



## 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 marginalised<sup>2</sup> genetically inherited red blood cell disorder, the fastest growing genetic disorder in the UK<sup>3</sup>, 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 condition<sup>4</sup>. 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 outcomes<sup>1</sup>.

A recent participatory qualitative study<sup>1</sup> 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 health<sup>5</sup>. 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 nutrition<sup>1</sup>. 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 methodology<sup>6</sup> (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 study<sup>1</sup> -

*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.

## References

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