vastly reduced.

I do feel that all low income families should qualify for help with Vouchers, for normal or special formula milk.

Whether the most vulnerable groups can afford Whether a clear cut diagnosis has been made or if the formula is being used during the diagnostics process Need for referral to dietician Increasing rates of breastfeeding

Yes some babies don't settle on the prescription milks and it can take a while of trial and error on the different types of milks to get it settled I don't feel parents should have to pay for the milk at all when the baby has these allergies.

Not penalise working families and "prioritise" those on benefits for vouchers. All families need help, regardless of their current financial situation.

Babies and children with milk protein allergy often have other illnesses too eg gerd, other food allergies etc. The milk protein allergy can lead to the child throwing up excessively and/or having numerous dirty nappies in one day compared to a child without this allergy. This increases the cost these families face, increased costs associated with washing clothes, bedding etc more frequently, increased costs due to the number of nappies that need changing in one day, increased cost in using alternative therapies that the parents try, to solve the problems associated with investigating the allergy. Using a voucher scheme to reduce the cost of the nonallergenic formula will still end up costing these families more than families without the allergy. As these people have the choice to shop around for their formula, are able to bulk buy when the formula is on sale and purchase the formula from numerous places including the highly competitive supermarkets who can sell the formula as a loss leader therefore making the voucher scheme untenable as it will still make the families of children with milk protein allergy pay more for their formula. It also isn't just formula for people who don't want to breastfeed or can't breastfeed for the usual reasons. When a baby has a milk protein allergy, for the mother to breastfeed and the baby not to react to the breast milk can take a long time to fine tune as often the baby can be reacting to things that the mother is eating, even the smallest of hidden milk protein in the mums food could cause a reaction in the baby and this reaction isn't immediate, it could take a few days to show, resulting in the mother having to follow a very strict elimination diet. There is not enough help and hands on support for the mother to do this and neither is there enough hands on support for those mums who don't breastfeed or stop breastfeeding after a short period of time. There is nothing easy about breastfeeding, neither the mum or the baby knows what they're doing. Lots of help and physical support is required for mums and babies to develop a long breastfeeding relationship. Once established this relationship is a wonderful thing but currently the nhs does not have the manpower nor the facilities to achieve this in babies without milk protein allergy let alone with those who gave this added complication. It is for these reasons I believe the formula should continue to be supplied free of charge.

Poorer parents should possibly be eligible for additional funding.

Low income families should receive it free

Breast feeding

Yes how do you plan on compensating those who breastfeed babies with CMPA as it costs extra to buy dairy free? The NHS should be encouraging breast feeding not supplementing formula

The importance of avoiding this issue at all by improving breast feeding initiation and maintenance rates. If health staff were able to identify mothers with a likelihood of an infant with allergies they could target them for breastfeeding advice and support

Those that wanted to continue breastfeeding but were forced to stop due to the allergy, they may have chosen to breastfeed for financial reasons (along with other reasons) and then expected to start paying for formula from no fault of their own.

Perhaps the voucher scheme should be introduced in conjunction with a drive to encourage mothers with babies/infants with milk protein allergy to breast feed.

Spending the money saved on education and support for new mums who breastfeed. Trying to boost the breastfeeding rates in the county would, I believe, in the long run save money by helping to keep babies healthier and mums happier

Promoting ways to continue breastfeeding (if already breastfeeding) rather than offering the formula as the "easiest" and "best way" to manage CMPA. Also making sure that it isn't being offered as something to try rather than actually having a diagnosis. It feels as though CMPA is over diagnosed and therefore gives the impression that it is not as severe/important for those with genuine allergies.

Encourage breastfeeding as much as possible.

That for Mum's who are breastfeeding, there is support to continue rather than just recommending they put their baby onto formula. This would be even more cost effective and I think this new way would help with the over diagnoses of CMPA.

Breast feeding support has been assessed by the RCM as often lacking so more support should be given to mothers to feed their babies themselves, if necessary expressing milk to be used if they are away. unless this is deemed medically impossible. The substitute of bottle feeding is always to least desirable option.

More breastfeeding support meaning less need for formula, no cost then for CMPA milk on NHS

All formula should only be available on prescription. If this scheme is implemented and money is saved it should go to breastfeeding support for mothers who want to breastfeed.

Provide advice and support to breastfeeding families whose child has a CMPA

Formula just isn't as good for any baby as breast milk, especially those with additional dietary needs like CMPA. The money saved by running this scheme should be ringfenced for breastfeeding support, possibly specialist support for families with specific difficulties like CMPA as too many end up using formula unnecessarily.

No but I think more money should be put into promoting breast milk.

Coma is mass I Ely over diagnosed and therefore a massive impact to Bobby health and prescription over spend. Breastfeeding should be more encouraged and mother support appropriately.

During my daughters initial assessment at the dietician I was asked if I would like a tin of Nutramigen incase I wanted to make certain meals up like a shepherds pie. I refused knowing the cost of the product and that the quantity I would use would be small thus wasteful. I have continued to breastfeed beyond a year. I have gone on a milk free diet too and received calcium supplements which I now pay for on subscription, which seems crazy when I am doing it for my daughter, yet a expensive tin of formula is free. I think good breastfeeding support in the early stages and encouragement to continue breastfeeding alongside weaning would go a long way to reducing the need to pay for these products. I understand not everyone wants to breastfeed and it doesn't always work out, but I do feel there is an over use and an assumption that this milk is the go too, regardless of how a baby is being fed.

Encourage and support mothers to breastfeed for at least the first few weeks.

More support for breastfeeding mothers with going dairy free, if there was more support less mothers might turn to formula, it took me 8 months to get a dietitian appointment, during that time I found everything out myself.

Voucher process

Try and keep the admin costs as low as possible by giving one ticket which will allow an adequate number of feeds to cover the whole 13 months for the baby

That parents shouldn't be made to feel embarrassed to use the voucher (perhaps it could be attached in some way to the prescription)

At the moment nurseries are able to claim for formula milk they purchase for under ones in the same scheme as claiming for 1/3 pint per child per day for under 5s . Will this CMA formula be added to claim list?

Ask parents eligible for vouchers if they actually need the vouchers or not. If not. If they feel they can afford to pay then it seems silly to give them vouchers.

Would be very complicated to enforce and implement. Would be confusing for both HCP's and Patients. If this is a cost saving initiative, the time and effort should be spent on better pathway management which would free up more savings than asking parents to part fund.

Sometimes the tins of formula are so small and families will always waste some (through baby not being hungry after all or vomiting etc). Therefore there may need to be a little flexibility around this so parents can be issued vouchers even when the GP surgery calculates they should not have run out.

How would this be managed in terms of price comparisons of various milks

MAKE SURE THAT PARENTS ARE NOT ABLE TO 'SELL' THE VOUCHER ON TO MAKE A PROFIT

I'm no longer in touch with prices but assume formula may be cheaper in supermarkets as compared to pharmacies. So could an agreement be made with local supermarkets as well? Alternatively perhaps the voucher could cover the difference between the prices as well so that formula could be bought at supermarket price from the pharmacy. I speak as a mum who 40 years ago had to buy Soya formula at an extortionate price ... It was worth it though to have a thriving rather than very sickly baby.

Over-complicated system? Children not receiving CMA milk, as they don't understand the new system.

There would need to be complete transparency as to the manner in which the part cost is calculated on the basis of standard infant formula milk. Using the RRP might disadvantage those requiring CMA as standard formula milk is often available at a discounted price in some shops

These families have no choice but to buy this milk off their child's medical needs so it is unfair to penalise but paying the same seems fine.

What are the implementation and running costs? Are community pharmacies on board with it? Buying cows milk free margarine/spread and other items does make following this diet more expensive. This has been negated by the free prescription of CMA formulas but if parents are paying £10 they will still need to buy separate spreads, milk alternatives for cooking etc. Lots of foods contain dairy as a cheap filler. Some parents may struggle to afford both the ingredients for dairy free cooking and the resource to cook separately. This may widen health inequalities for vulnerable families but seems reasonable for the majority.

In the past vouchers have been exchanged for other goods with unscrupulous traders.

Where parents will get the vouchers from? Getting prescriptions from a GP is sometimes difficult then to have to get a voucher at the same time. Will GP's provide the vouchers? They will not cover costs!!

It needs to be accepted at all chemists because I have found with a few of the other schemes there are only certain ones that participate. (Minor ailments as an example)

The CCGs should not have to cover the cost of the scheme it will be difficult to manage and police

Comments in favour of voucher scheme

There will be those who suggest that any payment is penalising their child because of a medical condition. However, all mothers have financial support for their child by way of child benefit and therefore their receipt of free milk would disadvantage others who do not have a child with this condition. Part payment would make a level playing field and provide the child with the milk essential for their health. My child had a milk allergy and in this instance we gave him goats milk.

Option B is fair and we would have been willing to contribute towards the cost.

It is only fair that these parents contribute to the cost of feeding their babies. Far more important and more equitable services are being cut across the board denying the public as a whole.

All parents should pay/contribute to feeding their babies and children. I fully understand that the price of CMPA formula may be higher than normal formula but would embrace a

contribution from the parent.

No but may I reiterate what a brilliant way to make it fairer to all...It should not be given free but at a discount to bring it in line with other parents that have to pay.

Consider a similar scheme for other specialist infant formulae, such as preterm infant formula, high energy, lactose free and other prescribable infant milks. However, I feel that the savings should be used to support breastfeeding support / postnatal support for all families (which would then also save money as many of these specialist formula would be unnecessary altogether if more families were supported with breastfeeding)

I think mothers should be encouraged to breast feed and not formula feed. Formula should not be available on prescription free or not. If a parent chooses to formula feed then they should pay for it, if for medical reasons breast feeding is not achievable then vouchers can be given for ALL formula.

People on benefits should be entitled to free milk as they are now. Supplying this formula for free undermines breastfeeding which is still possible when your child has CMPA.

Anyone on a low income is getting healthy start vouchers so they can use them to get money off other things in their shopping trolley. There should be far more education for GPs dietitians and the medical profession which is delivered by independent organisation on normal baby behaviour there should be an immediate stop to any training delivered or funded by formula milk manufactures. http://www.firststepsnutrition.org/pdfs/Specialised_infant_milks_January_2018b.pdf

It is fair to ask patients to pay the equivalent to other patients.

Breastfeeding is free. Parents shouldn't have to pay more for specialist formula...but they shouldn't get it free either

As long as parents are not paying ridiculous prices because a child has an allergy

We need to make choices how we spend the money the NHS is given this is not good use of that money

I feel this milk should be brought in line with other formulas. While I have sympathy with any baby having an allergy to any food product, it is therefore my opinion that there should be equal rights regarding the cost of milk formulas to all families, be it a milk allergy, or any other allergy eg: Gluten, or wheat, in a baby/ child attaining the age of 18 months.

Treat everybody fairly regardless of whether baby has allergies or not and regardless of whether parents work or not. Everybody should be treated equally.

Same price per gram as normal formula milk.

Inconvenience for families

I have had 2 children with CMPA. My first went undiagnosed for 10 months as health professionals (health Visitors, several GPs, 2 consultants and a dietitian) did not consider she

could be allergic as I was breast feeding. As such, I pursued with breastfeeding until at the age of 10 months she was misdiagnosed as lactose intolerant and I paid privately for lactose free formula, which inevitably still did not suit her. My son, now age 7 months, was diagnosed with CMPA at the age of 6 weeks. I had breastfed up until this point. Upon diagnosis, I was advised that my son was likely to have several other allergies due to family history and ongoing reactions, despite me having a dairy and soya free diet. In consideration of the difficulty with diagnosing allergies via diet elimination, I was advised to introduce a hypoallergenic formula. I was devastated to not be able to continue breastfeeding. We have had a long and complex journey so far with trialling different medications to control reflux. We now choose to pay privately for carobel, despite having been offered a prescription. Whilst I do not disagree entirely with charges for CMPA milk, I do have some issues for consideration. Firstly, it is so difficult to manage the ordering and collection of CMPA milk, incurring extra cost to the parent who can't simply collect from a local supermarket or order online with their shopping, but who has to go out of their way several times a month to go to a pharmacy. In my case, my choice to breastfeed was taken by CMPA, I would never have chosen to formula feed and I hate having to do so. Lastly, our tins cost over £80 for 8 tins of just 400g. Each tin lasts just over 2 days. The reduced quantity and extra expense of these formulas need to be factored in when consider the change of these milks, especially when low income families can use their milk vouchers in a much more accessible way.

Burden on parents with a sick child to deal with this additional bureaucracy

Ensure voucher scheme is timely and easily accessible for those that need it. Families with genuine cmpa will already be in a state of anxiety so it must be easy to obtain

Time spent by parents in hospital or GP

The difficulty I've heard from Mums is the amount they can get is an issue as babies are so unpredictable with feeding and feed

often they are often only given one tub at a time and often run outbid the feedback from parents do whether this can be looked at too?

CMPA

Cows milk protein allergy is a disabling medical condition and there should be no obstacle to getting the sort of milk the baby needs. Complicated arrangements with vouchers just make life difficult for mums who have quite enough to cope with. Poorer mums could do with a break because they will probably have to buy more expensive foods etc during the weaning process and we want to be sure all babies have the best chance and do what we can to support mums. The voucher scheme should not be introduced..what happened to free at the point of need.

My son was breastfed from birth his symptoms started immediately with no effect from cutting out dairy to be diagnosed with colic then silent reflux. It was only at 13 weeks old with a constant scream of pain that lasted all day we finally took him to A and E. It was the referral to paediatrics that we finally got the diagnosis after feeling like we were dismissed and treated like paranoid parents since his birth. This voucher scheme won't work as the milk is a vital life line for babies who are in so much pain and more importantly the parents that have to deal with this. Please don't double whammy them. They have had to deal with so much in the run up to a diagnosis to then be issued with this a cost for the specialist milk that will vitally save their baby and help it grow and develop. Parents will pay the cost via this voucher scheme as it's their baby and they will do anything to see it happy calm and more importantly not in pain. But is this fair no. At present it's free and it's proved to be a god send in supporting the parent and highlighting the support of the system as milk protein allergy is not the parents fault however they blame themselves for this so to add more pressure on the parents could have more of an adverse affect on the mental health of the people you are trying to add more burden on to.

This is a medical condition that was diagnosed by a medical professional - therefore it should be treated as one. My little girl needs the special formula for medicinal purposes and without it she would be very poorly. As a taxpayer I think it is very 'unfair' that this is even being suggested as this milk is the treatment/ medicine needed to manage the symptoms of CMPA. I'm sure most parents who have little ones with this allergy would prefer they didn't and pay for standard formula rather than receiving free prescription milk.

Babies with CMPA have a genuine clinical need for suitable milk. I do not think that there should be a voucher scheme so I cannot make a suggestion. Infants with CMPA should be eligible for free milk on prescription.

It is not my choice that my child has this allergy and it was not my choice my child could not latch on despite spending money on breast pumps for expressing - until I got mastitis - and various other things. If you take away free prescriptions what is the alternative? It is not just a product you can go and buy off the shelf so it shouldn't be paid for.

Improve service to properly diagnose CMPA in a timely fashion

As someone who wanted desperately to breastfeed but was unfortunately unable to I feel that it is unfair to be financially punished for this. I also feel that regular formula should be offered on prescription to mothers who are unable rather than unwilling to breastfeed.

I pay my national insurance and son does my partner. If my child is unwell and requires specialist milk why should we have to pay for his health care cost? I know it's milk but at the end of the day it's health care and needed!! Also find it highly offensive that you quote mum's who can't or choose not too breast feed. Not really anybody's business and always much more TO it than that.

Think methadone should be paid for , less spending on foreigners, drug addicts! CMPA is not a life choice it is a medical condition.

How will you be sure that the allergy is genuine and not just a trend

I think that parents with babies who are allergic to cow's milk protein have other costs to bear associated with this allergy which parents with babies who have no allergy do not. SO, the current practice of providing the formula free via prescriptions I believe is fair overall, if fairness is the driving force behind this policy. If the policy is being reconsidered from a solely cost-saving viewpoint, I would like to know the total saving made via the voucher scheme (eg costs of admin outweighing the income).

It would be great with family's with multiples "If all have the same problem" to have more help towards the payment or amount of milk that can be required.

13 months age limit

You state this is up to 13 months, my first child had to have formula up to two years for multiple allergies, how would this affect him?

The scheme needs to run past 13 months. We had our prescriptions stopped at 13 months for a child who had a limited diet having not been weaned till 6 months due to allergies and was still somewhat reliant on CMPA formula. It needs to be done on an individual basis not just issuing a cut off age and there's little available to replace unlike standard infant formula.

Should the length of time be extended beyond 13 months?

Many children with cows milk protein intolerance also have an intolerance to soy. Their intolerance continues well past their 1st birthday, so they still need the special formula beyond that date if they are to get the right nutrition when they are small. All young children need to continue to drink milk or eat dairy products beyond the age of 1. If this is not possible, the cost to the family becomes prohibitive. I think that if vouchers are provided, they should continue until the child no longer needs them and in quantities which reflect their needs. This is something which should be regularly reviewed.

I would question the 13mth cut off - we know lots of infants are diagnosed late, and may therefore not be correctly challenged with milk ladder in time.

Communications

Give the public plenty of notice that the voucher scheme is going to happen, and a clear pathway to be able to get the vouchers

Communicate the scheme to every mother when they are in hospital and advertise in doctor's surgeries - so they know about it - sometimes allergies aren't recognised until a later age but at least the parent may retain this information.

Additionally making sure people with learning difficulties understand the process.

Ensure that pregnant women are fully aware of the voucher scheme

Other comments

Co-produce the Equality Impact Assessment with people affected to ensure you do not unintentionally discriminate against certain people, especially those on low incomes.

As a parent who's child had CMPA when weaning commences food is more expensive when needing alternative ingredients.

How about ending exemptions for type 2 diabetics who currently get all prescriptions free as a reward for eating all the pies. Make obesity as socially unacceptable as smoking.

How about linking age related script charges to the state pension age instead of rewarding affluent 60 something year olds. How about stopping local GPs prescribing commonly available OTC medicines such as paracetamol at NHS expense. Just some random thoughts before North Staffs CCG ends up on the front page of the Mirror.

Why isn't there a formula we can buy at the shops?

If it has to be voucher scheme then why not Voucher schemes for over the counter medications ?

Appendix 3 – Demographics of Public Respondents

Please note that this section was not mandatory and not all respondents who did complete it, answered all of the questions

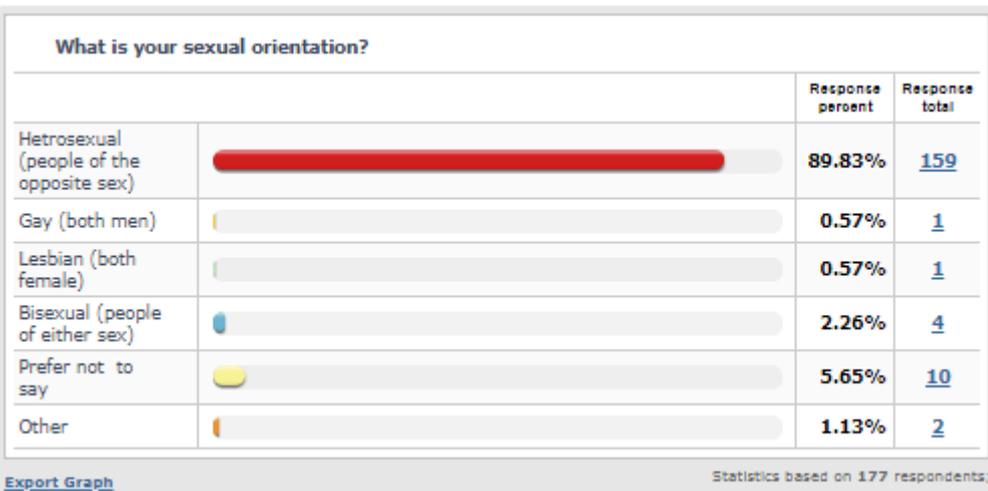
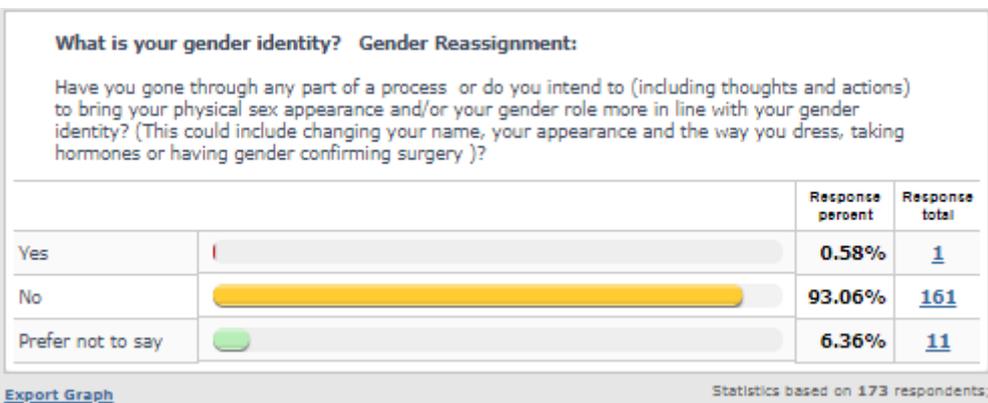
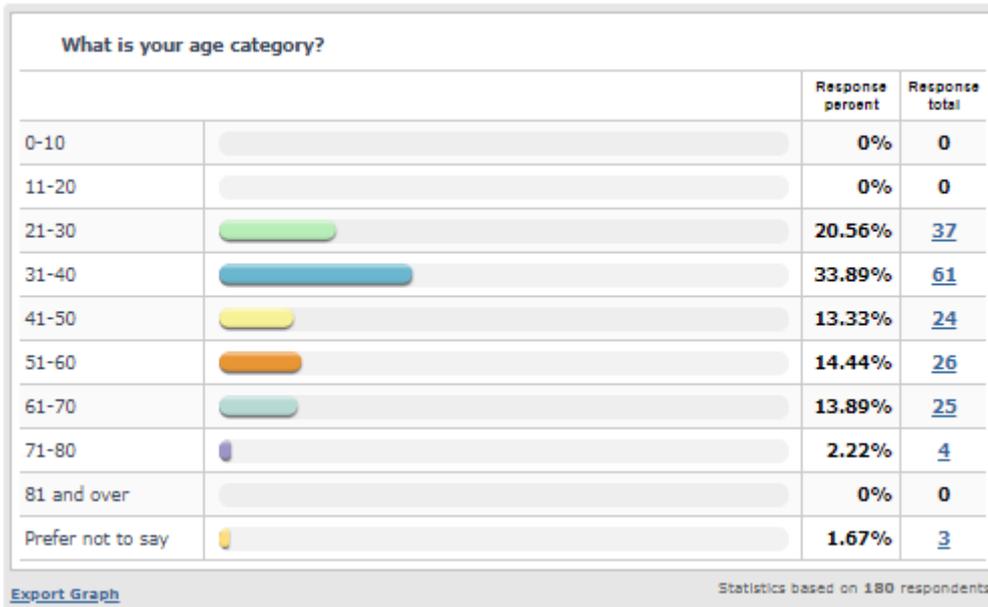
What is your ethnic group? (This includes colour, nationality, including citizenship and ethnic or national origins)		Response percent	Response total
English / Welsh / Scottish / Northern Irish / British		93.89%	<u>169</u>
White Irish		0.56%	<u>1</u>
Polish		0.56%	<u>1</u>
Indian		1.67%	<u>3</u>
Pakistani		1.11%	<u>2</u>
Bangladeshi		0%	0
African		0.56%	<u>1</u>
Caribbean		0%	0
Black British		0%	0
White & Black Caribbean		1.11%	<u>2</u>
White & Black African		0%	0
White & Asia		0%	0
Chinese		0%	0
Irish		0%	0
Gypsy or Irish Traveller		0%	0
Arab		0%	0
Other, please describe 		0.56%	<u>1</u>

(Other = Other white)

What is your religion or belief?		Response percent	Response total
Buddhism		0.56%	<u>1</u>
Christianity		58.99%	<u>105</u>
Hinduism		0.56%	<u>1</u>
Islam		1.69%	<u>3</u>
Judaism		0%	0
sikhism		0.56%	<u>1</u>
Prefer not to say		17.98%	<u>32</u>
Other, please describe 		19.66%	<u>35</u>

[Export Graph](#) Statistics based on 178 respondents;

(Other = 1 agnostic, 1 pagan, 1 spiritualist and the remainder atheist or no religion)



Marriage & Civil Partnership: What is your relationship status?

		Response percent	Response total
Married		67.6%	121
Single		5.59%	10
Divorced		6.7%	12
Lives with Partner		15.08%	27
Seperated		0.56%	1
Widowed		0%	0
Civil Partnership		0%	0
Prefer not to say		2.79%	5
Other		1.68%	3

[Export Graph](#)

Statistics based on 179 respondents;

Pregnancy and Maternity

(The Equality Act 2010 protects women who are pregnant or have given birth within a 26 week period). Please click as appropriate:

	Yes 	No 	Prefer not to say 		Response total
Are you pregnant at this time?	2.38% (4)	96.43% (162)	1.19% (2)		168
Have you recently given birth? (within the last 26 week period)	13.77% (23)	85.63% (143)	0.6% (1)		167

Statistics based on 172 respondents;

Do you consider yourself to have a disability?

(The Equality Act 2010 states a person has a disability if they have a physical or mental impairment which has a long term (12 month period or longer) or substantial adverse effects on their ability to carry out day to day activities).

	Yes ■	No ■		Response total
Physical disability (please describe)	9.85% (13)	90.15% (119)		132
Mental health need	8.73% (11)	91.27% (115)		126
Sensory disability eg Deaf, hard of hearing, Blind, visually impaired (please describe)	4.13% (5)	95.87% (116)		121
Long term illness (please describe)	10.08% (13)	89.92% (116)		129
Learning disability or difficulty	1.65% (2)	98.35% (119)		121
Prefer not to say	10.17% (8)	89.83% (53)		59

Other, please describe	
#	Responses
	(18 total)
10	N/A
15	Cancer
30	Hard of hearing & Pulmonary Fibrosis
51	Ehlers-Danlos syndrome which affects my day to day life and also impacts on my body's ability to heal itself, including stopping bleeding.
57	Knee trauma, I wear a large knee brace and walk with elbow crutches. Due to no knee cap and trauma from fall knee is not really suitable for a knee replacement.
62	Hypermobile Ehlers-Danlos Syndrome of which GPs and all doctors need education. Postural Tachycardia Syndrome, Thoracic outlet syndrome, pineal cyst in brain and diverticulitis.
67	I fail to understand why a question relating to milk allergy requires questions relating to ethnic origins, nationality and sexual diversity. It might prove more beneficial if the the question asked would be whether the voucher system proposed would be embarrassing to those using it.
79	pcos
84	mobility issues
120	Arthritis in my joints
124	Psoriatic arthritis, fibromyalgia, spinal fusion, chronic pain, restricted mobility.
125	My son is 2 years old. He relied on nutramegan from 13 weeks old until 18 months old. As a result of this we had added pressures of seeing additional specialist due to his weight and growth not stopping consistent he gained a food aversion and wouldn't eat food all as a result of his milk allergy. He is getting better by the day and now he is milk tolerant as part of the support we have received. It was mentally and physically a struggle to cope with a baby who has a milk protein allergy but we got there with the viral support we received and I know we were lucky. Don't add more pressure on to future families they have a lot to deal with with milk allergy babies already.
127	Multiple sclerosis
129	Ehlers danlos syndrome
137	Stroke, very marked left sided hemi-paresis
155	Depression. Need glasses for long and short vision. Osteoarthritis.
157	Rheumatoid arthritis
180	Balance issues.
	(18 total)

