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Developing a Foodtalk Game as a nutrition and health training tool for early years staff

Background:

In England there are approximately 105,000 childcare providers (NAO, 2016). A large proportion of the lives of under 5s are in the care of such providers and this period, prior to a child starting school, is one of the most influential times in relation to growth, development and dietary exposure. 'Nutrition Matters for Early Years' (2016) states that our health during childhood and adulthood are influenced by our established eating patterns in the first few years of life. Giving every child the best start in life is crucial to reducing health inequalities in the duration of life.

One in five children are already overweight before they start school. With a large proportion of children's nutrition being provided in child care, the responsibility of child health lies heavily within these settings. Yet, a survey of 700 early years settings conducted by the Pre-school Learning Alliance and London Early Years Foundation (2016) found that the majority of settings (79 per cent) do not receive any external nutrition advice (EYNP, 2016).

Foodtalk is a Community Interest Company run by Paediatric Dietetics and specialising in community nutrition interventions for families. Foodtalk has worked with hundreds of early years practitioners, most of whom express concern about their lack of nutrition education, however they have neither the time, nor the funds, to commission traditional training modules. This shows the need for a simple and cost-effective tool that could train early years practitioners in the basics of nutrition and healthy habits for children aged 1-5. By increasing staff knowledge and confidence, there is potential to impact millions of children and thus, bring about real and measurable change.

Practice Development:

Our aim was to develop an interactive training tool to train early years staff in the basics of nutrition and health for ages 1-5. The process of developing an early years nutrition training tool started with a survey of early years settings to determine barriers to accessing nutrition training for staff. Cost was cited as the main barrier along with high staff turnover and lack of time.

This led to a review of innovative training methods and it was decided that an educational board game would be used. Research shows that board games as a method for training are proven to be engaging and significantly effective in improving both knowledge and confidence within health and social care workers. Additionally, they are low cost, can be used repeatedly by new members of staff.

The Foodtalk Game was developed in 2015 as an educational board game designed for anyone working in Early Years. It provides staff with a basic knowledge of early years nutrition and health, which can then be disseminated to both the children and their parents during informal conversations, developmental reviews or routine appointments. The game was designed to be grounded in current evidence, it is aligned to the 'Eat Better, Start Better' guidelines and it meets both local and national public health strategies including The 5 Year Forward View, Sustainability and Transformation Plans, Public Health Outcomes Framework and the Healthy Child Programme. Locally, the game aligns with most public health team's childhood obesity or early years nutrition strategies.

Once developed, the Foodtalk Game was piloted across 4 London boroughs, including staff in children centres, nurseries and a Health Visiting Team. In addition to playing the game and monitoring outcomes, participants were consulted on design, wording, topics, complexity of questions and game play. Over the course of a year, the development of the board game was shaped by the results of the consultation, as well as input from Dietitians, marketing experts and the board game development team.

Measuring impact:

The Foodtalk Game was commissioned by the London Borough of Brent to be integrated into their Healthy Early Years award. The game was played by early years staff in nineteen settings and results showed 78% of participants increased their knowledge and 86% increased overall confidence in supporting families.

"I played [the Foodtalk Game] with a team of 12 people and we loved it! Everyone was so excited and eager to find out what the next question would be. People talked about the answers and shared their opinions/knowledge on various things. The feedback from the staff was great and our action would be to play it with a targeted group of parents."

- Children's Centre Manager

The game was also independently analysed by a team at Plymouth University. Analysis showed Median scores of all five knowledge questions combined increased from 1.0 at baseline to 5.0 ($p = <0.001$) post-intervention and median confidence scores changed from 3.0 at baseline to 4.0 ($p = <0.001$) post-intervention.

A small-scale ($n=29$) trial in Hertfordshire was conducted using the game as a method to train parent nutrition champions. Results showed **100%** of participants felt likely to share the knowledge they had gained with other parents. This

demonstrates the game is also an effective method for disseminating important nutrition messages to families.

“it was a laid back way of learning important information, I think it will stick in my mind more than a factsheet or other ways of learning”

- Parent, Hertfordshire

The Foodtalk Game costs £60 and achieves comparable outcomes to traditional staff training modules which range from £300-£500. Additionally, it can be used as a Tier 1 childhood obesity intervention providing an even bigger return on investment for local authorities.

Learning:

Developing and evaluating the Foodtalk Game provided an opportunity for many key learning points and takeaways.

The first key learning point arose during the background research prior to developing the game. We knew that in order to develop a useful intervention it was important to conduct a needs assessment with the target audience (Early years practitioners). This was done through an informal consultation and questions around previous nutrition training and barriers to accessing nutrition training were asked. However, we did not ask any questions around how much of a priority settings place on nutrition training, or, in fact, even on what they define as nutrition training. Because of our internal biases around the importance of early years nutrition we unconsciously assumed that all early years practitioners would deem it important as well. However, this seemed not to be the case and a study conducted by our nutrition intern in 2017 showed that nursery staff put a very low importance on nutrition as part of their role. Many felt it was the role of the cook only and that frontline staff had very little to do with food and nutrition thus requiring no nutrition training. Additionally, most nurseries interviewed felt that Food Safety and Hygiene training was equivalent to nutrition training and sufficient for their staff. Had we known the low importance nursery staff place on nutrition training prior to developing the game we would have included more questions and marketing material on why it is important and how nutrition training can improve your setting.

The second key learning point is around the use of an educational board game. Although board games are used for training in a variety of health and social care topics, they can still be seen as juvenile or childish. Because the Foodtalk Game is targeted at the early years, many settings assumed it was for the children and not for the staff. In retrospect, referring to the Foodtalk Game as an “interactive training tool” instead of an “educational board game” may have helped to avoid

some of this confusion.

The third key learning, came during the development of the individual questions for the board game. As with any health topic, early years nutrition can often be complex with no specific right or wrong answer and as Dietitians we had a tendency to want to display these complexities within the game and account for all eventualities. However, long complex questions and answers do not make for good game play and after much back and forth with the board game “experts” we eventually had to simplify both our topics and language resulting in much better game play.

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An Impact Evaluation Report on the 'Healthy Little Eaters' nutrition education cooking programme in Children's Centres in Brent

Context

The London Borough of Brent is one of the most deprived boroughs in London and has one of the highest rates of childhood obesity in England. Obesity unjustly affects children in more deprived areas, who are more than twice as likely to be obese. Once established, obesity is notoriously difficult to treat, so **prevention and early intervention** are paramount. Tackling childhood obesity continues to be a priority for Brent Council and Brent CCG.

In Brent, 27% reception and 40% year 6 children are overweight or obese compared with 22% reception and 35% year 6 in England.

Early Years settings play a critical role by establishing a safe and supportive environment that promotes healthy behaviors (including healthy eating). Nutrition & Dietetics Brent (London North West University Healthcare NHS Trust) successfully bid for funding over a period of 8 years (2008 – 2016) to provide '**Healthy Little Eaters**': a nutrition education and cooking programme for children from 1-5 years & parents in Children Centres.

It aimed to improve nutritional health and wellbeing of children under five and their families. Each session focused on a different nutrition topic, cooking with children and parents (familiarising them with real foods) and - of course - eating!

Participant recruitment was carried out by Centre staff, with promotional material provided by our team.

Practice development

'Healthy Little Eaters' was set up in Children's Centres across Brent and aimed to improve health and wellbeing of children under 5 and their families and ultimately reduce the rates of obesity in Brent. It was delivered over 8 weeks, each session focusing on a different nutrition and eating topic including: reducing sugar and salt, foods for bone health, label reading, importance of fruit and vegetables, preventing iron deficiency, fussy eating and weaning.

The programme team included Dietitians and Nutrition Assistants, working closely with Centre staff to deliver the agreed syllabus.

Each 2-hour session included a nutrition topic, learning through facilitated discussion, preparing from a healthy recipe and eating the food together afterwards. The recipes were cooked with the children, encouraging participation and were low budget, healthy, quick and easy. The classes were

free of charge and open to families that visited each centre. Working in partnership, Brent's Oral Health Promotion Team attended a session to promote good oral health.

Programme objectives agreed with Brent Council were to increase:

- understanding of the Eat Well Guide
- portions of fruit and vegetables
- knowledge of healthy eating and physical activity for children
- understanding on ways to eat healthily on a budget
- understanding of food labelling, selecting healthier options, the benefits of cooking from scratch, food hygiene and safe preparation of food

Each 'Healthy Little Eaters' programme could accommodate up to 15 families per cohort. Although the standard syllabus was created and continuously reviewed by the team, there was room to individualize some aspects depending on the needs of centres (eg some did not have facilities to cook food and so cold recipes used instead).

Since the commencement of the 'Healthy Little Eaters' programme in 2008 the team have delivered more than 500 programmes across 15 Children's Centres in Brent, reaching approximately 1000 families.

Measuring impact

An evaluation questionnaire was undertaken during the final week. Across all centres the 'Healthy Little Eaters' intervention resulted in positive changes:

- 65% reported an increase in pieces of fruit consumed per day (0.9 pieces of fruit a day)
- 75% reported an increase in serves of vegetable consumed per day

(0.75 serves of veg/day)

- 67% reported a decrease in days families add salt to meals per week (1.46 decrease in days not adding salt)
- 47% reported a decrease in days a child refuses food or meals per week (0.61 decrease in days a child refuses)
- 63% reported an increase in the frequency the child is included in a food preparation in a typical week (increase by 1.38 days per week)
- 87% reported an increase in confidence when reading food labels

As a result, family mealtimes became more relaxed and happy. Parents reported to be more trusting of children with regard to their eating and felt confident in giving smaller portion sizes:

"I've learnt not to stress when he doesn't finish a meal. Before I used to think 'oh he hasn't eaten' I will give him more milk and then he wouldn't eat properly afterwards, so I have learnt not to force them."- Mother, Alperton Children's Centre

The cooking part of the programme demonstrated ways to include children in the preparation and thereby increasing exposure to children and ultimately increased food acceptance. The programme

was seen as an opportunity to turn cooking into a positive family experience through increased skills and confidence, a broadened cooking repertoire and less reliance on takeaways.

"You get out of the habit of buying ready made things – you can make from fresh. For instance if I was going to give them dahl I would have got it readymade from the fridge section". Mother, Hope Children's Centre

Learning Points

Overall, the results reflect the positive impact of 'Healthy Little Eaters' to equip participants with the knowledge, skills and confidence to cook; also to change cooking, eating and purchasing behaviours towards a healthier diet.

Learning / Considerations:

- 60% of families finished the full programme at week 8. This varied between centres – possibly due to advertising methods, presence or absence of weekly reminders and commitment of parents.
- Certificates at the end of the session were given with a sticker of their choice. However, no other incentives were used to promote completion of these cohorts. Incentives had been used in previous cohorts and shown to work well (eg children's cooking aprons featuring our 'Healthy Little Eaters' logo). Wykeham Children's Centre uses a £5 refundable deposit scheme and has shown to have good retention rates.
- Recruitment via word of mouth from staff and other parents appears to be the most successful method. If time permits it would be useful for the dietitian to visit centres and promote the session to staff and encourage recruitment. If no more than 5 parents are signed up the programme should be postponed.
- There is a need for simplified evaluation forms especially for those who do not have English as a first language.
- To overcome this barrier a focus group was conducted to capture more in depth data and enable those with a low level of English be able to express themselves without the need for literacy skills.
- Whilst we would continue to provide evaluation forms pre and post intervention to ensure equity we would consider conducting focus group or interviews / recording quotes to gather data from parents with low literacy and/or to explore outcomes.
- In the evaluation, parents reported a preference for 11-1pm sessions and our past experience is that poor attendance rates occurred when sessions started in the afternoon (perhaps to avoid school-run times in future).
- At the end of each session the dietitian or crèche worker led on a rhyming session. This was a great opportunity for families to bond and provided a sound closure to a session and is something we would continue to develop in future.
- Sessions held at Centres without hot cooking facilities were limited and overall the retention rates weren't as high as others with hot cooking facilities. Parents reported to have enjoyed the food preparation and requested more recipes.

The early establishment of healthy nutrition practices should be seen as an integral component to any local and national strategies to prevent and manage childhood obesity. It is evident that 'Healthy Little Eaters' sessions had a positive impact on family's health behaviours and therefore the programme needs to become part of a key core component of the Children's Centre yearly programme. Commissioners should consider the constant roll out of these sessions at Children Centres in Brent to continue momentum, reduce staff turnover, maintain relations and to gain more traction from all stakeholders. 'Healthy Little Eaters' was a clinically effective programme and can be scaled up.



Dietitian-led intensive lifestyle intervention programme for children identified as overweight or obese by NCMP in the London Borough of Brent: an overview

Background

Brent is one of the most deprived boroughs in London and has one of the highest rates of childhood obesity across all London Boroughs and in England^{1,2}. Nutrition & Dietetics Brent (London North West University Healthcare NHS Trust) successfully bid for and delivered the **'Fit4Health' lifestyle intervention programme** from September 2015 to March 2016.

'Fit4Health' was designed to offer support to children identified as overweight and obese by the National Child Measurement Programme (NCMP)³. Provided by Dietitians and Nutrition Assistants, the programme encouraged positive lifestyle changes for the whole family through good nutrition and physical activity. A sub-contracted private company provided certified physical activity instructors for each session⁴.

'Fit4Health' had these objectives:

Short Term:

- 300 overweight / obese reception and year 6 children to complete the programme
- Overweight/ obese children unable to attend but still interested given telephone advice on a healthy lifestyle and ways to implement daily activities.

Medium Term after 10 weeks:

- Improved nutrition and physical activity outcomes at 3 & 6 month follow ups
- Increased knowledge of behaviour change and goal setting
- Maintenance or reduction in waist circumference and BMI post programme and 3 & 6 month follow ups.
- 80% positive feedback from participants

Long Term if programme continued:

- Those children completing the programme who were identified as overweight or obese in reception will measure a healthy weight in year 6
- Increased engagement in publicly available nutrition and physical activity programmes

- Overall decrease in number of overweight and obese children in targeted schools

Practice development

Fit4Health' delivered structured group education sessions: a 7 week intensive after school programme for child and one family member based on:

- Behaviour change through goal setting and rewards
- Nutrition workshops & interactive cooking classes
- Fun and active exercise

The nutrition component was led by a registered Dietitian with a syllabus covering topics such as fats and sugars, label reading, fussy eating and managing mealtimes, Eat Well plate, portion sizes and healthy snacks. The practical component saw the preparation of healthy foods including yogurt sundaes, fruit kebabs and rainbow wraps which culminated in the children making a healthy snack at home to bring for a group healthy picnic.

The physical activity component was led by an independent organisation specialising in children's sports activities. Each session consisted of one hour of physical activity that the children could take part in together. The games required minimal equipment so that families could replicate them at home or in the park. Families were also taught the recommendations for physical activity and the risks of sedentary behaviour.

This **whole family approach** supports the adoption of healthy lifestyle behaviours and sustainability of the intervention⁵. With guidance from 'Fit4Health' staff at individual consultations, families were asked to create SMART goals the entire family would aim to complete by the end of the programme. These goals were reviewed in the final consultation to assess progress and offer any further support.

Schools identified by NCMP data³ with the highest levels of obese children were given priority to participate. The programme was adjusted to include a Special Needs Primary School for the first time. 'Fit4Health' dietitians worked closely with school staff to ensure that appropriate adjustments were made.

Measuring impact

Overall, the 7-month programme reached 303 children and 338 parents, carers and family members.

There was a 66% attendance rate and the majority of children came from minority ethnic backgrounds and deprived areas. 'Fit4Health' worked with 13 mainstream primary schools, 1 special needs school and 2 community leisure centres.

Key outcomes of the 10 week programme:

- 78% maintained or reduced their waist circumference post programme indicating a reduction in adiposity, specifically in the central region.
- 63% maintained or reduced their BMI at the end of the programme. While lower than the desired 80% it is still a good result over a 10 week time period. As the participants are young children it would be expected for them to be growing in height and weight.
- 87% reported to have increased or maintained their intake of fruit since starting the programme

- 86% reported to have increased or maintained their intake of vegetables since starting the programme
- 85% reported to have increased or maintained their intake of water since starting the programme

All qualitative data was collected using validated questionnaires pre and post. These showed that 88% of families achieved at least one of their long-term SMART goals and 96% of participants would recommend the programme to a friend.

Participant comments included:

“The programme has really helped my child try new foods. Before I was cooking a meal for us and a separate meal for my son but now I only have to cook the one meal because he is more willing to be adventurous with his food.”

“The programme is really starting to make a difference. We have taken the messages on board as a whole family. I didn’t expect it to have such a big impact. We make sure we do our goals each week.”

Learning points

The clinical outcomes and participant feedback indicated that ‘Fit4Health’ programme methodologies can have a beneficial and lasting impact upon families to prevent childhood obesity. However there is an urgent need to continue involvement with families on a long term basis in order to have a sustainable influence on the health and weight throughout the growing years and into adulthood. This approach is only possible with longer term investment in the commissioning process for whole systems care pathway for obesity.

If ‘Fit4Health’ were to be commissioned in the future the following recommendations should be considered:

- Incorporate the use of gym equipment and sports (eg. volleyball) into the physical activity component of the sessions for year 7 children. Feedback from both parents and children indicated the decline in attendance that took place with the year 7 children was due to the Activity Instructor-led games being played repeatedly were not suited to the older age group. The use of the gym equipment would allow the year 7 children to feel more like young adults rather than young children and would be likely to promote continued attendance.
- Physical Activity Instructors to give renewed focus to addressing the benefits of physical activity to parents and ways to incorporate physical activity into their day to day lifestyles.
- Special Need Schools should be included as part of the mainstream programme to ensure children with special educational needs are not excluded and therefore encourage health equality.
- Comments from teachers indicated a number of overweight and obese children not identified by the NCMP hence not invited to take part in the programme. In future, would encourage other children not identified to take part in the programme to ensure all children and families are being reached. Teaching staff and health professionals are in an excellent position to assist with this.
- Use a total wellbeing approach to the programme rather than the whole emphasis of the programme being on overweight and obese children.

- Consider conducting the one to one consultations as a group consultation- this will allow parents to share concerns and possible strategies when dealing with the overall health of their children. It may also allow parents to feel as if they are not alone in their concerns and struggles around their child's diet and physical activity lifestyles.
- Efforts need to be focused on the Early Years settings and Year 1 children (primary prevention) in order to prevent childhood obesity in the first instance. Therefore, a combined approach is required in order to have an effective influence on reducing childhood obesity - targeting families in the early stages and secondary prevention measures to target those older children who have been identified as overweight or obese.
- A long term, well designed and streamlined approach to childhood obesity across all the life span stages is in need if we are serious about preventing or reducing the levels of the UK's childhood obesity with parental involvement and responsibility of paramount importance.

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A Nutrition Education and Cooking Intervention in a UK Foodbank

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A case study exploring the practicalities and experiences of implementing a healthy diet skills programme in a foodbank setting.

Background

There has been an exponential rise of foodbanks in the UK over the past decade. In 2008/09 25,899 people received 3 days emergency food from UK foodbanks, this rose to 1,084,604 people by 2014/15 (1). The leading UK foodbank charity, The Trussell Trust, is a Christian organisation distributing food to those in need out of local church rooms or community centres. To address the foodbank clients' broader needs, a 'more than food' approach has emerged aiming to improve health and wellbeing and advance social circumstances. As part of the 'more than food' approach Coventry Foodbank and Coventry University in partnership working applied for funding from Lottery Awards for All to fund for one year a graduate part-time dietitian to design and deliver a cooking and nutrition course.

This intervention was deemed necessary as food insecurity is a growing concern in the UK with 8.4million individuals (13%) food insecure in 2014 (2). The diets of foodbank clients usually fall short of healthy eating recommendations as they are unable to acquire or consume an adequate quality or sufficient quantity of food (3). Coventry Foodbank wanted to be able to provide practical skills and knowledge regarding healthy eating and cooking at a low cost to supplement the foodbank parcel they were giving to clients.

The aims of the intervention were:

- To communicate health messages in an appropriate way to support dietary and lifestyle change

- To explore the role of a dietitian in a UK foodbank
- To test the feasibility of delivering a nutrition intervention for foodbank clients and to measure change in nutrition knowledge, food choice and confidence of healthy eating and cooking

Practice Development

A two-week nutrition education and cooking intervention was delivered in a UK foodbank by a dietitian. The population was defined as foodbank clients accessing support at Coventry Foodbank. The intervention involved 2 x 2hour sessions, split into one-hour nutrition education and one hour on cooking fresh vegetable soup. The focus of the intervention was on 'Soups for Revival' as this was a stipulation of the funding grant. It was felt that soup was a simple nutritious meal to use as a starting point to improve skills and knowledge.

All foodbank distribution centres had posters for advertisement. The intervention took place at four of the busiest foodbank centres. The kitchen facilities at these venues were basic and sometimes portable cooking equipment was taken to the venue. Recruitment took place for 2 weeks and following this the intervention was delivered for 2 weeks. Recruitment took place whilst clients received soup and a roll whilst waiting for their foodbank parcel. Giving out the soup and collecting the empty mug created the opportunity to recruit onto the programme.

The length of the course was agreed with different stakeholders. Recommendations from research highlighted the challenge of delivering an intervention in a hard to reach group within longer timeframes (4). Two weeks was felt to be an attainable course length that would reach a wider audience. At the time of delivering the intervention there was a local 9 week 'cook well eat well' council-run course being delivered, so clients were also able to be signposted to this course.

The content of the nutrition intervention was developed from existing interventions and available resources. This included:

Week 1: learning about The Eatwell Guide, food budgeting tips and reducing food waste. The first week tomato soup was made. When making the soup there was the opportunity to discuss cooking tips and get to know one another.

Week 2: meal ideas using ingredients given at the foodbank, understanding food labels and physical activity ideas. The second week the soup made was chosen by the group during the first session. The nutrition information was tailored to foodbank client's needs and resources. For example, one foodbank client only had a kettle and no other cooking facilities therefore some of the content was adjusted accordingly to meet their needs. Clients attending both weeks received a hand blender,

recipe cards and ingredients to make the soup at home. The resources were used as an incentive to sign up to the course and encouraged participants to make the soup at home instilling new behaviours.

Measuring Impact

An intervention-specific questionnaire was completed pre and post intervention, to measure change in nutrition knowledge, food choice and confidence. Knowledge was measured by asking foodbank clients the recommendations for physical activity, fruit and vegetable intake and questions on The Eatwell Guide. Food choice options related to budgeting and shopping were measured by identifying and ranking statements such as 'writing a shopping list' as: already do it, will try to do it and not for me. Confidence was measured by ranking a variety of variables on a 5-point Likert scale, such as 'preparing healthy meals from the foodbank parcel'. Feasibility was measured through client's uptake and attendance rates. A Wilcoxon test, McNemar paired sample test, and 2-tailed paired sample T-test were run on the data. 95% confidence intervals around the mean change was presented and statistical significance was accepted at $P < 0.05$.

42 foodbank clients completed the intervention, and on average there were 2-4 foodbank clients on each course. Only 2 foodbank clients (5%) did not complete the intervention. The low dropout rate (5%) demonstrated acceptability of the intervention. Attrition from recruitment of the intervention to attendance was high (42%). The mean age of participants was 36 years (± 12 s.d.), 70% were female and 68% identified as single.

Following the intervention there was an increase in clients' knowledge of the recommendations for physical activity (55%) and The Eatwell Guide (40%) ($P < 0.001$). Foodbank clients knew the recommendations for fruit and vegetable intake pre intervention, but their intake was low; on average 2 portions per day. Many of the food choice statements used to determine budgeting and shopping habits, were already observed, for example buying value brands ($P > 0.285$) and 'using tinned/frozen fruit and vegetables' ($P > 0.614$). Confidence was identified as the most improved measured variable. Across all variable's confidence increased with statistical significance, for example 'How confident do you feel in planning meals?' ($P < 0.001$).

Learning

Positive features of the intervention:

- There was a low dropout rate between week 1 and week 2 of the intervention (95%).
- Improvements were noted in nutrition knowledge and confidence.

- Many of the clients stated that their cooking confidence had increased, and they were planning to try to cook more meals at home.
- Many participants reported that they enjoyed the social aspect of the course.
- At recruitment, offering homemade soup and a roll engaged potential participants and provided a nutritious meal whilst they were waiting for their foodbank parcel.
- Incentives to participate were well received, they encouraged attendance and empowered foodbank clients to instil new behaviours.
- Feasibility has been tested for the role of dietitians' in UK foodbanks.
- The dietitian provided an advocate role to other services within the foodbank network, for example referring on to the job club.

Challenges of the intervention:

- Advertising and recruitment of the intervention to the target population took a significant amount of time for the dietitian.
- Many people signed up for the intervention but did not attend. Of the 96 people recruited for the intervention only 42 (42.7%) attended.
- Transporting the cooking equipment between venues.
- Foodbank clients seeing improving health as important. Many of the foodbank clients had other important factors to address in their life such as housing and finance. Attending the programme was a low priority.
- A part time dietitian role meant that not all foodbanks within the Coventry Foodbank network were able to be targeted. It was also challenging to complete the objectives of the role in the time available.
- Relying on volunteers to support delivery of the intervention as not always were they able to help due to other commitments.
- Limited evidence base in the subject area.

Recommendations:

- On the spot interventions may work better instead of asking clients to return on a future date. For example, delivering a health promotion topic as a stand which foodbank users are encouraged to access as they are waiting for their foodbank parcel. There could be different topics delivered each week, that are put on a repeated cycle, examples could be cheap but healthy snack ideas, getting your five a day and increasing fibre in the diet.

- The clients supported are facing extreme hardship so it is important to understand what would be helpful in times of crisis. For example, by providing a key take home message and keep nutrition knowledge and terminology basic to increase engagement, as baseline knowledge was low.
- Adding recipe cards to food parcels using ingredients enclosed would also be a simple yet effective intervention as many foodbank users feel unsure what to do with the ingredients they are given. This is something some but not all foodbanks do.
- Text messaging to be used as the main method of communication to remind foodbank clients about the intervention.

Conclusion

The intervention identified that a dietitian working within a foodbank is a feasible and worthwhile asset and produced similar findings to other published research (5). The intervention made an important contribution to the foodbanks 'More than Food' model. Improving confidence to prepare healthy meals is important to support behaviour change and should be a key focus in interventions like this. This case study highlights the evolving role of an allied health professional in the community setting developing on existing assets such as community buildings and volunteers.

'Food is a simple medium through which powerful positive change can take place within our community'

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Nutrition Skills for Life® (NSFL): Providing quality assured nutrition skills training for community workers and support for the development of community food and health initiatives

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Description

NSFL is a programme of nutrition training for health, social care and third sector workers, developed and co-ordinated by dietitians working in the NHS in Wales. Working with local communities and partner organisations, **NSFL** aims to build community capacity to access a healthy balanced diet, a major determinant of health, wellbeing and quality of life.

NSFL trains frontline workers, volunteers and peer leaders to promote healthy eating by incorporating evidence-based food and nutrition messages into their work. There are two key aspects to the programme;

1. Accredited nutrition skills training for community workers to help them to competently cascade nutrition messages and to support those working in community settings to provide healthy/nourishing food and drink options e.g. in nurseries, play groups, after school clubs, residential homes and care settings for older adults.
2. Co-production of healthy eating initiatives with community groups. This can include offering accredited practical cooking skills, nutrition skills or weight management courses depending upon identified need. All courses are accredited by the Welsh awarding organisation, Agored Cymru, enabling people to gain credit for learning; a potential route into further learning and employment opportunities.

Context

Launched in 2006, funded by Welsh Government and evaluated by Glyndwr University¹, **Nutrition Skills for Life®** operates in all seven NHS Health Boards in Wales.

Nutrition Skills for Life® aims to build capacity of communities to support healthy eating and prevent malnutrition.

The objectives are to:

- Increase the capacity of the community workforce in Wales to inform and support communities in healthy eating and prevention of malnutrition

- Develop a standardised approach for accredited nutrition training across Wales, promoting consistent nutrition messages and contributing to preventing nutrition related disease
- Support the development of healthier environments and improved access to nutritious foods through training and professional advice
- Support local action e.g. supporting development of local community food initiatives ensuring they are evidence based
- Support local partnerships to raise the profile of nutrition and help to achieve better outcomes in relation to nutrition and health for their population
- Focus on lower socioeconomic/hard to reach groups
- Focus on 0-25's and vulnerable older people

Poor diet is a risk factor for obesity and other chronic conditions such as type 2 diabetes, hypertension, cardiovascular diseases including heart disease and stroke, respiratory problems, joint problems, lower back pain, and some cancers e.g. breast and colon cancer. In Wales 61% of adults are overweight or obese, including 25% obese². More than a quarter of 4-5 year olds are classified as overweight or obese (26.4%) including 12% obese³. Obesity is steadily increasing with greater prevalence among lower socio-economic groups. Prevalence of obesity in 4-5 year olds is 6% higher in those living in the most deprived areas. This rises to a 13% difference in adults. High Body Mass Index (BMI) is the leading risk factor for Years Lived with Disability (YLD). The top 3 risk factors are directly linked to diet and obesity⁴.

Method

Dietetic services in Wales experienced increasing demand from partner organisations for quality assured nutrition training. The development of the health care support worker role and national programmes in Wales including Flying Startⁱ and Families Firstⁱⁱ, provided significant opportunities to train the wider workforce in nutrition. The development of a national nutrition skills training programme would provide a standardised, consistent, evidence-based approach to meet this increasing demand. Utilising dietetic expertise to train and support community workers to cascade evidence-based nutrition messages would reach more people than the dietetic service would be able to do alone.

During 2005, Public Health Dietitians in NHS Wales worked in partnership with Welsh Government, Agored Cymru and community workers to plan, develop, deliver and evaluate an accredited nutrition skills training programme. Since launching in 2006 a range of standardised learning, teaching and assessment resources including tutor facilitation manuals, learner workbooks and evaluation tools have been developed for all courses. This 'once for Wales' approach avoids duplication and benefits from economies of scale in line with prudent health care principles. The training model successfully supports implementation of nutrition elements of national schemes including the Healthy and Sustainable Pre School Scheme, Designed to Smile oral health projects, Welsh Network of Healthy Schools Scheme, Corporate Health Standard and the implementation of the Best Practice Guidance for Food and Nutrition for Childcare Settings⁵ and in Care Homes for Older People⁶. **NSFL** has achieved recognition as a model of good practice at local, national and UK wide level*. It has been successfully embedded into national programmes in some areas e.g. Flying Start and Families First and is firmly embedded in Welsh Government strategic priorities e.g. digitalisation of **NSFL** is a commitment within the Welsh Government's renewed priorities for **Healthy Weight: Healthy Wales 2020-2022**⁷.

Outcomes

External evaluation was undertaken by Glyndwr University from 2006-2010. Since then annual reports are submitted to Welsh Government. The Results Based Accountability approach to programme performance monitoring is used to monitor the extent to which **NSFL** programme objectives are being met and to ensure a standard all Wales approach.

Performance measures have been identified by Public Health Dietitians in Wales and data is collected using standard evaluation questionnaires and databases.

Evidence of impact between April 2018 and March 2019 includes:

- **91** Level 2 accredited courses were accessed by **902** staff
- **174** Level 1 nutrition skills courses were accessed by **1150** members of the community
- **157** non accredited training sessions were accessed by **2839**
- **100%** staff attending Level 2 courses rated the course as good (**16%**) or excellent (**84%**)
- **100%** staff attending Level 2 courses reported they would recommend the course to others
- **99%** individuals attending Level 1 courses rated the course as good (**13%**) or excellent (**86%**)
- **97%** staff accessing Level 2 courses gained credit for learning
- **84%** individuals accessing Level 1 courses gained credit for learning
- **99%** staff completing Level 2 CFNS training reported feeling confident (**72%**) or very confident (**27%**) to deliver the Level 1 accredited course
- **91%** reported learning something new about food and nutrition as a result of attending Level 1 course
- **88%** reported making changes to what they eat as a result of attending Level 1 course
- **94%** reported making changes to what their family eat as a result of attending Level 1 course
- **79%** reported eating more fruit and **70%** eating more vegetables as a result of attending Level 1 course
- **83%** reported eating less fatty /fried foods and **84%** less sugar/sweet foods as a result of attending Level 1 course

Key learning points

- We have worked nationally as a profession, avoiding duplication, sharing good practice, and collaborating to continually update and develop standardised, national nutrition learning and teaching resources.
- Working in partnership with an awarding body -Agored Cymru- enables learners to gain credit for learning and has ensured the quality and integrity of the programme is maintained.
- Continued to develop to support new initiatives e.g. the infrastructure has supported the roll out of other programmes utilising the same model i.e. 'Foodwise for Life' structured weight management programme and the School Holiday Enrichment Programme (SHEP).
- Maximised opportunities for partnership working with other organisations and initiatives to strengthen the nutrition component e.g. Flying Start, Welsh Network of Healthy Schools Scheme, Healthy and Sustainable Pre School Scheme.

The programme stalled during 2020 due to the Covid-19 pandemic. With physical distancing requirements likely to continue for some time we needed to transform our accredited traditional face-to-face training to online teaching and virtual face-to-face delivery to continue to reach communities to support healthy eating.

The Welsh Government has committed to 'Invest in fully digitalising the all Wales **Nutrition Skills for Life®** programme, enabling continuation, through virtual delivery, of all community-based initiatives including Foodwise for Life, Foodwise in Pregnancy and Community Food and Nutrition Skills programmes'.

Our future priorities are:

- Ensure every child has the best start in life by optimising nutrition in the first 1000 days.
- Ensure the early years and childcare workforce and those caring for older people have the knowledge and skills to be able to improve nutrition and hydration for those they care for.
- Embed healthy eating into the school curriculum by training others to deliver nutrition and food skills training for children and young people, including the School Holiday Enrichment Programme.
- Widen access to accredited Level 1 nutrition, practical cooking skills and weight management course enabling more people to gain credit for learning.

The programme is on track to be fully digitalised by April 2021. This will provide renewed opportunities to further integrate nutrition skills training into local and national initiatives in Wales and to have far wider population reach.

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* Winners of the UK wide Bevan prize for "Health and Wellbeing 2014"

Winners of an NHS Wales Award in the category of "Promoting Better Health and avoiding disease 2014"
<http://www.wales.nhs.uk/sitesplus/901/news/33500>

Winners of Cwm Taf University Health Board "Health and Wellbeing Award 2013

Finalist in the Royal Society of Public Health- Health and Wellbeing Awards 2017

<https://www.rsph.org.uk/about-us/news/health-wellbeing-awards-2017-shortlist-announced.html>

ⁱ Flying Start is a Welsh Government funded programme and is available in targeted areas supporting all families to give children aged 0-3 year 11 months a Flying Start in life.

ⁱⁱ Families First is a Welsh Government funded programme designed to improve outcomes for families with children & young people aged 0-25 years. It places emphasis on early intervention, prevention and providing support for whole families, rather than individuals helping families become confident, nurturing and resilient.



Slow cooking for communities, Northern Ireland

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Introduction and context

In February 2019, the Cook it! Team in partnership with North Ballymena Community Cluster (NBCC) group devised a cross community project “Slow cooking for communities” in the Dunclug & Doury Road areas in Ballymena. The NBCC aims to “increase social cohesion within the North Ballymena Area, reducing anti-social behaviour and sectarianism and increasing community confidence and wellbeing”¹. Dunclug was identified as one of the most deprived super output areas within Mid and East Antrim for four of the seven domains including health and disability, income, education, skills and training and crime and disorder, resulting in them reaching the top 10 multiple deprivation list².

Evidence shows those living in deprivation are 47% more likely to be obese than those living in non-deprived areas³. Obesity is a significant health concern in Northern Ireland with 65% of adults being overweight or obese.

The National Diet and Nutrition Survey Northern Ireland shows that food energy from saturated fat exceeds the recommended maximum level, by 15-20% in children aged 4 years upwards and 20-27% in adults. Excessive amounts of saturated fats are linked with cardiovascular disease⁴.

Conversely, AOAC fibre intake (American Association of Analytical Chemists method) and fruit and vegetables intake, did not meet recommended levels⁵.

An interactive cooking class was the chosen programme design as research has shown that this type of intervention can improve confidence with cooking as well as improving dietary intake⁶. It was felt slow cooking was a convenient and cost-effective way to encourage families to cook from scratch whilst reducing reliance on processed convenience foods and takeaways. These foods tend to be higher in saturated fats and salt, and red and processed meats in excess is linked to an increased risk of colorectal cancer⁷.

Method

An open invite was sent via WhatsApp and word of mouth by a NBCC community worker to two housing areas within the NBCC catchment area. An informal coffee morning was set up to allow participants to find out more about the project, get to know the Cook it! team, choose their favourite recipes and if desired, to sign up to the programme.

Four weekly interactive sessions lasting 2 hours were delivered by a Registered Dietitian covering theory on food safety, how to use a slow cooker, general healthy eating principles, sustainable diets, sugar, and fat. We used the British Dietetic Association's environmentally sustainable diet project, 'One Blue Dot' to demonstrate how sustainable eating can also be cost effective and good for one's health. A group activity demonstrating how useful store cupboard items can be in creating multiple dishes was included. Visual displays demonstrating the sugar and fat content of foods was discussed with participants.

During each session, the group prepared a recipe as a team. At the end of the session, they were encouraged to taste the recipe - a batch pre-prepared by the Cook it! Team. Participants who did not own a slow cooker, were provided with one funded by NBCC. Ambient ingredients were provided for each attendee to encourage replicating the recipe at home. The Cook it! team decided against providing high-risk foods, such as beef or poultry to minimise the risk of food poisoning.

A WhatsApp group was set up and managed by NBCC, to encourage group interaction and social cohesion. Each participant received a copy of the Causeway Coast and Glens Borough Council Slow Energy Efficient recipe book ⁸ and some kitchen utensils.

An intervention specific questionnaire was carried out pre and post programme, using remote devices from Turning Technologies. This allowed responses to be kept anonymous.

Outcomes

Despite the small pilot size, this programme showed promising results. Following the programme participants reported a 57% increase in cooking from scratch, 100% participants felt confident using a slow cooker and using a slow cooker once a week or more. 80% of participants reported making healthy changes to their diet and reported improved awareness of healthy eating. Takeaway consumption reduced from 86% of participants purchasing 2-4 times per week to 80% having takeaways once or less per week, with the remaining 20% having takeaways no more than twice per week. There was a reduction in the use of processed foods. At baseline, 43% of the group consumed processed foods daily, this reduced to 100% consuming these foods twice or less per week, following the programme. A study by Mills et al (2017) supports home cooking for health.

"...eating home cooked meals more frequently was associated with better dietary quality and lower adiposity" ⁹.

Fruit and vegetables intake did not change with 100% of the group consuming 0-2 portions per day.

Participants from both communities attended and interacted well with each other, sharing ideas on WhatsApp and working together.

A focus group at eight months post initial intervention revealed:

- 100% of participants would recommend the programme and the use of a slow cooker to their friends/family.

- 50% of participants have used their slow cooker at least 1-2 times per week since attending and the remainder used it at least a few times.
- 57% reported consuming takeaways once or less per week.
- 57% reported consuming processed foods once or less per week.
- 100% found the sessions interesting and enjoyed learning more about food and nutrition.
- The group enjoyed practical cooking, food sampling and interactive displays.
- No one used the Causeway Coast and Glens Slow Energy Efficient recipe book.

Key learning points

The group reported enjoying the short interactive educational sessions on healthy eating, followed by a practical cooking session. A slow cooker is not required for everyone and participants indicated they would have attended irrespective of the provision of a slow cooker, therefore the need for this could be checked at registration. Ambient ingredients did not have the positive impact of encouraging the recipe replication at home, therefore we would review the provision of these items in future.

A printed recipe book was provided to each member. However, from feedback these were not used. Supplying a PDF version via the group WhatsApp or use of online resources would save cost and would be more environmentally friendly. Participants suggested a series of 'fake-away' recipes would be useful to include in future recipe books.

It is widely accepted that the cause of obesity is multifactorial but participants provided feedback they would like to know more about portion sizes and calories.¹⁰ Although obesity rates in this group were not reviewed, this desire to increase knowledge of portions sizes and calories is encouraging, given the link with larger portion sizes and increased energy intake.¹¹

Follow-up at 8 months showed the sustained use of the slow cooker. However, we did not review the type of recipes being prepared in the slow cooker. This would have been useful to review to understand more detail on the types of food prepared.

This pilot was presented to and reviewed by our regional colleagues in the Public Health Dietitians group in Northern Ireland and has since been adapted into a train-the-trainer model, with training sessions being delivered virtually and knowledge passed on to groups, including those from socially deprived areas, throughout Northern Ireland.

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Title: Get Nourished: preventing, identifying and treating malnutrition in older people in Dundee

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Description

This project used five initiatives to prevent and improve the detection and management of malnutrition in older people in Dundee. The project had started in 2019 and it was predicted that the emergence of the COVID-19 pandemic would exacerbate nutritional risk in older people due to restricted access to shopping and a reduction in essential care and support. Restrictions on face-to-face activities required innovative ways of working and partnership with a number of organizations. It has resulted in increased awareness and detection of malnutrition risk, improved access to first line nutritional advice, improved nutritional intake, reduced social isolation and enabled delivery of accessible, consistent nutritional training.

Context

It is estimated that one in ten people over the age of 65 are malnourished or at risk of malnutrition. It is both a cause and consequence of ill-health but is often overlooked¹. Research has shown that providing timely first line nutritional advice can prevent further disease as well as protect people from falls and frailty and improve recovery time following illness².

It was predicted that the COVID-19 pandemic would exacerbate nutritional risk due to limited access to shopping and a reduction in essential care and support³. Restrictions on face-to-face activities required innovative ways of working and partnership with a number of organisations.

The aim of this project was to prevent and improve the detection and management of malnutrition in older people in Dundee, while working within the restraints imposed by the COVID-19 pandemic, and consisted of five objectives:

1. To increase awareness and detection of malnutrition risk through use of nutritional screening
2. To increase access to nutritional advice by establishing a telephone advice line
3. To deliver nutritious snacks (Boost Boxes) to people identified as being at risk of malnutrition

4. To provide support to vulnerable people through a weekly meal delivery service and social check in
5. To increase access to standardised nutrition training by developing online training videos

Method

Staff from the NHS Tayside Falls Prevention Team and volunteers from the Royal Voluntary Service were trained to use the Patients Association Nutrition Checklist (PANC)⁴ to identify people at risk of malnutrition, give basic advice and signpost to services for further support. PANC was chosen instead of the Malnutrition Universal Screening Tool (MUST) as it is simpler to complete remotely because it does not require measurement of height or weight. PANC has been shown to have moderate agreement with MUST when used to screen for the prevalence of malnutrition risk in older adults in the community⁶.

A telephone advice line was established for people concerned about malnutrition risk either in themselves or someone they care for. It was manned by trained healthcare support workers for three hours on three days per week. Additionally, the service could be accessed via a dedicated email account. Information was gathered from individuals using a locally produced, standardised form and they were then provided with first-line nutritional advice and signposted or referred to other services where appropriate. The advice line was publicised using posters in GP surgeries and community pharmacies, social media platforms and emailing multiple partner agencies.

People identified as being at risk of malnutrition either through nutritional screening or after calling the telephone advice line were offered Boost Boxes. These contained 14 high energy/ high protein snacks such as milk puddings, malt loaf, dried fruit and drinking chocolate powder and were designed to provide extra nourishment when appetite was reduced. The content of the boxes was adapted for anyone with special dietary requirements. Trained volunteers from Dundee Volunteer and Voluntary Action delivered the Boost Boxes, reviewed their use weekly and refilled the boxes where appropriate for up to three weeks. Ideas for suitable snacks were discussed if appetite remained reduced after the three-week period, enabling self-management of long term conditions to prevent avoidable admissions to hospital or care homes.

An existing supper club, which had been providing a fortnightly evening meal to 30 diners, was adapted to provide a weekly meal delivery service and social check-in. People who were identified as at risk of social isolation by partners or community members were referred to the Community Development Worker, who would then assess whether the service was appropriate for the individual. Meals were cooked by staff in a local school that had been furloughed and delivered by healthcare support workers. Additionally they received weekly telephone calls to reduce social isolation. Funding for the Boost Boxes and meals was obtained from the Scottish Government Covid Response Fund.

Short training videos were developed and made available on YouTube to address the following topics:

- Signs and symptoms of undernutrition
- Food Fortification
- Nourishing Drinks
- How to fortify your milk
- Get Nourished Advice Line

Outcomes

Feedback from those trained to use the PANC⁴ indicated that it was easy to use.

Over a one year period, 70 people called the advice line, with the majority of callers (80%) seeking advice for themselves. On review, 51% of callers reported that they had been able to fully implement the advice provided and 25% had implemented it partially. Twenty-two percent of callers were referred to the Nutrition and Dietetic Service for more specialist support. Almost half of the callers had been signposted to the advice line by the Falls Prevention Team.

Over a one-year period, 48 people were identified as requiring support due to poor appetite and over 150 Boost Boxes were delivered as some required support for longer than three weeks. No referrals to other services were required. Initially there were regular referrals but this decreased over time. Approximately seven people were receiving Boost Boxes at any one time.

Between March and October 2020, over 3000 meals were delivered and over 1600 phone calls were made, providing support, advice and companionship to older people across Dundee. An evaluation survey was issued to 24 households and 16 responses were received. These 24 households were selected as they were within the geographical area of the existing supper club. The survey asked in which ways the service had helped them and the results are shown below.

	Yes	No
I am better nourished	15	1
I am more socially connected to my community	16	0
I am physically healthier	15	1
My mental health has improved	15	1
My general and emotional wellbeing has improved	14	2
I am less lonely	14	2
I feel valued and supported by the community	16	0
My overall morale has improved	16	0

One recipient commented “It has helped me a great deal especially as I have no family nearby. Getting a phone call and knowing where to turn for support is brilliant. I really appreciate everything. I would like to come to the supper club when it starts up again.”

Use of videos enabled training and information to be shared quickly, efficiently and consistently. Each video has been viewed approximately 100 times and care home staff reported that they found the one on Food Fortification particularly helpful.

Key learning points

Five partner organisations were involved in this project and it would not have been possible without strong partnership working.

There have been fewer calls to the advice line than expected. This highlights the need for a communication plan to ensure greater awareness of the service. Red flag signs should be agreed to allow identification of those requiring urgent referral to other services.

Many people offered Boost Boxes were given advice to fortify their milk. Therefore, skimmed milk powder was later added to the boxes to make it easier to implement this advice. Some of those referred for a box had often complex and chaotic lives and food insecurity was the main issue rather than poor appetite. Availability of Boost Boxes needs to be continuously advertised to promote their use.

As restrictions were eased, the supper club was replicated in other areas within Dundee.

As a follow-up to the videos that were developed in-house, a series of professionally produced training videos⁶ on preventing, identifying and treating malnutrition have now been developed. These are endorsed by the Care Inspectorate and care providers across Scotland include them within their mandatory training.

This project was undertaken at a time when restrictions imposed by the COVID-19 pandemic necessitated a change in working practices. If circumstances had allowed collection of baseline data and evidence of economic impact, this would have strengthened the outcome data of the project.

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Title

Applying a novel outcomes based public health model to co-design nutritional resources and information in Sickle Cell Disease

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Description

This case study outlines how a novel outcomes-based model and a participatory learning alliance methodology was effectively applied to co-develop evidenced based nutritional resources and information, to address key knowledge and information gaps affecting people living with Sickle Cell Disease (SCD). The case study project was underpinned by the findings of a recent qualitative study conducted by a dietitian, to identify influencing factors affecting the integration of nutrition into standard care in SCD.

Four main themes were identified following data analysis including the following: invisibility of SCD, under recognition of the importance of nutrition, lack of priority to nutrition and the multifactorial factors affecting nutrition and service provision. These themes reflect both the complexity of sickle cell nutrition and myriads of knowledge and care gaps impacting on the safety and quality of care available to this patient population.

Further analysis of these themes resulted in the development of the concepts of Prevention, Education, Empowerment, Contextual Factors and Engagement (PEECE) model. The PEECE model was used as a health improvement strategy for the case study project to address the knowledge and information gaps in sickle cell nutrition to improve the health and wellbeing outcomes of the sickle cell patient population

Context

SCD is a marginalised² genetically inherited red blood cell disorder, the fastest growing genetic disorder in the UK³, with an estimated 17,500 people living with the condition. The main clinical features of SCD, chronic hemolysis, vaso-occlusion and impaired immunity are directly responsible for the medical and nutritional implications in this condition⁴. However, nutrition in SCD is overlooked, underdeveloped and not part of standard care provision resulting in the lack of nutrition services, poor knowledge, awareness, information and resources surrounding nutrition available to the SCD patient population, impacting their health and wellbeing outcomes¹.

A recent participatory qualitative study¹ confirmed several knowledge and care gaps in sickle cell nutrition. The findings revealed that both the sickle cell service user/carer participants had to self-research what they know about SCD and nutrition online, general and often unverified sources, leaving patients at risk of misinformation to self-manage their complex nutritional problems/risks. Similarly, the provider participants had to self-research SCD and nutrition– identifying serious concerns about the level and quality of nutritional care in SCD, necessitating urgent action to improve the health and wellbeing outcomes of people affected by SCD and empower them to better self-manage their condition.

Poor access to health and education are recognised determinants of health⁵. As such the lack of nutrition knowledge, awareness, information and resources adds to the health inequalities experienced by people affected by SCD, negatively impacting their experience, access and outcomes of nutrition¹. Therefore, the PEECE model, an outcomes-based model, was used in conjunction with the learning alliance methodology to address the knowledge gaps in SCD. The case study, a co-design project in collaboration with sickle cell patients and carers, aimed to co- develop nutritional resources and information to address the knowledge, resources and information gaps in SCD, to improve patient outcomes on a population level.

Method

The methodology and methods adopted for the project were largely determined by the co-design approach to the project to foster high levels of engagement, collaboration, knowledge sharing and empowerment. To ensure a wide-ranging patient/carer participation, recruitment of participants was undertaken in collaboration with the network managers of the 10 NHSE Haemoglobinopathy Coordinating Centre's (HCCs) in England, recognised as key gatekeepers to ensure good representation from across England.

The project was designed as a four phased participatory learning alliance methodology⁶ (LAM), an emerging methodology in healthcare research and effective when working with participants from Black and Minority Ethnic (BME) groups. Four focus groups (Phase 1), co-design of resources (Phase 2), evaluation of the resources (Phase 3) and wide dissemination (Phase 4) were the main methods and processes used in the project, facilitating high levels of participant engagement, knowledge sharing and learning thereby promoting co-development.

A key motivation for using the PEECE outcomes-based model as the implementation strategy of the project is the participatory methodology with the study participants (sickle cell patients/carers). The PEECE model reflects key principles of healthcare management, public health (prevention), health promotion (education and empowerment), personalised care (contextual factors), co - production (multi-stakeholder engagement) and knowledge sharing.

Therefore, the PEECE model helped to facilitate the co-development of nutrition resources, personalised and tailored to the unique nutrition needs, risks and challenges of the sickle cell patient population. The model helped reinforce the concepts of prevention, education and empowerment, whilst also learning firsthand from the participant's perspectives, the multiple contextual factors influencing their nutritional needs.

The participatory co-design approach was successful in supporting the co- development of nutritional resources and information tailored to the needs of the sickle cell population, thereby addressing the knowledge, resources and information gaps and improving patient health and wellbeing outcomes.

Outcomes

The initial insights shared by the participants about the project being a vehicle through which their voices could be heard and their nutritional needs identified and recognised as a problem to be addressed, shed light on the project's value and importance.

These are reflected in the comments from sickle cell service user/carers (SU-C) and service providers (SP), from a recently published study¹ -

SU-C (6) – “nutrition for me I think plays a major part in staying well ...I’ve never directly been asked about my nutrition and how I eat...I’ve kind of looked up myself”.

SU-C (6) – “I think it boils down to availability of the information”.

SU-C (3)- “... nutrition has been a massive part of my mental health”.

SP (1) – “I work in the community, it’s not very well managed to be honest... nobody really knows what I know, it was just what I’ve kind of researched myself”.

A total of eight leaflets and two infographics were developed as the main outputs of the study, targeting an audience that includes both patients, caregivers, providers, health planners and policy makers. Plans are in place to produce short and longer videos on the topic. The following participant perspectives: *this is groundbreaking stuff’; thank you, I didn’t know about pica, I’m so glad I was part of this project’; I really found the information very helpful’; we need to share this nationally’*, illustrates the impact of the resources.

Moreover, the participant perspectives demonstrate the impact of the project to address the knowledge and information gaps affecting the health and wellbeing outcomes of the sickle cell patient population, whilst also informing a wider audience. Thus, this pioneering project has the potential to make a valuable contribution to improving the health and wellbeing outcomes of the sickle cell population in the UK and globally.

Key learning points

The project provided a few key learning points, the first being accounting for the time delays from confirmation of the project to conducting the focus groups, that has resulted in many participants not being available when the focus groups were eventually scheduled. Other learning points included having support with the project proposal costings, and importantly, having a clear vision for achieving the aims and objectives of the project.

Time and money were saved on recruitment, having the support of all 10 HCC Network managers, and having available a project information sheet with clear aims and objectives for the project and the time commitment. Holding online focus groups enhanced participant participation, which was facilitated by a student dietitian who made additional field notes.

Not being able to secure enough participants to attend the in-person co-design meeting was a challenge. To overcome this limitation, those who attended in person focused on designing the resources and a follow-up online meeting was scheduled with the remaining members to discuss what was designed and provide their input and suggestions for the designs to be taken forward.

Future project considerations include, having more representation from all patient cohorts especially the paediatric and pregnancy groups. All the resources are now available on a dedicated online platform – The Optimising Sickle Cell Nutrition Compendium

(<https://bit.ly/scnacomp>) hosted by a non-profit organisation, Sickle Cell Nutrition Academy. These resources are the first of its kind and having a dedicated website will enhance the patients' access to these and future reliable evidenced based nutritional resources and information.

Dissemination of the resources include key strategic and statutory organisations, including the SCD and thalassaemia APPG, NHSE HCC's and the UK Forum for Hemoglobinopathy Disorders. A key lesson learnt is not being afraid to ask for help and having a clear vision and mission for change.

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