Priority setting for adult malnutrition and nutritional screening in healthcare: A James Lind Alliance

Abstract

Introduction Malnutrition is one the greatest global health challenges of our generation leading to increased utilisation of healthcare resources, morbidity and mortality. Research has primarily been driven by industry, academia and clinical working groups and had little involvement from patients and carers. This project aims to establish a priority setting partnership allowing patients, carers, and health care professionals an opportunity to influence the research agenda.

Methods A national survey was conducted to gather malnutrition uncertainties and identify key issues (areas within scope where an evidence-base is lacking) from those with experience of malnutrition. Uncertainties were analysed according to themes. Similar questions were grouped and summary questions were developed. A second survey was conducted and respondents were asked to choose their 10 most important summary questions. A workshop was conducted to finalise the top 10 research priorities from the most frequently indicated uncertainties on the interim survey.

Results Overall, 1128 uncertainty questions were submitted from 268 people. The interim survey had 71 responses and a list of the top 26 questions was generated for the workshop. There were 26 questions discussed, ranked and agreed by health care professionals, carers and patients at the workshop. The top 10 research priorities were then chosen. These included questions on oral nutritional supplements, vulnerable groups, screening, community care, use of body mass index and technology.

Conclusions The top 10 research priorities in malnutrition and nutritional screening have been identified from a robust process involving patients, carers and healthcare professionals.

Keywords: Malnutrition, nutritional screening, James Lind Alliance, Priority setting, healthcare research agenda.

Introduction

Malnutrition in all forms continues to be one of the greatest global health challenges of our generation(1) with an estimated 462 million adults worldwide being identified as underweight(2). Every country in the world is affected by malnutrition in one form or another and in the UK malnutrition affects around 2.65 million people and costs the National Health Service £19.6 billion each year(3-5). Malnutrition usually manifests as nutritional deficiencies or excesses causing measurable, adverse effects on tissue or body form and function influencing clinical outcome(6). For the purposes of this manuscript the term malnutrition will be used to refer to under nutrition only, which includes being underweight or having inadequate vitamins and minerals(2).

Nutritional screening is used in the majority of hospitals in the UK to detect malnutrition. The malnutrition universal screening tool (‘MUST’), which is validated and recommended in national guidance(7), has been implemented in most hospitals throughout the UK since its development in 2003(6). A recent survey(5) indicated that 29% of patients in hospital are identified as malnourished when assessed using ‘MUST’(8). Despite the implementation of ‘MUST’ in hospitals, malnutrition is often unrecognised and is left untreated in many acute and community environments(9; 10). However, there is evidence demonstrating that when malnutrition is identified and treated appropriately there are direct patient benefits in relation to morbidity and mortality shown in a variety of clinical situations and settings(11-13).

Patients and carers have had little opportunity to be involved in setting the research agenda in malnutrition(14) and in general healthcare research is often funded by industry, in particular pharmaceutical companies in healthcare and academics(15-17). Healthcare research is often undertaken without taking the needs of patients and healthcare professionals into consideration(18-20).

The James Lind Alliance (JLA) is a non-profit making initiative, which was established to encourage patients, carers and clinicians to come together to corroborate their joint needs and set research priorities(21). This type of collaboration is known within the JLA process as a: Priority Setting Partnerships (PSPs). The aim of these partnerships is to identify uncertainties, or ‘unanswered questions’, about the effects of a particular treatment or disease and then prioritise those uncertainties. The JLA process can help to ensure that those who fund health research are aware of what really matters to both patients and clinicians. The priority setting process, which is supported by the National Institute for Health Research (NIHR), is systematic, transparent and contributes to part of a widening approach to patient and public involvement in research.

The aim of this project was to establish a JLA priority setting partnership to give patients, carers, and health care professionals the opportunity to influence research priorities in adult malnutrition.

Methods

The Nutritional Screening and Malnutrition PSP was led by the University of Manchester and managed within JLA structures and processes(22) and methods were informed by JLA. A robust process was used to ensure patients, carers and professionals were brought together from an equal position of power, without any hierarchy, to determine the priorities for research. The project was registered with JLA and followed pre specified JLA processes in order to establish research questions that were of direct relevance to patients and professionals. A JLA advisor supported and facilitated the process and ensured consistency throughout. The full JLA process included: i) set-up of a steering group committee and agreement of the scope and protocol (supplementary A); ii) gathering evidence from literature; and iii) a four step priority setting process (1. gathering uncertainties; 2. organising uncertainties into themes; 3. interim priority setting; and 4. final priority setting), see figure 1.

i) Set-up of the steering group committee and project partners

Potential healthcare and charitable partner organisations, who could provide access to a wide range of participants, were identified and invited to be involved in the PSP. Organisations that accepted were partnered and agreed to promote work and progression. Potential steering group members, with experience of malnutrition, across a broad range of settings, including patients and carers, were also identified and contacted. Steering group members from a healthcare background were identified by purposive sampling, whereby key organisations and individuals with a specific focus on malnutrition were contacted. A list of these organisations can be found in supplementary material B. Advertisements were used to purposively recruit patients and patient carers to become steering group members using patient specific websites including ‘People in research’ and ‘Salford citizen scientist’. Patients and carers who were interested, contacted the research team directly and those who became members were offered hourly payments for their time.

A steering group was established and met quarterly throughout the project. To engage members of the public and partners; a MalnutritionPSP twitter account was set up and used for promoting activities and progress.

ii) Gathering evidence from the literature

In addition to gathering malnutrition uncertainties this project also gathered data from existing literature and carried out an umbrella review. Details of this can be found in the PROSPERO registered protocol CRD42018094702. This allowed us to understand current evidence and determine if the uncertainties submitted had already been answered within published literature. Supplementary C lists the uncertainties that were considered to be out of scope and why, including uncertainties that had already been answered by previous research.

iii) Four step priority setting process

1. Gathering uncertainties

A survey was created by the steering group members, using the example surveys provided by JLA from previous PSPs. An initial first draft of the survey was created and all steering group members reviewed and commented on the layout, content and wording. In particular, lay members of the steering group were able to provide useful feedback on the clarity, acceptability and comprehension of the survey.

Broad question categories were provided in the survey in order to guide participants and ease submission of their uncertainties; these broad categories were based on similar categories used by previous PSPs. The exact layout and phrasing of the survey was redefined after a pilot survey involving nine people diagnosed with malnutrition, five malnutrition healthcare professionals and five people with a general interest in malnutrition.

After development and piloting, the survey was distributed nationally to gather ‘uncertainties’ in malnutrition from those with any kind of experience of malnutrition including patients, carers, health care professionals and academics. Partners promoted the survey and we advertised online through ‘people in research’, ‘Salford citizen scientist’, ‘University of Manchester’, and @malnutritionPSP twitter account. Participants included those 18 years and over with lived-experience of malnutrition either as a patient, carer, health and social care professional, non-clinical researcher, or representative of a patient group. Respondents were asked about three main areas in malnutrition: Screening and identification; treatment and prevention; and different settings or different patient groups. Respondents could also respond on any other areas they felt were relevant. Due to a low response rate from patients and carers and through feedback from some healthcare professionals that the term ‘malnutrition’ was not necessarily understandable by patient groups, a second version of the survey was created. This version removed the word ‘malnutrition’ and used ‘patient friendly’ language, including the phrases ‘eating less’, ‘poor appetite’ and ‘unplanned weight loss’. The second version was developed and reviewed by the steering group using the same process as the first version. Due to time constraints we were not able to pilot this version. Both the original version and second version were made available online and as paper-based copies with prepaid reply envelopes.

2. Organising uncertainties

The analysis of the initial survey data followed methods of data processing of uncertainties from JLA(23). This was a detailed process involving the steering group, where ratification and confirmation were required for each key procedural point to ensure accountability and transparency.

The consultation process (initial survey) produced “raw” unanswered questions about diagnosis and effects of treatments for malnutrition. These raw questions were entered into an electronic database verbatim. Data were then assembled, categorised and refined. Questions were firstly grouped according to themes based on keyword phrases and then similar questions were combined into one ‘collated indicative question’. All indicative questions were written in a format that would be clear, amenable to being answered by research design methods, and comprehensible to all. The steering group was informed about questions and themes that were emerging and asked to verify. Once the list of uncertainties had been developed the steering group ratified by checking off duplicates and ensuring adherence to pre-specified project scope. A clear inclusion and exclusion criteria applied to determining any out of scopes uncertainties. This criteria was specified a priori in the protocol. Systematic reviews and guidelines were identified by the umbrella review and uncertainties were cross checked with the evidence base.

Indicative questions, which had not been adequately addressed by previous research were collated and recorded as an interim list by the data management team and checked and confirmed by the steering group.

3. Interim priority setting

A second interim survey was created using the list of indicative questions from the initial survey. This survey was a straight forward list of the indicative questions and therefore no layout design or pilot was required. A few sentences, agreed by the steering group, were constructed at the start of the survey to provide brief instructions to users. Participants of this survey were presented with a list of questions and asked to select their 10 most important indicative questions.

The aim of the second survey was to begin prioritisation of identifying uncertainties. The number of times a question was selected by any given participant was recorded, so questions could be ordered according to popularity. The data were split into two groups: patient, carers and patient representatives; and healthcare professionals, allowing for recognition of the top priorities for each group. Responses were analysed according to frequency and a list of the top questions was generated to go forward to a final workshop.

The survey was only available online due to the nature of the survey, which involved a long list of questions. It was considered that this could not be appropriately managed on paper and would be overwhelming to the user. The distribution channels mirrored those used in the first survey. In addition, respondents from the first survey were contacted directly if details had been provided. However, as responses were anonymous we were not able to track the number of participants that responded to both surveys.

4. *Final priority setting*

The final workshop was arranged and a balance of patients, carers and clinicians were invited to agree the top 10 priorities. The same routes of promotion were used as in the surveys.

The workshop was facilitated by three James Lind advisors to ensure transparency, accountability and fairness when discussing the questions. The prioritisation exercise was organised over a full day and participants were provided with the 26 questions in advance. Selection and prioritisation of the top 10 questions during the workshop included discussions, group work and use of question cards for ranking using; the nominal group technique(24). Staff from an independent living service contributed to the process remotely prior to the workshop occurring. This contribution involved participants ranking the questions in order of importance with reasons and then stating their top and bottom three questions. This feedback was integrated into the discussions at the workshop by a representative for each small group discussion.

Ethics

The surveys and group work within this PSP were considered to be patient and public engagement activities, which do not require formal ethical approval. However, to ensure the safeguarding of participants we established standard operating procedures for collecting information. All surveys were answered anonymously by participants. Personal details of participants provided were handled in accordance to the University of Manchester privacy policy and a privacy notice was included on the survey. Respondent's personal details were password protected and stored securely in line with the Data Protection Act and data management policy of the University of Manchester. All data collected from the surveys was stored on an anonymised, electronic database.

Results

i) Set-up of the steering group committee and project partners

The project's partners were established and agreed between February to April 2018 and included: The British Association for Parenteral and Enteral Nutrition (BAPEN), The British Dietetic Association(BDA), The Malnutrition Action Group (MAG), Macmillan, Hertfordshire Independent Living Service (HILS), Salford Royal NHS Foundation Trust, Age UK Salford, Malnutrition Task Force, Wessex Academic Health Science Network (WAHSN), National Care Association, and Care England. The main role of the partners was to support the project and promote the surveys to relevant members of staff and patient groups.

The project steering group included: dietitians (n=4); nutrition nurse specialists (n=2); a voluntary sector representative; a gastroenterologist; nutrition and healthcare professionals and lecturers (n=2); a patient representative; patients with experience of malnutrition (n=2); and carers (n=2).

ii) Gathering evidence from the literature

The umbrella review of the systematic reviews was completed and used alongside the four step prioritisation process.

iii)Four step priority setting process

1. *Gathering uncertainties*

The first survey was launched in June 2018 and was open for 8 months. Overall, 1128 uncertainty questions from 268 people were submitted. This including 194 professionals and 74 patients and carers, 86% were female and 78% were White British. The age range was 21 to 93 (median 45) years and respondents were located across the UK, plus a few international locations (Table 1).

2. *Organising uncertainties*

Of the submitted uncertainties the steering group deemed that 65 were out of scope and 32 had already been answered (Figure 1). The remaining 1031 uncertainties were categorised into 7 themes and then into 30 different subthemes (Table 2). Questions with repeating items were grouped together and formed into one indicative question. In total 81 indicative questions were created and put forward for the second interim survey.

3. *Interim priority setting*

The interim survey was conducted in April 2019 and asked people to choose which 10 questions in the long list of uncertainties were most important to them. During this survey 71 people responded, of these 53 were health care professionals and 18 were patients and carers, 79% were female and 60.5% were White British. The age range was 19 to 77 (median 48) years and respondents were located across the UK (Table 1). The top 15 question from patients and carers were put forward to the final list for the workshop. Due to equal positions of questions selected by healthcare professionals only the top 13 were selected and taken forward. The next four questions from healthcare professionals were in an equal position at 14. The steering group were asked to determine the order of priority of these four questions and decided that one question was important enough to be carried forward, creating a final list of 26 questions for the workshop.

4. ***Final priority setting***

The final workshop was held in Manchester in June 2019. The workshop was facilitated by three James Lind advisers and was attended by 17 people from across the UK, including dietitians (n=5), a speech and language therapist, a policy officer for the BDA, a nurse practitioners, a Dietetic Assistant, a Macmillan Project Dietitian, voluntary sector representatives (n=2), patients (n=3) and carers (n=2).Seven people attended the separate meeting for the independent living service, this including four community dietitians, a registered nutritionist, a member of the administration team and a team member with experience of malnutrition as a carer.

During the workshop attendees were split into three groups and each group was managed by one of three JLA advisors. The groups separately agreed and ranked the 26 questions for importance. Groups were then mixed up and questions were ranked again. Ranking was recorded from all group sessions and a final overall ranked list was created (Table 3). The workshop finished with a whole group discussion and the final top 10 priorities were decided and agreed (Figure 2).

Discussion

The aim of the partnership was to address the uncertainties of those with experience of malnutrition, and prioritise the most important uncertainties that should be addressed by research. The partnership brought together people with a wide range of malnutrition experiences, including those working in the area and those affected by the condition. The project was a valuable opportunity for people with lived experience and professionals to work together and shape the research agenda for malnutrition in adults.

Over 300 respondents from across the UK were involved in the two stages of identification and prioritisation of malnutrition uncertainties. Respondents represented those living across the UK and included responses from a wide age range. The majority of respondents were White British but both stages of the prioritisation process saw representation from Asian, Black African, Black Caribbean and White Irish backgrounds.

The final workshop culminated with a list of the top 10 research priorities for malnutrition. The priority considered to be of most importance was ‘early intervention in vulnerable groups to help prevent malnutrition’ and the second most important was asking ‘what is the best way to carry out screening in the community’. This highlights the need to be reaching vulnerable groups in the community and being able to identify issues before they develop. This would include: practical ways to measure nutritional status and body composition validated against criterion measurements(25); improvements in communication post discharge(26); and adaptation of the current screening methods according to the circumstances(27).Improvements in this area have already been made with novel developments in self-screening tools that are more suitable for community use in the voluntary sector domiciliary care and with social care partners. The Paperweight Armband™ is a public health signposting tool created in Salford and being piloted in five boroughs in Greater Manchester(28). Also, there has been development of new tools for earlier identification of malnutrition risk around a conversation for the wider workforce including volunteers and family carers, such as the Patients Association Nutrition Checklist(29) and an interactive version such as the ‘Nutrition Wheel’(30). However, further work is imperative in this area in order to raise awareness, increase recognition of malnutrition and understand what works for the vulnerable and in the community.

Other topics covered by the top 10 priorities included: oral nutritional supplements, screening, community care, use of body mass index, and use of technology (table 3). These results can now be used to help funders identify important priorities for future research, which are relevant to both healthcare professionals and patients and their carers. This will potentially lead to more valuable research in malnutrition, including screening and assessment, as it will clearly identify research questions that will be of use in clinical practice and be meaningful to patients, carers and members of the profession of dietetics. There are many examples where research priorities, identified in the top 10 by a JLA PSPs, have resulted in research funding and projects including: Crohns PSP, colitis PSP and Palliative care PSP(31). It is hoped that the valuable work undertaken for this PSP will lead to similar successes and outcomes.

Limitations of this project include a limited numbers of people recruited from diverse ethnic backgrounds who would have been able to read and write in English to complete the surveys.

Therefore, the results of this project may be more representative of the White, English-speaking population. Future PSPs should consider engaging with more diverse ethnic groups including Black, Asian and Minority Ethnic communities and creating surveys in multiple languages would also be of benefit to support engagement. In addition to this there were fewer patients responding to the surveys than healthcare professionals, and we found that there appeared to be a lack of understanding around risk of malnutrition, malnutrition and the definition of malnutrition. Similarly, fewer patients and carers attended the final workshop, which may have provided a disproportionate representation of the patient and carer populations. It is also worth noting that malnutrition crosses all diseases and so it is difficult to assess patients readily in the way that a PSP for a specific condition may be able to do.

Another limitation was the exclusion of children and adolescents as this was considered to be a separate but just as important issue, which would require its own PSP. Therefore a future PSP could also be considered for childhood and adolescent malnutrition in the UK.

Feedback from this PSP will be provided to all patient groups, healthcare professionals and organisations that have been involved and could be involved in future funding and research. It is the aim of this PSP to influence the national agenda so results will be made available to funding and research agencies to assist with setting research priorities and funding calls on malnutrition and screening.

Conclusions and dissemination

After conducting the JLA PSP, we now have 10 research priorities identified in malnutrition and nutritional screening from a robust process involving both healthcare professionals and patients and carers. It is anticipated that these results will be used nationally to inform the research agenda in malnutrition and nutritional screening in adults.

Transparency declaration

All authors affirm that this manuscript is an honest, accurate, and transparent account of the study being reported. The reporting of this work is compliant with PRISMA guidelines. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned with James Lind Alliance and as stated in the protocol have been explained.

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