

1 **Priority setting for adult malnutrition and nutritional screening in healthcare: A James**

2 **Lind Alliance**

3

4 **Abstract**

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

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

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

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

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

28

29 **Introduction**

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

39

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

49

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

55

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

66

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

70

71 **Methods**

72 The Nutritional Screening and Malnutrition PSP was led by the University of Manchester and
73 managed within JLA structures and processes⁽²²⁾ and methods were informed by JLA. A
74 robust process was used to ensure patients, carers and professionals were brought together

75 from an equal position of power, without any hierarchy, to determine the priorities for
76 research. The project was registered with JLA and followed pre specified JLA processes in
77 order to establish research questions that were of direct relevance to patients and
78 professionals. A JLA advisor supported and facilitated the process and ensured consistency
79 throughout. The full JLA process included: i) set-up of a steering group committee and
80 agreement of the scope and protocol (supplementary A); ii) gathering evidence from
81 literature; and iii) a four step priority setting process (1. gathering uncertainties; 2. organising
82 uncertainties into themes; 3. interim priority setting; and 4. final priority setting), see figure 1.
83

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

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

97

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

101

102 *ii) Gathering evidence from the literature*

103 In addition to gathering malnutrition uncertainties this project also gathered data from
104 existing literature and carried out an umbrella review. Details of this can be found in the
105 PROSPERO registered protocol [CRD42018094702](https://doi.org/10.1111/CRD4.2018094702). This allowed us to understand current
106 evidence and determine if the uncertainties submitted had already been answered within
107 published literature. Supplementary C lists the uncertainties that were considered to be out of
108 scope and why, including uncertainties that had already been answered by previous research.

109

110 *iii) Four step priority setting process*

111 *1. Gathering uncertainties*

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

117

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

123

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

142

143 ***2. Organising uncertainties***

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

148

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

162

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

166

167 ***3. Interim priority setting***

168 A second interim survey was created using the list of indicative questions from the initial
169 survey. This survey was a straight forward list of the indicative questions and therefore no
170 layout design or pilot was required. A few sentences, agreed by the steering group, were
171 constructed at the start of the survey to provide brief instructions to users. Participants of this

172 survey were presented with a list of questions and asked to select their 10 most important
173 indicative questions.

174

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

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

187 ***4. Final priority setting***

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

190 The workshop was facilitated by three James Lind advisors to ensure transparency,
191 accountability and fairness when discussing the questions. The prioritisation exercise was
192 organised over a full day and participants were provided with the 26 questions in advance.
193 Selection and prioritisation of the top 10 questions during the workshop included discussions,
194 group work and use of question cards for ranking using; the nominal group technique⁽²⁴⁾.
195 Staff from an independent living service contributed to the process remotely prior to the
196 workshop occurring. This contribution involved participants ranking the questions in order of

197 importance with reasons and then stating their top and bottom three questions. This feedback
198 was integrated into the discussions at the workshop by a representative for each small group
199 discussion.

200

201 **Ethics**

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

211

212 **Results**

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

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

222

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

227

228 *ii) Gathering evidence from the literature*

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

231

232 *iii) Four step priority setting process*

233 *1. Gathering uncertainties*

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

238

239 *2. Organising uncertainties*

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

245

246 *3. Interim priority setting*

247 The interim survey was conducted in April 2019 and asked people to choose which 10
248 questions in the long list of uncertainties were most important to them. During this survey 71
249 people responded, of these 53 were health care professionals and 18 were patients and carers,
250 79% were female and 60.5% were White British. The age range was 19 to 77 (median 48)
251 years and respondents were located across the UK (Table 1). The top 15 question from
252 patients and carers were put forward to the final list for the workshop. Due to equal positions
253 of questions selected by healthcare professionals only the top 13 were selected and taken
254 forward. The next four questions from healthcare professionals were in an equal position at
255 14. The steering group were asked to determine the order of priority of these four questions
256 and decided that one question was important enough to be carried forward, creating a final
257 list of 26 questions for the workshop.

258

259 ***4. Final priority setting***

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

267

268 During the workshop attendees were split into three groups and each group was managed by one of
269 three JLA advisors. The groups separately agreed and ranked the 26 questions for importance.
270 Groups were then mixed up and questions were ranked again. Ranking was recorded from all group

271 sessions and a final overall ranked list was created (Table 3). The workshop finished with a whole
272 group discussion and the final top 10 priorities were decided and agreed (Figure 2).

273

274 **Discussion**

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

281

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

287

288 The final workshop culminated with a list of the top 10 research priorities for malnutrition.
289 The priority considered to be of most importance was ‘early intervention in vulnerable groups
290 to help prevent malnutrition’ and the second most important was asking ‘what is the best way
291 to carry out screening in the community’. This highlights the need to be reaching vulnerable
292 groups in the community and being able to identify issues before they develop. This would
293 include: practical ways to measure nutritional status and body composition validated against
294 criterion measurements⁽²⁵⁾; improvements in communication post discharge⁽²⁶⁾; and
295 adaptation of the current screening methods according to the circumstances⁽²⁷⁾.Improvements

296 in this area have already been made with novel developments in self-screening tools that are
297 more suitable for community use in the voluntary sector domiciliary care and with social care
298 partners. The Paperweight Armband™ is a public health signposting tool created in Salford
299 and being piloted in five boroughs in Greater Manchester⁽²⁸⁾. Also, there has been
300 development of new tools for earlier identification of malnutrition risk around a conversation
301 for the wider workforce including volunteers and family carers, such as the Patients
302 Association Nutrition Checklist⁽²⁹⁾ and an interactive version such as the ‘Nutrition
303 Wheel’⁽³⁰⁾. However, further work is imperative in this area in order to raise awareness,
304 increase recognition of malnutrition and understand what works for the vulnerable and in the
305 community.

306

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

318

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

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

331

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

335 Feedback from this PSP will be provided to all patient groups, healthcare professionals and
336 organisations that have been involved and could be involved in future funding and research.

337 It is the aim of this PSP to influence the national agenda so results will be made available to
338 funding and research agencies to assist with setting research priorities and funding calls on
339 malnutrition and screening.

340

341 **Conclusions and dissemination**

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

346

347 **Transparency declaration**

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

353

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