



Nutritional Screening and Malnutrition Priority Setting Partnership PROTOCOL June 2018

1. Purpose of the PSP and background

The purpose of this protocol is to set out the aims, objectives and commitments of the Nutritional Screening and Malnutrition Priority Setting Partnership (PSP) and the basic roles and responsibilities of the partners therein. It is recommended that the Protocol is reviewed by the Steering Group and updated on, at least, a quarterly basis.

The James Lind Alliance (JLA) is a non-profit making initiative, established in 2004. It brings patients, carers and clinicians together in Priority Setting Partnerships (PSPs). These partnerships identify and prioritise uncertainties, or 'unanswered questions', about the effects of treatments that they agree are the most important. The aim of this is to help ensure that those who fund health research are aware of what really matters to both patients and clinicians. The National Institute for Health Research (NIHR – www.nihr.ac.uk) funds the infrastructure of the JLA to oversee the processes for priority setting partnerships, based at the NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC), University of Southampton.

The Nutritional Screening and Malnutrition PSP is funded by the General and Educational Trust (GET), which is part of the British Dietetic Association (BDA), and is managed by a research team within the University of Manchester. The University of Manchester and GET aim to identify and prioritise uncertainties of people who have malnutrition or who will go through the nutritional screening process within our health care system. This will help nutrition researchers identify questions of importance and therefore inform the priorities of other research funders.

2. Aims, Objectives and Scope of the Malnutrition PSP

The aim of the Nutritional Screening and Malnutrition PSP is to identify the unanswered questions about Nutritional Screening and Malnutrition diagnosis and treatment from patient and clinical perspectives and then prioritise those that patients and clinicians agree are the most important.

The objectives of the Nutritional Screening and Malnutrition PSP are to:

- work with patients, carers, social care professionals, and clinicians to identify uncertainties about the effects of Nutritional Screening and treatments for undernutrition.
- agree by consensus a prioritised list of those uncertainties, for research
- publicise the results of the PSP and process through our partners, social media and scientific publications
- take the results to research commissioning bodies for health and social care, to be considered for funding.

The scope of this PSP: Malnutrition means poor nutrition and is a serious condition which happens when **not enough food** or **too much food** is eaten. When not enough food is eaten the body starts to use up its own stores of energy (sugar and fat) and protein. This is known as **undernutrition** and can have harmful effects on the body. When too much food is eaten the body becomes overloaded (**over nutrition**), which can also lead to harmful effects on the body. **Nutritional screening** means the steps taken in healthcare to identify those who may be **at risk of malnutrition**, and who may benefit from **suitable nutritional support**. In many UK healthcare settings the Malnutrition Universal Screening Tool (MUST) is used for nutritional screening.

What we are going to include in this work?

For the purposes of this work we are only focussing on **undernutrition** (including undernutrition in obesity) and **nutritional screening**. Undernutrition can be difficult to recognise, especially in people who are overweight or obese to start with. Some symptoms may include:

- Loss of appetite
- Weight loss – clothes, rings, jewellery, dentures may become loose
- Tiredness, loss of energy
- Reduced ability to perform normal tasks
- Reduced physical performance – for example, not being able to walk as far or as fast as usual
- Altered mood – malnutrition can be associated with lethargy, depression or a general lack of interest
- Poor concentration

This project will consider malnutrition across **all diseases, in all settings**, and in the **adult population** (18 yrs and over). Malnutrition in children is a large field of study and would benefit from its own separate PSP.

Malnutrition in **specific groups** will be included in this PSP, including but not limited to: the elderly; those with difficulties accessing food; Black, Asian and Minority Ethnic (BAME) groups; travelling communities; those who are homeless; those in secure units and prisons; refugees; those with social and psychological issues: and those with mental health issues or conditions, some of which may be severe.

Treatments for malnutrition that will be included in this work must be a strategy involving combinations of macro and micronutrients aiming to improve nutritional intake using the oral route. Therefore any oral, supplementary, and alternative therapy treatment for malnutrition will be included; any treatment that is considered artificial (i.e. feeding via a tube or vein) will be out of scope.

What will be excluded in this work?

This project will not include malnutrition issues relating to specific diseases, but will take a generic approach across all disease states. Parenteral and enteral (artificial tube feeding) treatments and single nutrient treatments for malnutrition will be excluded. Issues relating to access to health care and health care services will be excluded. Any questions that are asking for help, advice and access to services will be out of scope (if possible signposting will be implemented for these responses).

3. The Steering Group

The Nutritional Screening and Malnutrition PSP will be led and managed by patients, carers and clinical professionals. We have endeavoured to recruit representatives from all 3 areas as we recognise that all perspectives are important:

Patient representative/s:

Individuals with a lived experience of Malnutrition (patient or carer)

- Margaret Ogden (Carer)
- Ruth Day (Carer)
- Marie McDevitt (Patient)
- Philip Paulden (Patient)
- Sue Lynne (Patient and Carer)

Clinical representative/s:

- Prof. Simon Lal, Consultant Gastroenterologist Salford Royal NHS Foundation Trust

- Dr Christine Baldwin, Lecturer in Nutrition and Dietetics, Kings College London
- Dr Elizabeth Weekes, Senior Consultant Dietitian, Guy's and St Thomas' NHS Foundation Trust
- Prof. Jane Murphy, Co-Lead Ageing and Dementia Research Centre, Bournemouth University
- Dr Emma Stanmore, Lecturer in Nursing, University of Manchester
- Liz Anderson, Nutrition Nurse Specialist, Stoke Mandeville Hospital and rep for Malnutrition Action Group (MAG), part of BAPEN
- Loraine Gillespie, Dietetic Manager, The Christie, Manchester
- Kirstine Farrer, Consultant Dietitian, Salford Royal NHS Foundation Trust and Salford Age UK / MTF
- Emma Connolly, Salford Age UK / MTF
- Natalie Welsh, Lead nutrition practitioner and rep for National Nurses Nutrition Group

The Partnership and the priority setting process will be supported and guided by:

- University of Manchester
 - Dr Sorrel Burden, Senior Clinical Lecturer in Dietetics (PSP Lead)
 - Debbie Jones, Nutrition Research Associate (PSP coordinator and information specialist)
- The James Lind Alliance (JLA)
 - Toto Gronlund, JLA Advisor

The Steering Group includes representation of patients, carers and clinicians¹.

The Steering Group will agree the resources, including time and expertise that they will be able to contribute to each stage of the process. The JLA will advise on this.

4. The Wider Partners

Organisations and individuals will be invited to be involved with the PSP as partners. Partners are groups or individuals who will commit to supporting the PSP by disseminating the PSP survey and helping the PSP to gather questions and uncertainties of practical clinical importance relating to the treatment and management of the health problem in question. Partners represent the following:

- people who have had Malnutrition
- carers of people who have had Malnutrition
- medical doctors, nurses, social care professionals and professionals allied to medicine with clinical experience of Malnutrition.
- Volunteers from support groups

It is important that all organisations which can reach and advocate for these people should be invited to become involved in the PSP. The JLA Adviser will take responsibility for ensuring the various stakeholders are able to contribute equally to the process.

Exclusion criteria

Some organisations may be judged by the JLA or the Steering Group to have conflicts of interest. These may be perceived to adversely affect those organisations' views, causing unacceptable bias. As this is likely to affect the ultimate findings of the PSP, those organisations will not be invited to participate. It is possible,

¹ In some cases, it has been suggested that researchers are represented at this level, to advise on the shaping of research questions. However, researchers cannot participate in the prioritisation exercise. This is to ensure that the final prioritised research questions are those agreed by patients, carers and clinicians only, in line with the JLA's mission.

however, that interested parties may participate in a purely observational capacity when the Steering Group considers it may be helpful.

5. The methods the PSP will use

This section describes a schedule of proposed stages through which the PSP aims to fulfil its objectives. The process is iterative (repetitive for improvement) and dependent on the active participation and contribution of different people. The methods adopted in any stage will be agreed through consultation between the Steering Group members, guided by the PSP's aims and objectives. More details can be found in the Guidebook section of the JLA website at www.jla.nihr.ac.uk where examples of the work of other JLA PSPs can also be seen.

Step 1: Identification and invitation of potential partners

Potential partner organisations have been identified and invited to be involved in this PSP. Partner organisations include BAPEN, BDA, MAG and Macmillan. Any other potential partners will be identified through a process of peer knowledge and consultation, through the Steering Group members' networks. Additional potential partners will be contacted and informed of the establishment and aims of the Nutritional Screening and Malnutrition PSP and may be invited to attend and participate in an initial stakeholder meeting if this is being arranged.

Step 2: Initial stakeholder meeting / awareness raising ²

The initial stakeholder meeting / awareness raising will have several key objectives:

- to welcome and introduce potential members of the Nutritional Screening and Malnutrition PSP
- to present the proposed plan for the PSP
- to initiate discussion, answer questions and address concerns
- to identify those potential partner organisations which will commit to the PSP and identify individuals who will be those organisations' representatives and the PSP's principal contacts
- to establish principles upon which an open, inclusive and transparent mechanism can be based for contributing to, reporting and recording the work and progress of the PSP.

Step 3: Identifying treatment uncertainties

Methods will be identified for the obtaining of questions and uncertainties of practical clinical importance and cost effectiveness relating to the treatment and management of Nutritional Screening and Malnutrition. These methods will be designed and implemented and a period of 1-2 months will be given to finalise methods and a period of 4 months will be given for the consultation and collection of information and uncertainties. The methods must be as transparent, inclusive and representative as is practicable. Methods may include membership meetings, email consultation, postal or web-based questionnaires, internet message boards and focus group work.

Existing sources of information about treatment uncertainties for patients and clinicians will be searched. These can include question-answering services for patients and carers and for clinicians; research recommendations in systematic reviews and clinical guidelines; protocols for systematic reviews being prepared and registers of ongoing research.

² PSPs will need to raise awareness of their proposed activity among their patient and clinician communities, in order to secure support and participation. Depending on budget this may be done by way of a face-to-face meeting, or there may be other mechanisms by which the process can be launched.

The starting point for identifying sources of uncertainties and research recommendations is NHS Evidence: www.evidence.nhs.uk.

Step 4: Refining questions and uncertainties

The Steering Group will need to have agreed exactly who will be responsible for this stage – the JLA can advise on the amount of time likely to be required for its execution. The JLA will participate in this process as an observer, to ensure accountability and transparency.

The consultation process will produce “raw” unanswered questions about diagnosis and the effects of treatments. These raw questions will be assembled and categorised and refined by **Debra Jones (coordinator and information specialist)**, into “collated indicative questions” which are clear, addressable by research and understandable to all. Similar or duplicate questions will be combined where appropriate.

Systematic reviews and guidelines will be identified and checked by **Debra Jones (coordinator and information specialist)** to see to what extent these refined questions have, or have not, been answered by previous research. Sometimes, uncertainties are expressed that can in fact be resolved with reference to existing research evidence - ie they are "unrecognised knowns" and not uncertainties. If a question about treatment effects can be answered with existing information but this is not known, it suggests that information is not being communicated effectively to those who need it. Accordingly, the JLA recommends strongly that PSPs keep a record of these 'answerable questions' and deal with them separately from the 'true uncertainties' considered during the research priority setting process.

Uncertainties which are not adequately addressed by previous research will be collated and recorded on a template (supplied by the JLA) by **Debra Jones (coordinator and information specialist)**. This will demonstrate the checking undertaken to make sure that the uncertainties have not already been answered. This is the responsibility of the Steering Group, which will need to have agreed personnel and resources to carry this accountability. The data should be submitted to the JLA for publication on its website on completion of the priority setting exercise, taking into account any changes made at the final workshop, in order to ensure that PSP results are publicly available.

Step 5: Prioritisation – interim and final stages

The aim of the final stage of the priority setting process is to prioritise, through consensus, the identified uncertainties relating to the treatment or management of Nutritional Screening and Malnutrition. This will be carried out by members of the Steering Group and the wider partnership that represents patients and clinicians.

- The interim stage, to proceed from a long list of uncertainties to a shorter list to be discussed at the final priority setting workshop (e.g. up to 30), may be carried out over email or online, whereby organisations consult their membership and choose and rank their top 10 most important uncertainties. There are examples of how other PSPs have achieved this at www.jla.nihr.ac.uk in the Key Documents of the [Anaesthesia and Perioperative Care PSP](#) section and the [Childhood Disability PSP](#) section.
- The final stage, to reach, for example, 10 prioritised uncertainties, is likely to be conducted in a face-to-face meeting, using group discussions and plenary sessions.
- The methods used for this prioritisation process will be determined by consultation with the partner organisations and with the advice of the JLA Adviser. Methods which have been identified as potentially useful in this process include: adapted Delphi techniques; expert panels or nominal group techniques; consensus development conference; electronic nominal group and online voting; interactive research agenda setting and focus groups.

The JLA will facilitate this process and ensure transparency, accountability and fairness. Participants will be expected to declare their interests in advance of this meeting.

6. Dissemination of findings and research

Findings and research

It is anticipated that the findings of the Nutritional Screening and Malnutrition PSP will be reported to funding and research agenda setting organisations such as the NIHR and the major research funding charities. Steering Group members and partners are expected to develop the prioritised uncertainties into research questions, and to work to establish the research needs of those unanswered questions to use when approaching potential funders, or when allocating funding for research themselves, if applicable.

Publicity

As well as alerting funders, partners and Steering Group members are encouraged to publish the findings of the Nutritional Screening and Malnutrition PSP using both internal and external communication mechanisms. The Steering Group may capture and publicise the results through descriptive reports of the process itself in Plain English. This exercise will be distinct from the production of an academic paper, which the partners are also encouraged to do. However, production of an academic paper should not take precedence over publicising of the final results.

7. Agreement of the Steering Group

Signed by the Steering Group

The undersigned agree to follow the Nutritional Screening and Malnutrition Priority Setting Protocol.

Name:

Organisation (If applicable):

Signature:

Date:

Partnered with:



GPs interested
in Nutrition