



A Holistic Approach to Nutrition and Diet in Palliative Care

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Summary

Enabling change that meets the needs of patients and carers and is accepted and built into practice by a multi-professional team is always a challenge. This report describes the journey undertaken by a multi-professional group working in a local hospice who used a practice development approach to ensure that they assessed and met the nutritional needs of patients and carers in an effective, holistic way. Drawing on a strong team ethos and commitment to meeting patients' needs across all disciplines in the hospice, they listened to patient and carers' experiences. This led them to develop an assessment tool for nutritional care (PLANC) that assessed the needs of both patients and their carers. It was audited and found to be more appropriate for use in palliative care than the MUST tool (malnutrition universal screening tool) currently in use. The practice development approach also led to unforeseen and beneficial changes in communication with the kitchen staff and the provision of food across the hospice.

Background

Dorothy House Hospice is a charitable organisation based at Winsley in Wiltshire. It provides specialist palliative care across the area of Bath and north east Somerset, west and north Wiltshire and the Mendip area of Somerset. The total population is approximately 500,000 and includes both urban and rural areas. Holistic palliative care is offered throughout the community to patients who have a life limiting illness with complex palliative care needs and their carers. The majority of the patients have cancer but patients can include those with MND, MS, dementia, mental impairments, end stage heart failure and COPD. The facilities include a 10 bedded inpatient unit, a day patient unit and two outreach centres in the community. Patients and their families are cared for by highly skilled multidisciplinary teams which can include doctors, nurses, physiotherapists, occupation therapists, lymphoedema specialist practitioners, chaplains, social workers, complementary therapists, bereavement workers, a dietician and creative therapists.

This project was influenced by two separate but related issues. On the one hand, the Care Quality Commission requires that every healthcare establishment should meet their patients' nutritional needs and Dorothy House Hospice's NHS contract stipulates the need for nutritional assessments. On the other hand, palliative patients have complex and varying needs regarding their food and nutrition.

In 2010, the Care Quality Commission released the 'Essential Standards of Quality and Safety' where it recommends that every healthcare establishment should meet their patients' nutritional needs (Outcome 5). In conjunction with this, part 1b of the Dorothy House Hospice NHS contract schedule quality requirement indicates that all patients admitted to Dorothy House Hospice should have a nutritional assessment performed, applied and reviewed regularly (personal communication). Therefore, in September 2012, in order to comply with national standards, a dietician was employed who introduced a screening tool and supported patients with nutritional advice in combination with an appropriate care plan (Dorothy House Hospice, 2013). A small group, consisting mainly of nurses, was formed to encourage the implementation of this tool and as a result a Nutritional Link practitioner group was introduced to help with the implementation of an adapted version of the Malnutrition Universal Screening Tool (MUST) across the organisation. The MUST is a widely used nutritional screening tool in primary and secondary healthcare settings in the UK (Elia, 2003) and includes the weighing of patients as part of the assessment. However, due to the time constraints dictated by the Clinical Commissioning Group contract, there was very little time to assess the appropriateness of the tool for palliative care patients. It is not generally used in hospices (Elia and Smith, 2009) and there was concern within the organisation about its appropriateness for palliative care patients.

Palliative patients have complex and varying needs regarding their food and nutrition. Evidence suggests that, in the UK, between 40-80% of cancer patients suffer from loss of appetite, with many of these patients also experiencing cachexia (weakness and wasting of the body due to severe chronic illness) (Addington Hall and McCarthy, 1995.) This can have a significant effect on quality of life, both physically and emotionally. While, there are many potentially reversible causes for this loss of appetite and cachexia, if these have been excluded, it's likely that weight loss in cachexia is a symptom resulting from the biochemical changes produced by the tumour and can be independent of nutritional intake (Bruera, 1997). In addition, more recent studies have demonstrated no differences in nutritional status, survival, tumour response and quality of life between groups receiving nutritional intervention and groups receiving no nutritional intervention (Macmillan Cancer Support, 2007). However, other research (Addington-Hall and McCarthy, 1995; Souter, 2005) has demonstrated the considerable impact that a patient's loss of appetite has on family members who are caring for them, with up to 87% experiencing anxiety related to this (Hawkins, 2000).

Twycross (2004) argues that cancer-related loss of appetite and cachexia are often best managed by helping the patient and family to adjust to a largely irreversible situation as there is currently no convincing evidence that interventions are able to reverse it. Macmillan Cancer Support produced the Durham cachexia pack (Macmillan Cancer Support, 2007) encouraging appropriate nutritional care depending on the stage of the illness. This states that, for patients in the later stages of terminal illness (which includes most of our patients in the inpatient unit):

'The goal of nutrition therapy should NOT be weight gain or reversal of malnutrition, but it should be about quality of life, including comfort, symptom relief and enjoyment

of food. Aggressive feeding may not be appropriate, especially if eating and drinking cause discomfort and / or anxiety to the patient. Therefore weighing patients is not advised.' (Macmillan Cancer Support, 2007)

The National Institute of Clinical Excellence (2006) recommends that clinicians should act in the patient's best interests and be aware that nutritional support is not always beneficial for patients. In fact, during the end of life phase, Holder et al. (2003) stated that nutrition may worsen quality of life, actually causing unnecessary distress. Acreman (2009) expanded on this by stating that palliative patients' nutritional needs and nutritional support should be directed towards the improvement of their quality of life, not otherwise.

Help the Hospices Food and Nutrition Group (2009) identified the need for nutritional support and guidance in hospice care which should rely on clinicians' expertise and the nutritional needs of the specific individual being cared for. Research into the lived experience of patients with cancer-related loss of appetite found that what they most wanted was for their experience to be listened to and their limitations with regard to nutritional intake to be acknowledged and that their carers also had significant needs (Souter, 2005).

Arrowsmith (1999) and Green (2013) observed that by using a nutritional screening tool to support effective nutritional care, practitioners should be able to demonstrate benefits from its use and these should be documented in appropriate care plans. Within Dorothy House Hospice after six months of using the MUST tool, the project lead carried out an evaluation with staff focus groups and questionnaires. This evaluation highlighted that the hospice clinical staff had little confidence in the value of the MUST tool for palliative patients. As a result of this and in the light of the research quoted above, the project lead applied to the Foundation of Nursing Studies (FoNS) for support in developing a new person-centred and sensitive nutritional screening tool suitable for people with life limiting conditions.

The aim of the project

The aim of the project was to develop and implement an appropriate nutritional screening tool for palliative patients, which would be acceptable across all settings and meet the expressed needs of patients and carers.

Objectives of the project

- To identify and engage stakeholders in the project
- To explore the lived experience of palliative care patients and their carers under the care of Dorothy House in relation to eating and drinking
- To utilise the information gained from the stakeholders and especially the patients and carers in order to guide the project and the development of an appropriate tool and enhance nutritional care
- To utilise a practice development framework to implement changes in practice
- To evaluate the changes in practice and their impact on patient experiences and redesign the tool where necessary

Methods

A number of methods and approaches were used within the project:

Methods & Approaches	Activities	Time scale
1Stakeholder engagement	Power Point Presentation to Dorothy House staff to engage them with the project and familiarise them with the current literature and standards in palliative care nutrition.	04/02/2014
2Nutritional steering group (NSG)	The group consisted of hospice staff from across the organisation with an interest in end of life nutrition. In addition, a patient and volunteer came forward and offered their support and expertise for the project. This multidisciplinary nutritional steering group met approximately monthly to discuss the project, to analyse patients' stories and use them to guide practice.	01/12/13 - present
3Values and beliefs clarification questionnaire	The project team asked staff directly to complete this questionnaire during the monthly meeting or, for kitchen staff, in their free time due to their heavy workload. The aim was to explore their individual beliefs and values regarding nutrition and then to develop an expression of the team's values. The NSG presented their joint mission statement arising from their own values and beliefs around nutrition in palliative care in the form of a poster.	04/12/13 - 31/01/14
4Team culture questionnaire	This questionnaire aimed to establish staff work culture and their willingness for change.	04/12/13 - 31/01/14
5Evoke cards	This approach aimed to engage with the stakeholders to explore their views about nutrition in a more creative way.	Used during NSG meetings and with patients and carers in their interviews
7Patient stories	A number of patients and carers from each of the care settings across the hospice such as inpatient, day patient and the community were asked to volunteer to take part in the project. They were interviewed and the recorded interviews played to the NSG to increase their understanding of patient's and carer's needs. This was used to develop suggestions for improving the delivery of nutritional care across the organisation.	01/05/2014 - 30/12/2104
8Claims, concerns and issues exercises with the NSG	This approach, where claims of positive advances were discussed, concerns about problems encountered turned into questions and issues to be worked on, was used by the NSG throughout the project.	31/04/14 - 30/12/2104
9Research and development of PLANC (Patient Led Assessment of Nutritional Care)	Tool developed by the NSG and amended in consultation with Dorothy House staff.	01/01/15 - 01/01/16
8Audit of PLANC vs. MUST tool	Inpatient unit staff to trial each tool with 10 patients and then dietician to undertake retrospective case review to determine if PLANC determines appropriate care plans as effectively as or better than MUST.	15/04/2015 - 01/02/2106

1. The Nutritional Steering Group

The studies quoted above suggest that palliative patients have complex and varying needs regarding their food and nutrition. Therefore a person-centred, holistic approach to nutritional care by a multidisciplinary team is essential for patients' (and their carers') quality of life, wellbeing and satisfaction at the end of their life and as they are dying. The nutritional steering group (NSG) arose from the presentation of the project to the multidisciplinary team by the project lead. The current literature about nutrition in palliative care was presented together with the findings from the 'MUST' evaluation project. After the meeting several members of the multidisciplinary team offered to support the project with their expertise. The group consisted of a doctor, physiotherapist, psychologist, dietician, day patient unit nurse, inpatient unit nurse, community nurse specialist, the head of education and the head chef. The group also included a patient and volunteer who added their views around current nutritional care in the hospice.

2. Identification and engagement of project stakeholders

At the beginning of the project, the project lead, together with the NSG, prepared a presentation which aimed to inform all staff about the project and encourage them to take an active part and make a difference for palliative care patients to improve end of life nutrition. The aims and objectives for the project, together with the current literature review about food and diet in palliative care, were presented as part of the monthly in service training. Unfortunately only three members of staff were able to attend this session due to heavy workloads. Therefore the presentation was placed on the hospice's computer drive so staff could access it at any time. In addition the project lead put information about the project's aims and objectives in hospice's newsletter.

In discussion with the NSG, all people directly or indirectly providing every day nutritional care for our patients were recognised as stakeholders. The list proved to be a large one, covering all the clinical staff within the hospice, volunteers who worked in the clinical areas and the kitchen staff. In the community the list extended to carers, nursing and residential home staff, the primary health care team, and domiciliary care staff.

3. Values and beliefs clarification exercise

The project team decided to use a values and beliefs clarification exercise (Warfield and Manley, 1990) in order to develop a joint team statement of values and beliefs with regard to nutrition. The following questions (see Appendix 1a) were used:

- I believe the ultimate purpose of nutrition in palliative care is:
- I believe this purpose can be achieved by:
- I believe the factors that help us achieve this purpose are:
- I believe the factors that hinder us from achieving this purpose are:
- Other values and beliefs I consider important in relation to nutrition in palliative care are:

Members of the NSG worked with a number of teams across Dorothy House in differing ways depending on the availability of the team members at the time. Wherever possible it was done by individuals and then drawn together as a team. The NSG then worked together to create a group mission statement regarding nutritional care for palliative care patients. By using this approach the project team enabled individuals working at Dorothy House Hospice to explore their own beliefs and values and share them with each other to develop a common mission statement. This generated

discussion and modification of individuals' views about nutrition in palliative care and various informal discussions in the hospice ensued regarding the improvement of nutritional care and the patients' engagement with the nutrition and dietetics service.

The following table shows the response rates to the exercise by the various groups within Dorothy House.

Group	Question sheets given out	Responses returned
Inpatient unit	16	14
Day patientunit	5	4
Volunteers	10	6
CNS	25	6
District nurse	5	5
Kitchen staff	5	3
NSG	9	9

The response rates were generally very high, demonstrating a desire across the organisation to engage with the project. The hardest group to engage with proved to be the CNSs, in part because they were based in local outreach centres and felt distant from central projects, but also because they already included patient and carer centred nutritional care as a high priority and were very sceptical of the previous attempt to introduce the screening tool.

The values and beliefs captured through this exercise are shown in the tables in Appendix 1b. The main themes reflect the ethos of palliative care in their desire to prioritise patient needs and wellbeing, but also show the need for good communication, education, knowledge and information about nutritional care.

The NSG also created a poster to reflect their collective values and beliefs (see Appendix 1c).

4. Team Culture Questionnaire

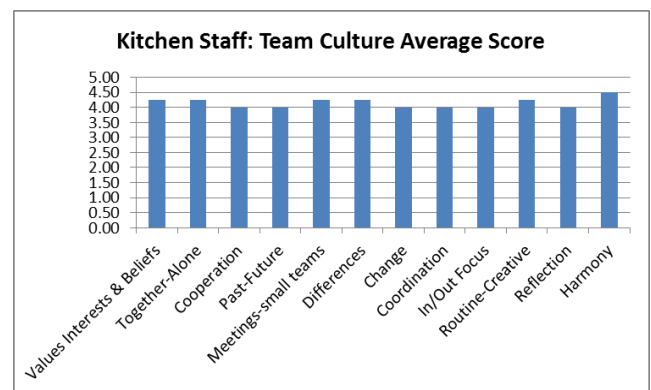
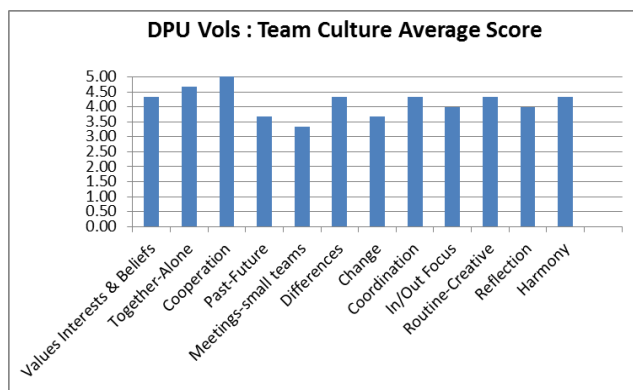
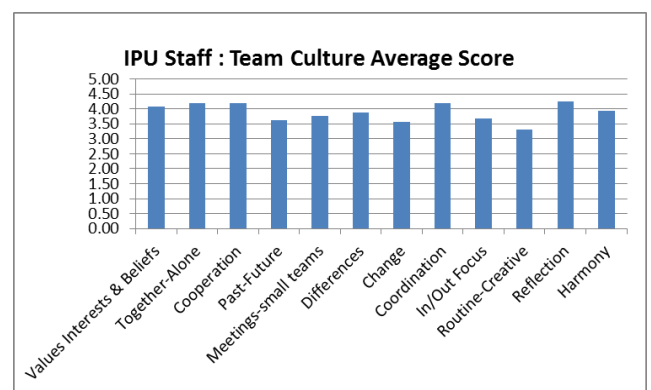
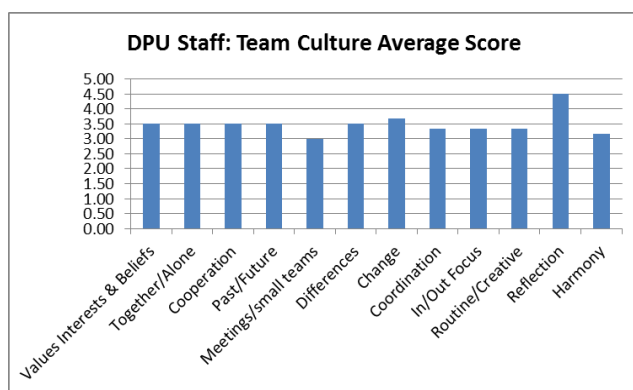
The project team/NSG wanted to explore the existing work culture within specific departments and the attitudes of the teams regarding change and service improvement in their work place. A 'Team Culture' questionnaire (see Appendix 2) was used by team members from the inpatient unit (IPU), day patient unit (DPU), volunteers and the kitchen staff.

The questionnaire asked to what extent (on a scale of 1 to 5):

- People in the team share values, interests and beliefs
- People in the team pull together
- There is community spirit and co-operation in the team
- The team is ruled by visions of the future
- Working in small teams is an aspect of the culture in the team
- People confront and move beyond their differences in the team
- The team is change oriented
- There is strong co-ordination in the team

- The team is outward looking and does not focus on itself
 - The team is creative and ideas dominated
 - People reflect about their work in the team
 - There is harmony in the team
-
- The DPU received and returned 6 questionnaires
 - The IPU received and returned 16 questionnaires
 - The volunteers received 5 and returned 3 completed questionnaires
 - The kitchen staff received and returned 4 questionnaires

The outcomes are shown in detail in Appendix 2a and in summary below. In each case, a higher score means more respondents believed the statement was true.



Average Team Scores

In general, the teams scored themselves relatively highly for effective team working across all the domains. The responses indicated an ability to embrace change and a strong shared team culture which boded well for the introduction of new ideas.

5. 'Evoke' cards

Evoke cards (Evokecards.com) depict a range of objects and scenes and were used to explore feelings about nutritional care. They were used as an ice breaker and discussion starter in the NSG and to encourage patients and carers being interviewed to explore feelings about nutrition in palliative care in a more creative way.

This was very well received and this activity was found helpful, engaging and relaxing. It enabled strong feelings to be elicited and then explored. As one patient said *'This is a bit left field but very helpful'*.

6. The Nutritional Steering Group (NSG) meetings

The NSG Meetings took place every one to two months and a summary of the meetings is contained in Appendix 3. To encourage attendance, a different type of snack food was offered at each meeting. The initial meeting focused on developing the team and encouraging them to work collaboratively. Although the clinical staff were used to the concept of multidisciplinary working, it was unusual for the catering team and the patient and volunteer to be included. It was felt that the use of Evoke cards, the sharing of values and beliefs and the creation of a joint statement facilitated the sense of collaborative team working.

At subsequent meetings the focus was on the patient experience, either as reported by the staff or listening to a recording of the interviews with patients and carers. The group then considered the claims, that is the positive achievements or what was working well, and the concerns, that is areas that needed to be worked on or considered, that were raised each time. The concerns were used to develop questions that needed to be answered or issues that needed to be worked on. Many of these issues were practical issues regarding the provision of food to patients in the hospice and as the project developed it was noticed that there was increased engagement of the catering staff with patients and increased enthusiasm for the project and for meeting patients' needs. The written information leaflets that are given to patients and carers were rewritten in the light of comments heard and were used more widely across Dorothy House than before, especially to back up information given verbally to DPU patients or those about to be discharged so their family could have a greater understanding of their needs.

Having listened to the patients and carers, the NSG worked together to develop a nutritional assessment tool and algorithms to guide care planning. This was based on and developed from the Macmillan Durham Cachexia Pack (Macmillan Cancer Support, 2007) tool which was felt to be the best fit for our patients from the tools currently available. It was noted that it did not include information about dietary needs, modified texture and thickened fluids so this was added. Crucially, in the light of the evidence about the effects of patients' poor appetite and weight loss on carers, questions were included about carers' needs and the impact on them. See Appendix 4 for the Patient Led Assessment of Nutritional Care (PLANC) tool and algorithms.

Following discussion with the dietician, nursing managers and hospice nursing staff as to the best way forward, it was decided that all the patients were potentially at risk of malnutrition and therefore a screening tool for malnutrition (such as MUST), which would then require further assessment, was not appropriate. The staff were keen to have a single tool that would also meet the needs of patients in the last few days of life; they felt strongly that MUST was not appropriate in these situations. The dietician and the ward staff agreed to a three month trial and audit (see Appendix 5) whereby MUST and PLANC would each be used with 10 consecutive patients and the nutritional care plans audited against best practice. If PLANC was as good as or better than MUST at helping to plan appropriate nutritional care for palliative care patients and their carers, then the challenge would be to embed its use throughout the hospice. This would require input from the IT department to ensure it is available on the electronic records, and sufficient support and teaching to ensure that all staff are aware of it and were confident in its use. The biggest challenge would

probably be with the CNS team who already do a reasonably thorough but not systematic assessment.

Assessment by itself is only useful if it generates an appropriate care plan for the individual concerned that is then put into practice. It is planned that the algorithms will be available as guidance, in each patient's notes and on the electronic note system, detailed information leaflets readily available both in hard copy and electronic versions and samples of the supplements suggested would be available in the clinical areas. The effectiveness of this will need to be audited in the future.

7. Patients Stories and ethical considerations

The project team wanted to engage directly with the patients and their carers and to hear their stories and views regarding nutrition at the end of life. The team wanted to elicit these stories using open-ended questions and prompts, but understood that there may be ethical issues.

The Clinical Governance Committee of Dorothy House was approached for and granted ethical approval as it was essential to ensure that the patients were not put at risk of harm, especially as they are already in a potentially vulnerable position due to their frailty and illness. Additionally, the whole project needed to follow ethical guidelines and good practice in each of its stages (Seymour and Ingelton, 1999; Dean and McClement, 2002; Sivell, 2015).

The patient information leaflets and consent form (for participation) and the interview questions were produced by the project team (see Appendices 6 and 7). These were approved by the Nutritional Steering Group and piloted with a patient and carer. During this exercise patients and the carers were again informed about the anonymity, including data relating to their opinions and views. The five simple open questions were used by the nurse conducting the interview:

1. Tell me about yourself.
2. Can you tell me your experience with food and diet (past, present)?
3. Can you choose a few postcards (Evoke cards) which describe how you feel about food, drink and diet?
4. Can you tell me about your experience of food and how we care for your nutritional needs in our hospice?
5. Is there anything that you can suggest to improve your nutritional care?

Following the successful pilot, four semi-structured interviews were performed using the above open-ended questions in the IPU, DPU and community. The patients were selected carefully by the project team, they needed to be well enough and willing to be interviewed and to have experience of nutritional problems. The project was explained orally and in writing and fully informed consent was obtained.

The patient and carer interviews were then conducted by the project team, recorded and later transcribed. This method allowed the team to explore in greater details patients' and carers' feelings about nutrition at the end of life and its impact on their wellbeing, and as a result, quality of remaining life. The recordings were played in full to the NSG to guide their discussion and planning.

The main themes to emerge from the interviews were the need for smaller portion size for those who have little or no appetite, the variety of meals available each week, the difficulty of eating with fickle taste changes, the importance of the social aspect of eating and the impact on carers.

The patient being cared for in the community had never had a nutritional assessment and would have welcomed one. He said:

'Yeah, I think I would [welcome a nutritional assessment] actually, I think I would. I think again it's very um, engaging with the Oncology, my Oncologist, this is just not a topic that really is discussed or that he, that the Oncology Centre seems to be particularly switched on to really.'

While his wife described the impact his loss of appetite had on her and the dearth of information available about this. She said:

'I think I was sort of forewarned about how it would make me feel because I saw it happen to my mum who felt inadequate when she couldn't give food to my dad that he wanted to eat, so I think forewarned was forearmed ... I think mum did take it a bit personally, I completely understand why you would, I think I probably would have if I hadn't seen that happen, so I think that would be the initial thing to warn people about and understand how they might feel about that if they'd been the one that does most of the cooking.'

A different patient chose the postcard (Evoke Card) with a picture of a sponge cake on it. She said

'That one is my card for not feeling too hungry – I would want it, I would probably look at it and think "ooh I could just eat that" but the closer I get to it I would just feel there is no way I could get that down and I would struggle, as much as I like cake I would struggle to eat that, so that's on the days where I don't feel that hungry but I get pushed to eat something to make sure I'm having some food and that's a sign that, yes I would love it but no way could I eat it.'

'The only problem was getting (my husband) to not pile it up, obviously he wanted me to pick my strength up and the last thing I needed was to see a big plate of food in front of me, I could look at it and think much as I want it I can't eat it. Now whatever we cook he will tell me dish my own up and then I put as much as I need on my plate – that does make a big difference and if I need any more then I just help myself to more.'

'I think back to the nutrition side of things, the only thing that may be beneficial is when you've been discharged from hospital is for somebody to have a chat to say that the patient wouldn't be back to a normal appetite so that the partner or whoever is doing the meals, doesn't feel that it's the patient refusing it – it's just the fact that we're not up to a point where we can actually eat it. In that way it doesn't make him feel that he's cooked it and I've not eaten all of it, whereas if someone explained at the start that there may be days that I won't fancy it and as time goes on you do tend to pick up again.'

Discussion

Outcomes

The dietician's evaluation of PLANC vs. MUST showed little difference in the care plans produced for patients in the inpatient unit in the early stages of palliative care. However, for patients at the end of their life, PLANC could still be used appropriately, unlike MUST. Perhaps more importantly, inpatient unit staff felt that using PLANC enabled conversations with relatives that would not have happened if they had been using MUST and felt overwhelmingly that it was more appropriate for their patients.

Dorothy House is in the process of rolling out PLANC across the organisation and despite earlier reservations, the community CNS team are keen to use it once it is on the electronic record system and are already starting to use the algorithms. The hospice at home carers who nurse patients at home overnight listened to the interviews and, whilst they do not undertake formal assessments, felt they had a much greater understanding of the emotional impact of loss of appetite/cahexia on both patients and carers which would enable them to care more holistically and give more appropriate advice.

There were a number of positive outcomes as a by-product of this project which, the team believed came about as a direct result of the practice development approach used. It is hoped that this approach and its benefits will encourage its use in other areas and stimulate user involvement throughout the hospice.

The person-centred approach of practice development (McCormack et al., 2013) shares much of its ethos and philosophy with palliative care and was felt to be a natural 'fit' for the project by the NSG. The concept of multidisciplinary team working has always been at the heart of the hospice movement (St Christopher's hospice originally had all its staff wear the same uniform to emphasise this) but the increased medicalisation of palliative care and the specialisation and fragmentation of teams within palliative care has tended to limit the scope of this concept in recent years. However, the practice development approach used by this project helped to reverse that trend for the Dorothy House teams involved, enabling the multidisciplinary NSG, which included catering staff, patients and volunteers, to work collaboratively and effectively, focusing on an issue that the nursing staff had already highlighted and both patients and carers felt to be important. This gave the group an impetus, direction and enthusiasm which kept it going.

The catering staff in particular were drawn into the project and enabled to connect with patients and their needs and had many practical ideas on how to meet those needs. The new thirteen day menus, the emphasis on meeting individual needs, the volunteer hosts who now ensure each patient on the IPU gets the food appropriate for them, and the increased understanding by the DPU volunteers of the importance of portion size for those with small appetites have all been a consequence of this project.

Staff working in palliative care tend to be highly motivated to meet patient needs, as seen by the responses to the values and beliefs clarification exercise and team culture questionnaires. Recording the patient stories enabled the staff to connect with the expressed needs of the patients and carers and was especially powerful for those staff (such as the catering team) who did not routinely listen to patients talking about their needs. The project team believed this motivated the NSG and the teams they worked with to deliver the changes despite a heavy workload, staff and management changes and changes within the project team.

Other hospices and community nursing teams have expressed an interest in the tool and its use in their settings. It is questionable whether it would be sufficient for them simply to adopt and use the tool as it stands or whether the use of the practice development approach as described above would be more effective in ensuring that nutritional care is assessed and delivered appropriately to palliative care patients and carers in their culture and context. The project team's experience would suggest that it is the whole process and approach which has led to the success of this project, rather than just the tool itself.

Limitations

The project happened at a time when the catering staff were under considerable pressure; there were staff shortages across the organisation and major changes in the management team. This meant that not all members of the NSG were able to attend meetings and the project proceeded more slowly than the project team had hoped. In addition, the team had hoped to do more than four interviews, but it proved difficult to find appropriate patients, especially on the IPU. However, their responses were in accordance with those found in other research projects (see the background section above) and it was felt that the interviews that were conducted gave sufficient information to guide the team.

Two disciplines with the hospice failed to connect with the project – the medical team initially had a member on the NSG but no replacement was given when he could not attend and, with hindsight, the project team should have made more effort to keep the medical team informed of developments. The community CNS team initially felt little need for an assessment tool that encompassed their usual practice and was not available on the electronic record system. At the time of writing the project team are involved in introducing PLANC to the community CNS team.

Conclusion

The practice development approach fitted well with the ethos of palliative care and enabled many effective changes in practice which have continued. The PLANC tool that was developed was acceptable to patients, carers and the staff and it is hoped that it will be introduced more widely. A practice development approach which focused on patient experience facilitated this despite considerable managerial changes and staff turnover within the hospice.

Post Script

PLANC has been adapted by the Dorothy House in-patient unit to incorporate some of the information that they need routinely on admission. They do not include information on fatigue as this is covered in another area of their assessment (see Appendix 9).

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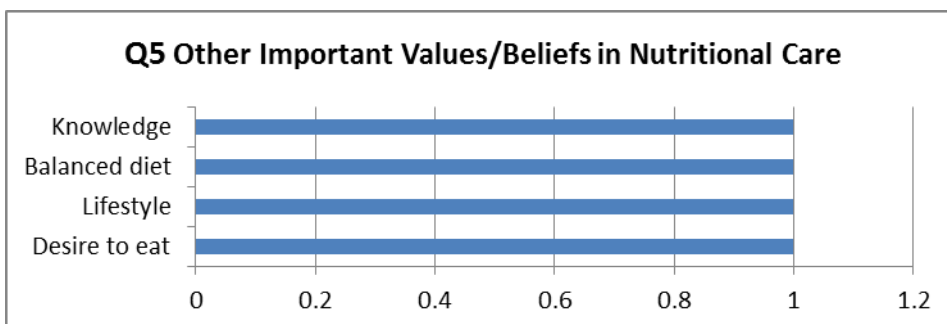
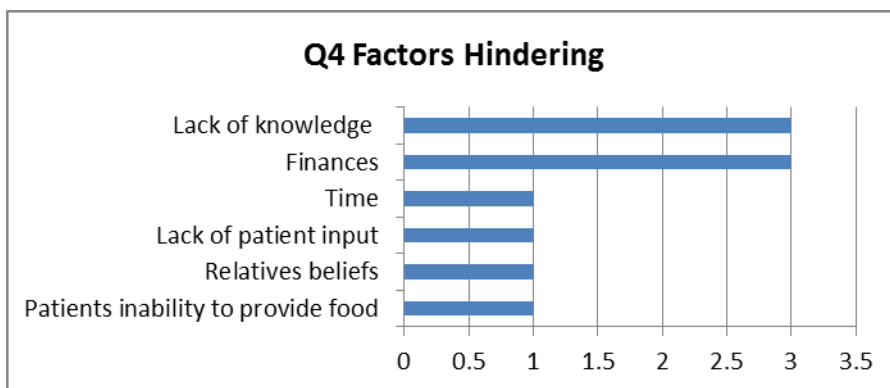
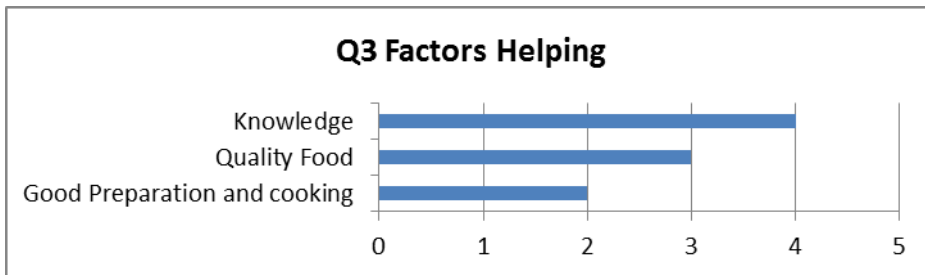
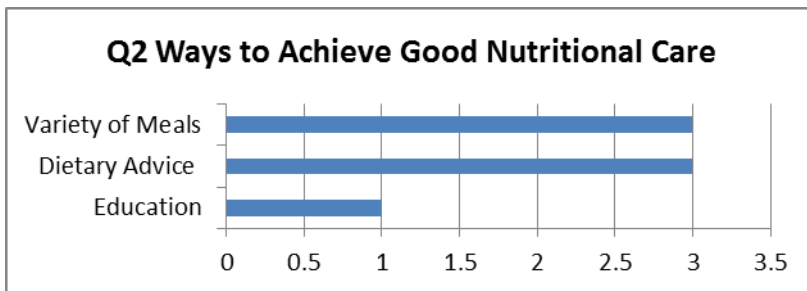
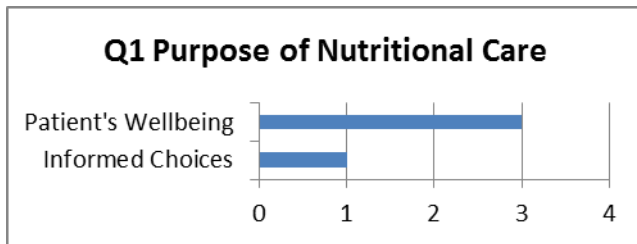
Appendix 1: Template used in the values and beliefs clarification exercises

Values and beliefs template
I believe the ultimate purpose of nutrition in palliative care is:
I believe this purpose can be achieved by:
I believe the factors that help us achieve this purpose are:
I believe the factors that hinder us from achieving this purpose are:
Other values and beliefs I consider important in relation to nutrition in palliative care are:

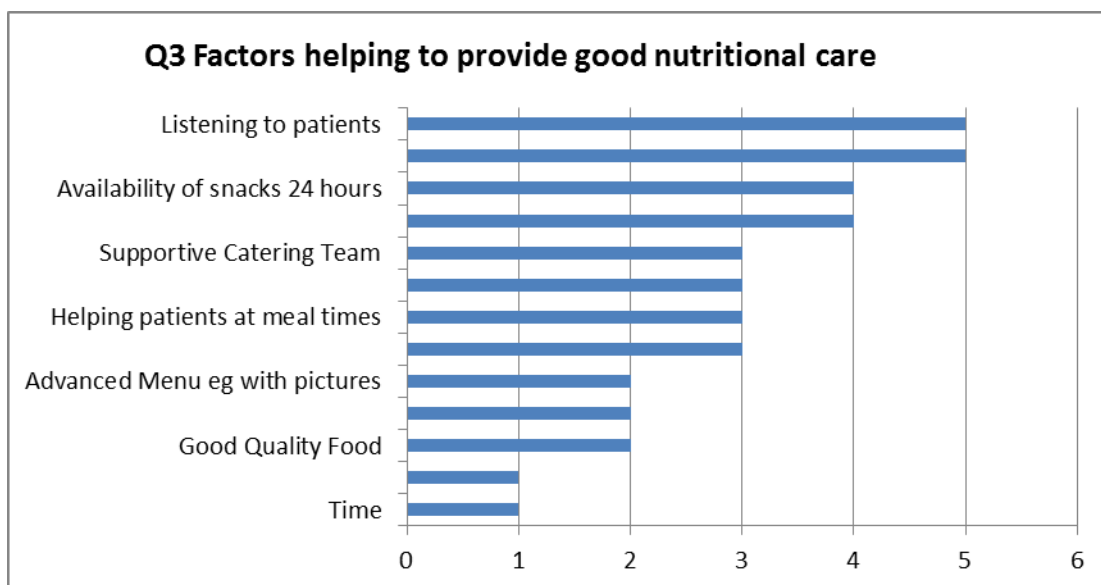
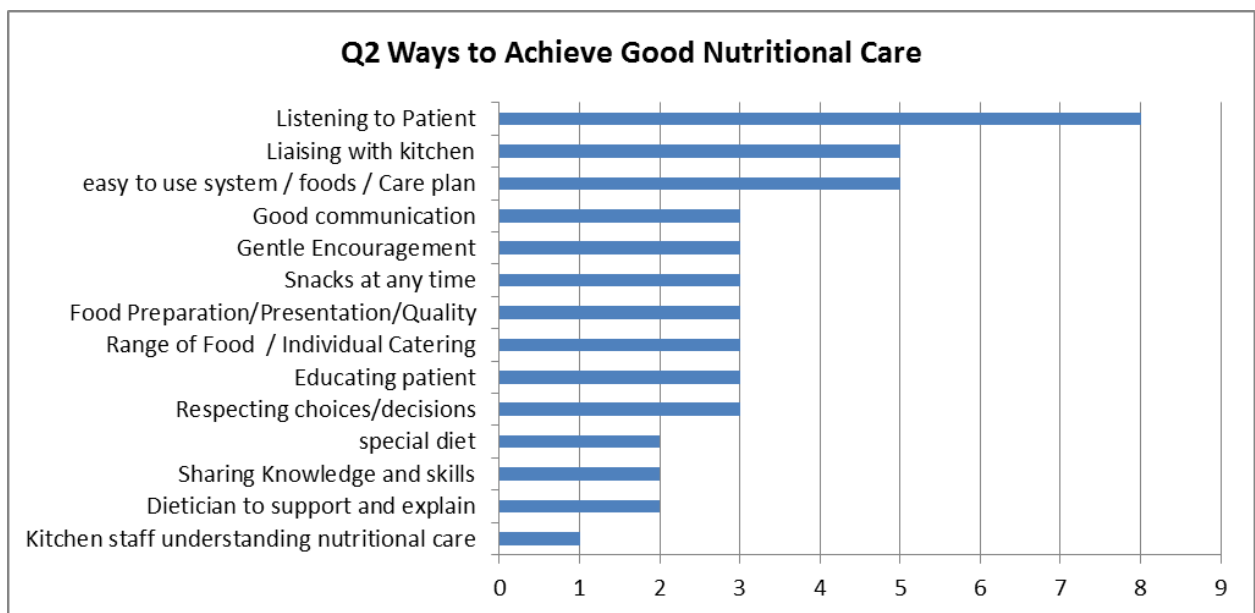
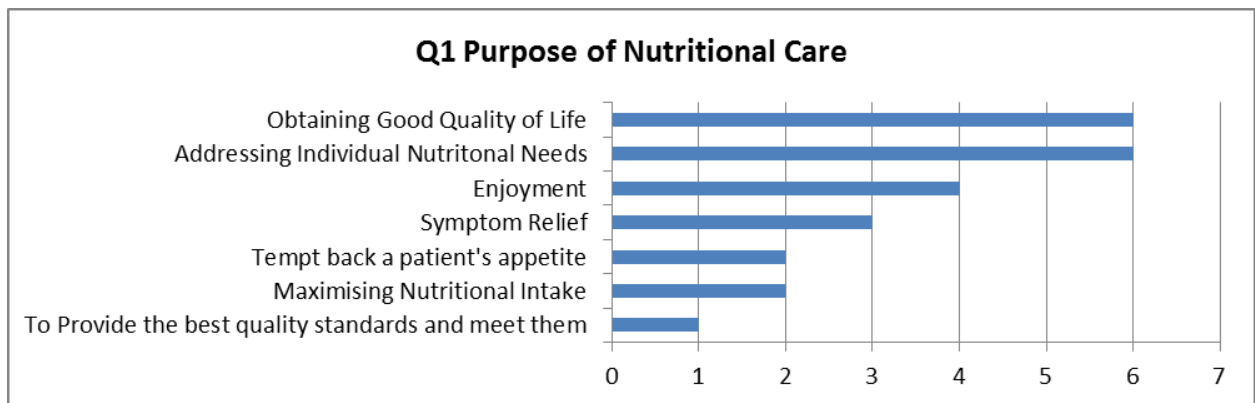
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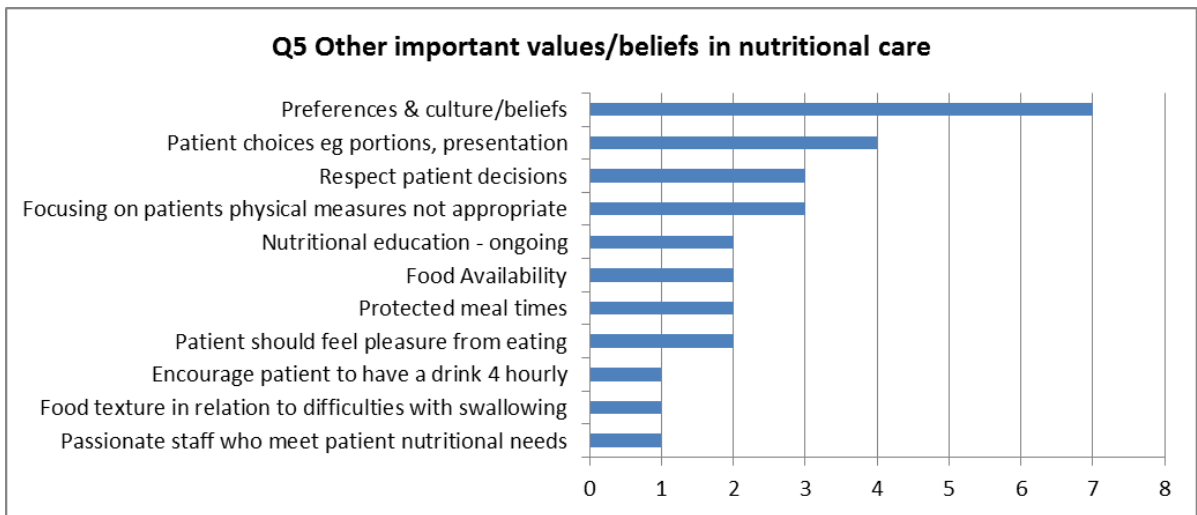
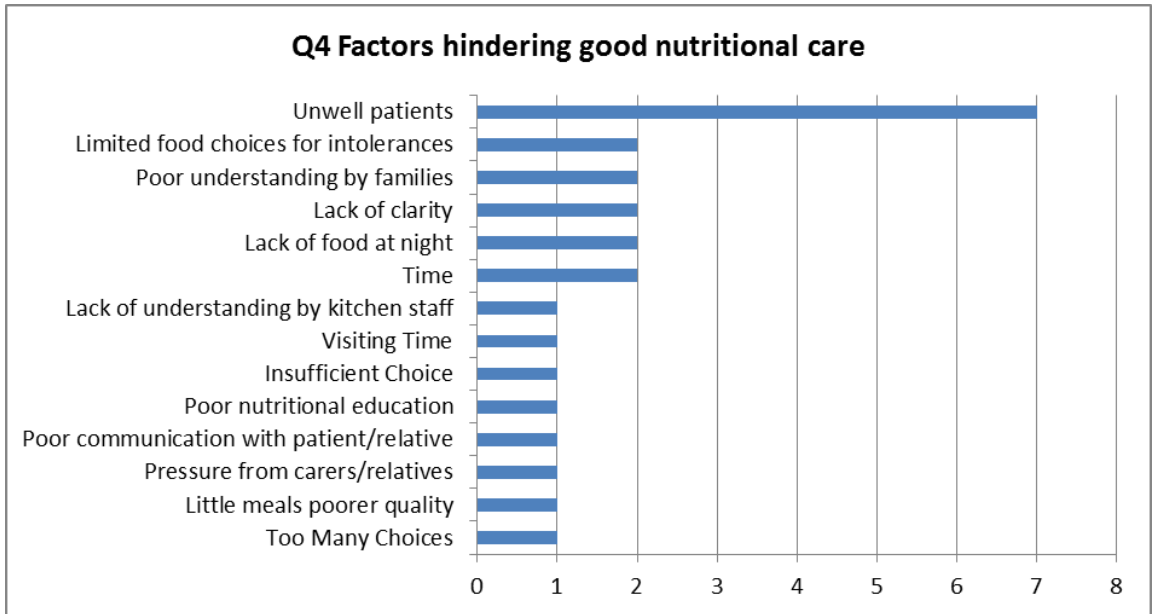
Appendix 1a: Results of the values and beliefs clarification exercise

a) Day patient (DPU) Unit (n=4)

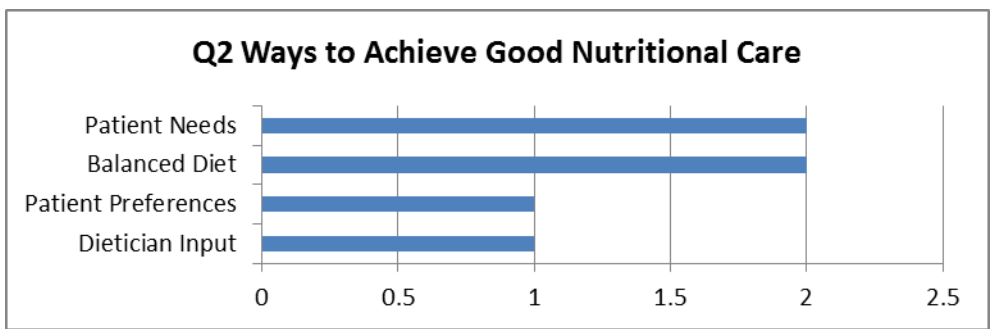
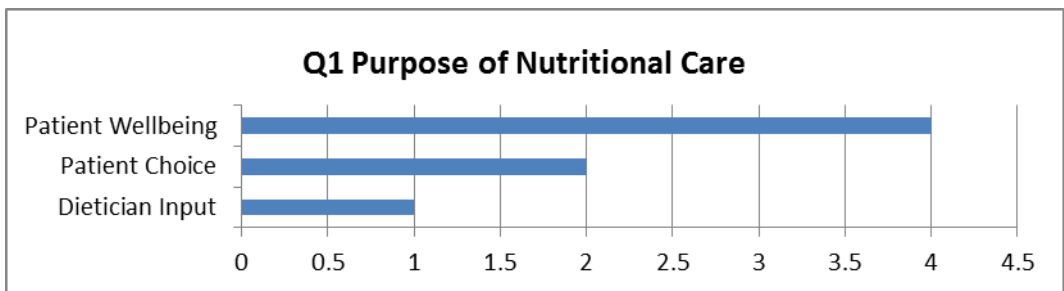


b) Inpatient Unit (IPU) (n=14)

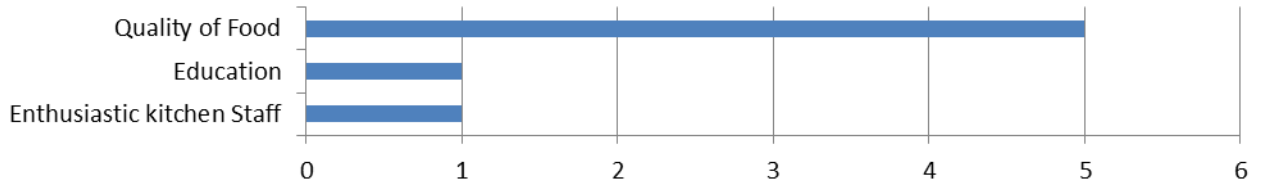




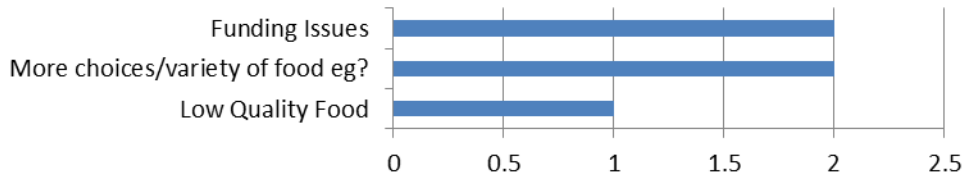
c) DPU Volunteers (n=6):



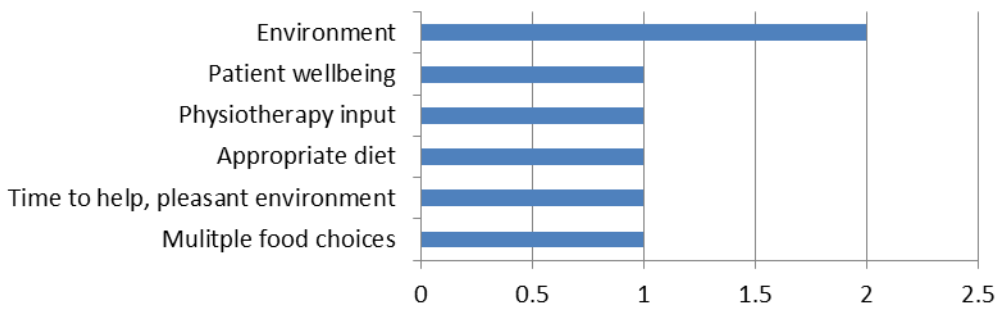
Q3 Factors Helping to Provide Good Nutritional Care



Q4 Factors Hindering Good Nutritional Care

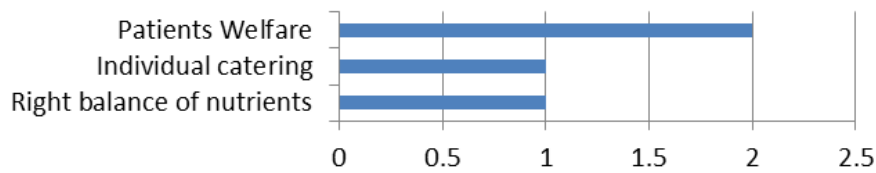


Q5 Other Important Values/Beliefs in Nutritional Care

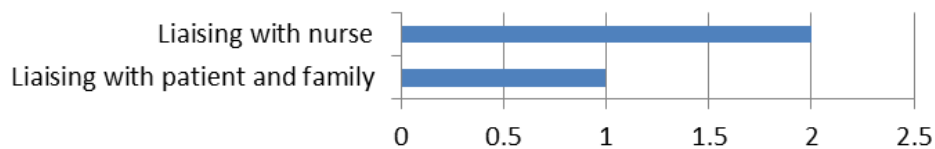


d) Kitchen Staff (n=4)

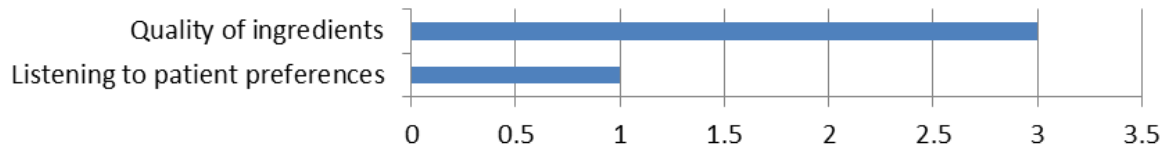
Q1 Purpose of Nutritional Care



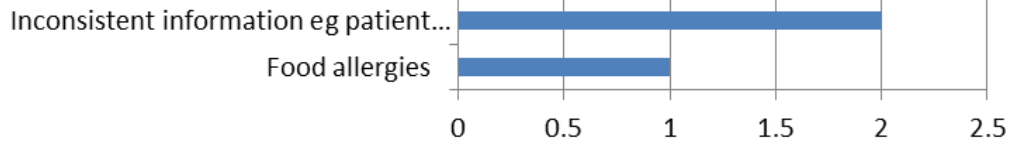
Q2 Ways to Achieve Good Nutritional Care



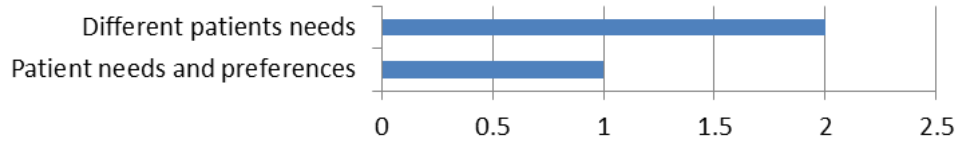
Q3 Factors Helping to Provide Good Nutritional Care



Q4 Factors Hindering Good Nutritional Care

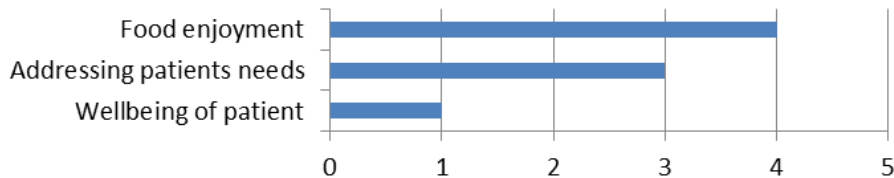


Q5 Other Important Values/Beliefs in Nutritional Care

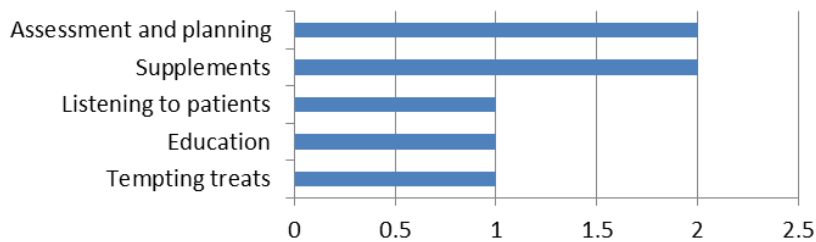


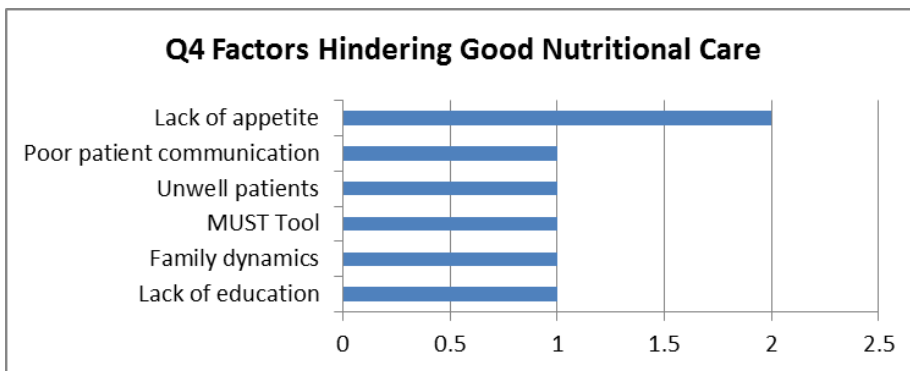
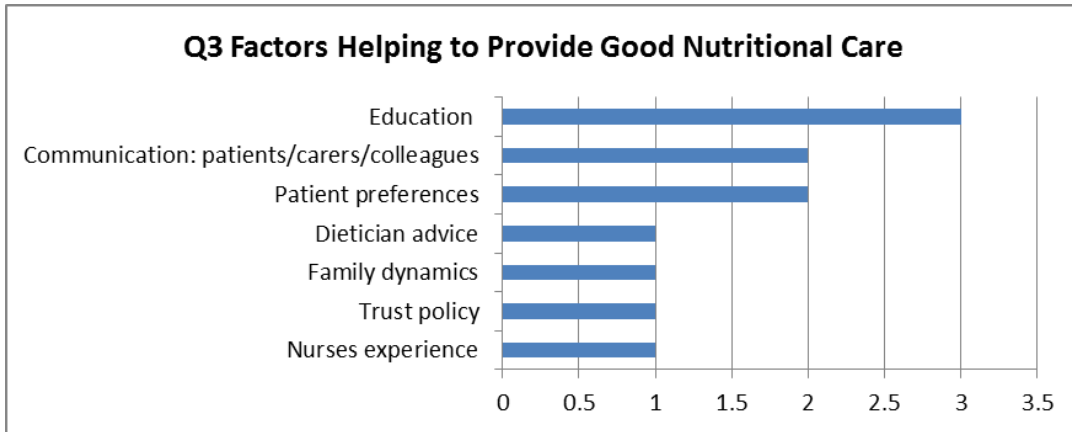
e) District Nurses (n=5)

Q1 Purpose of Nutritional Care

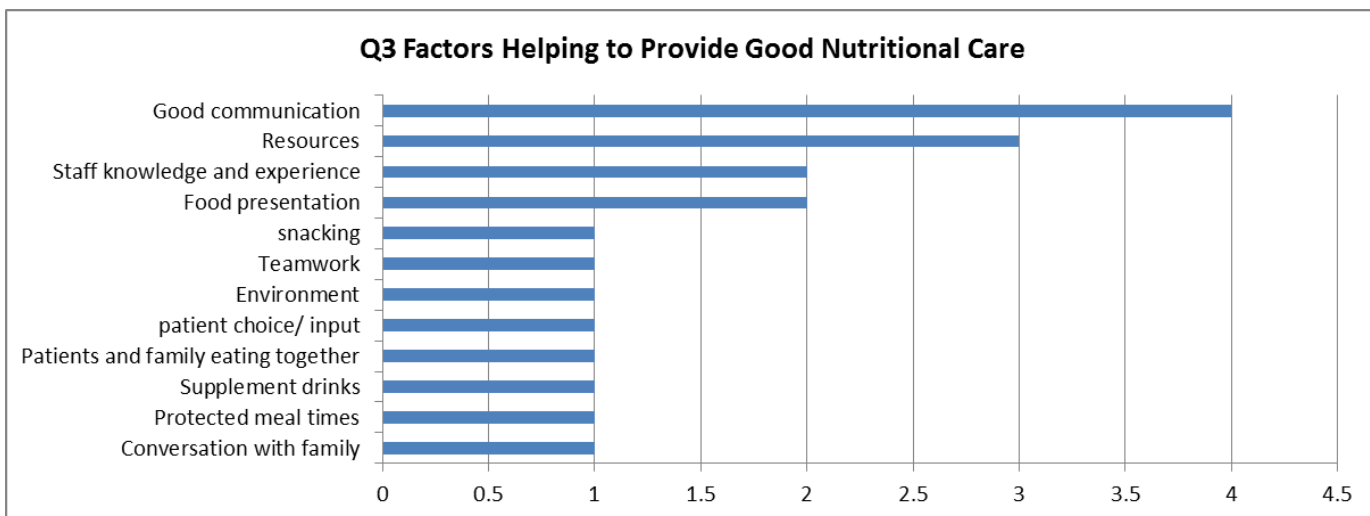
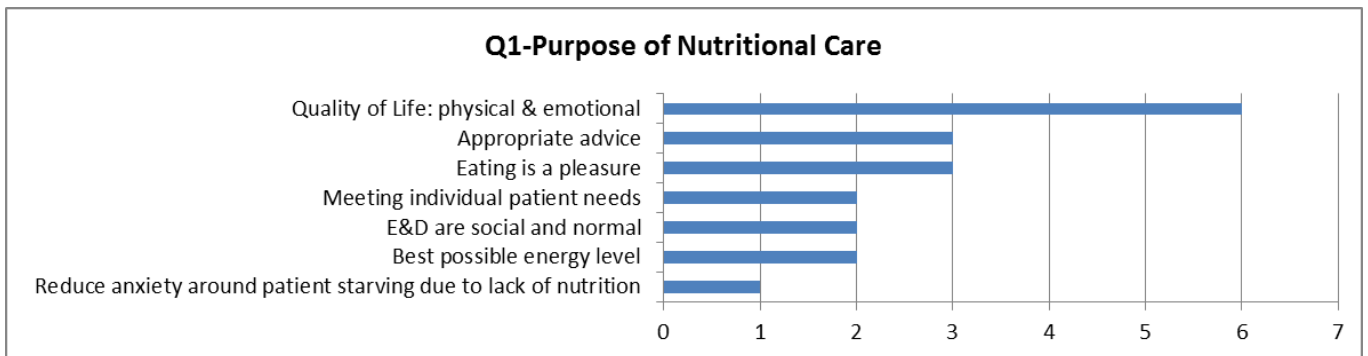


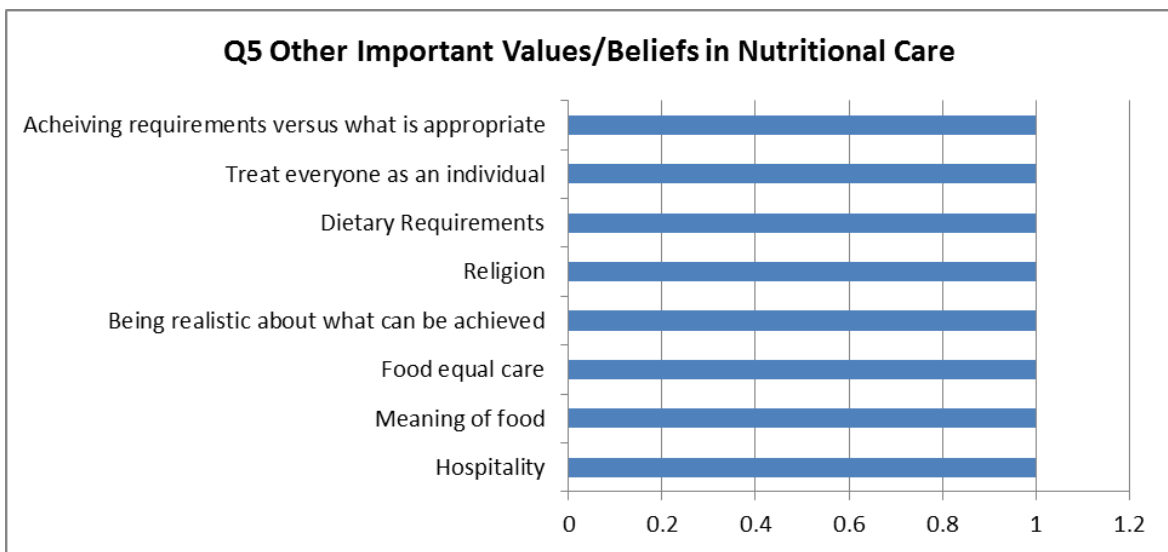
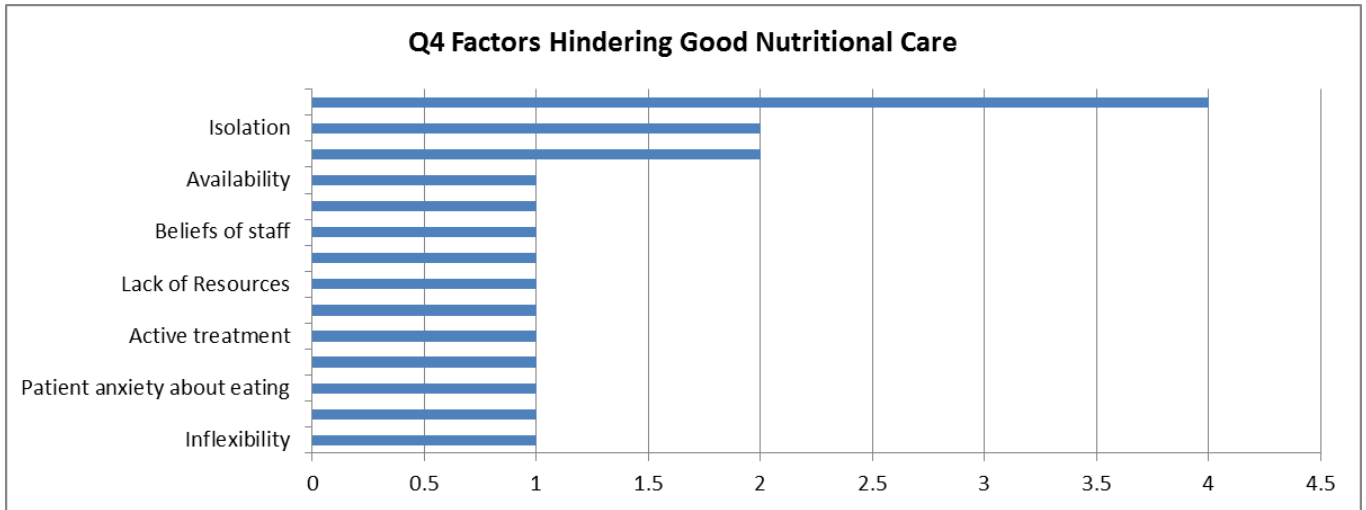
Q2 Ways to Achieve Good Nutritional Care



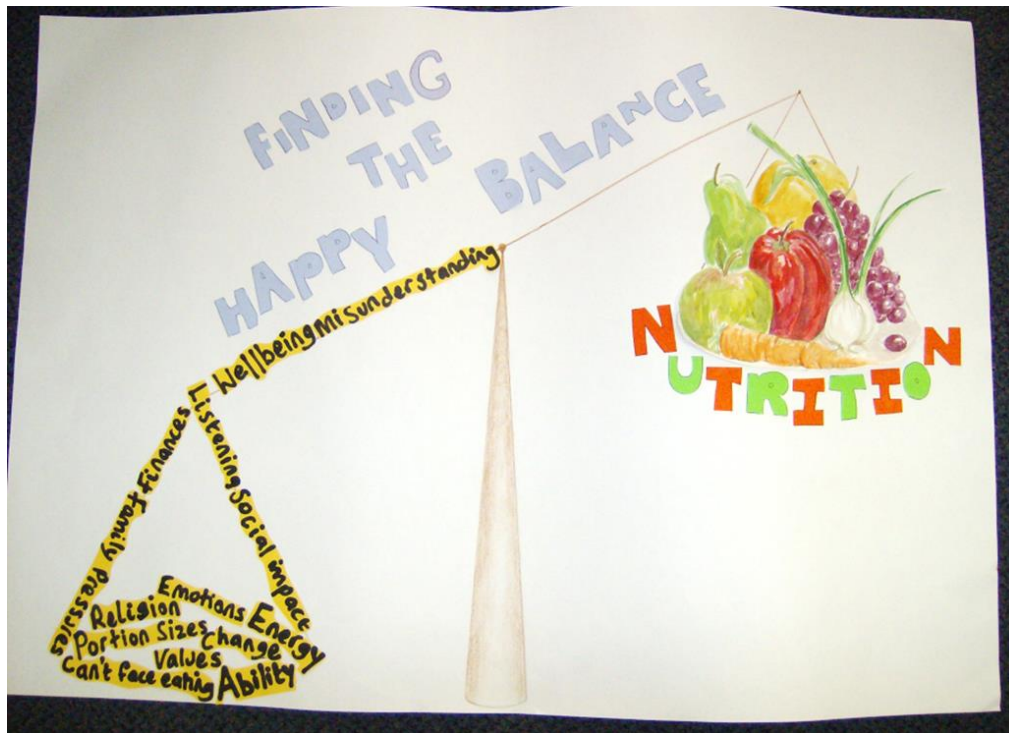


f) Nutritional Steering Group (NSG) (n=10)





Appendix 1b- Poster created by NSG to demonstrate shared values and beliefs in relation to nutrition



Appendix 2: Team culture questionnaire

TEAM CULTURE

Read through the list below and circle the number on each question that identifies the nearest to where you think YOUR TEAM is.

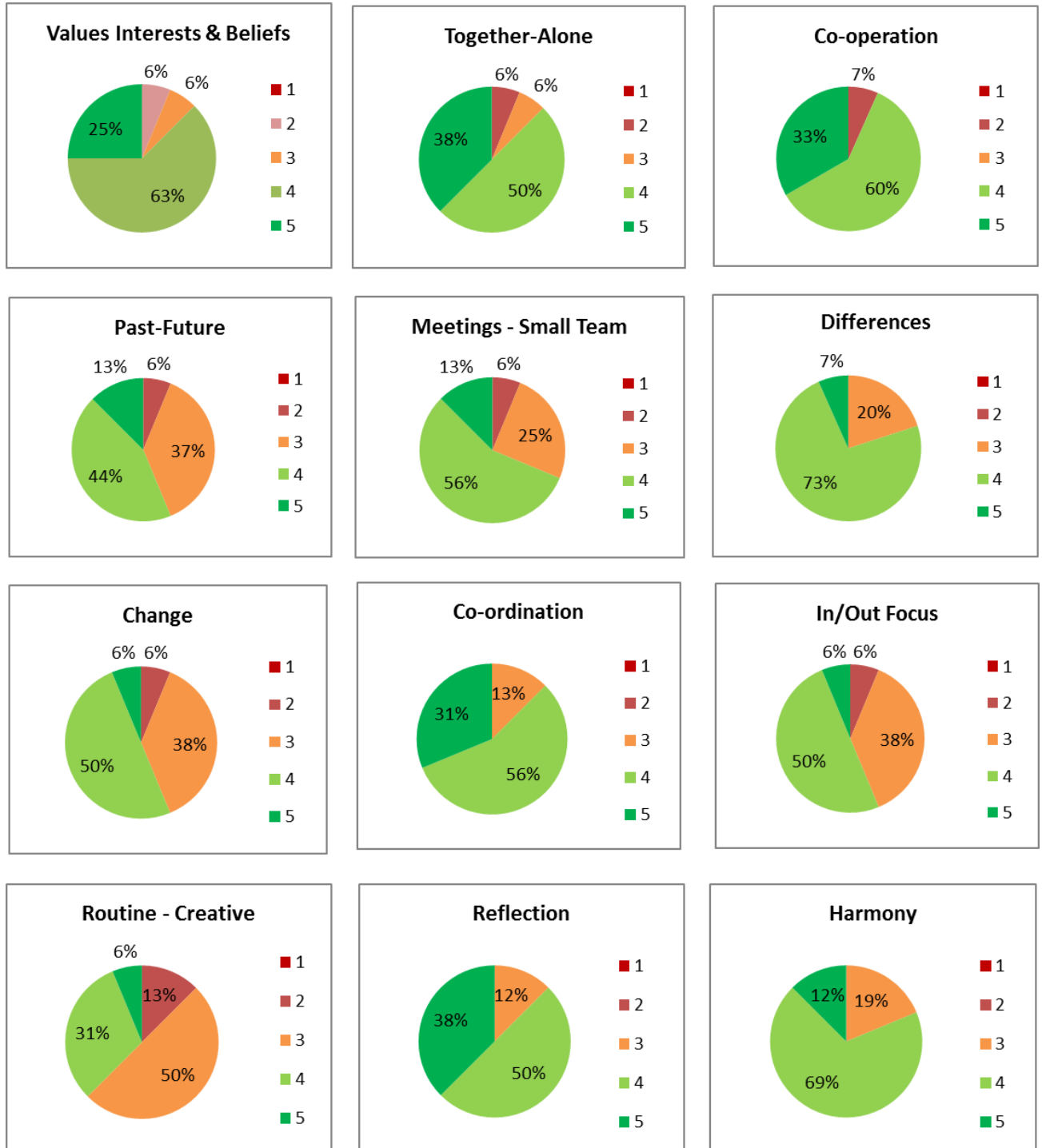
People in my team have dissimilar values, interests and beliefs	1	2	3	4	5	People in my team share values, interests and beliefs
People in my team break rank and go it alone	1	2	3	4	5	People in my team pull together
Individuals in my team operate alone and there is conflict between them	1	2	3	4	5	There is community spirit and co-operation in my team
My team is ruled by standards of the past	1	2	3	4	5	My team is ruled by visions of the future
Meetings are an aspect of the culture in my team	1	2	3	4	5	Working in small teams is an aspect of the culture in my team
In my team there are winners and losers, them and us	1	2	3	4	5	People confront and move beyond their differences in my team
My team is anti-change	1	2	3	4	5	My team is change oriented
There is weak coordination in my team	1	2	3	4	5	There is strong coordination in my team
My team is inward looking and is focused on itself	1	2	3	4	5	My team is outward looking and does not focus on itself
My team is dominated by routine and systems	1	2	3	4	5	My team is creative and ideas-dominated
People do not reflect about their work in my team	1	2	3	4	5	People reflect about their work in my team
There is disagreement in my team	1	2	3	4	5	There is harmony in my team

Thank you for completing this questionnaire.

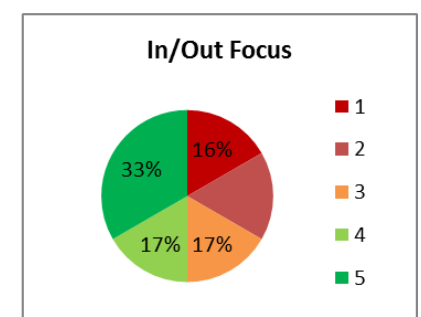
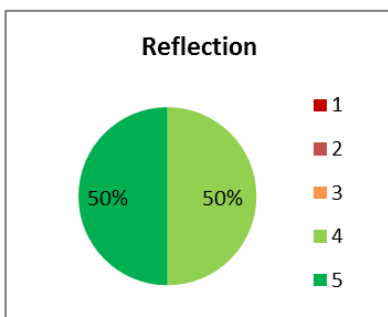
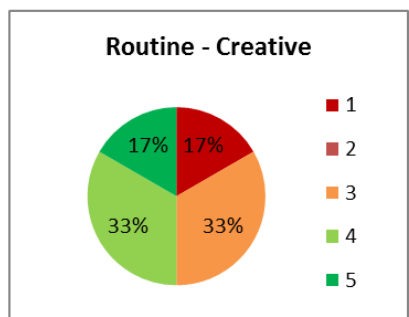
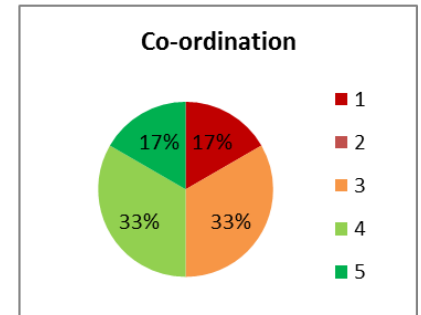
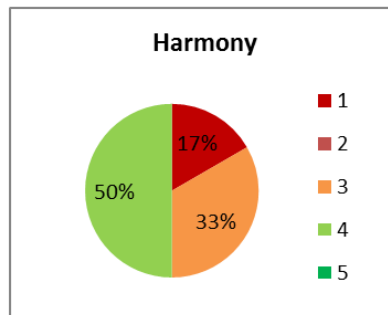
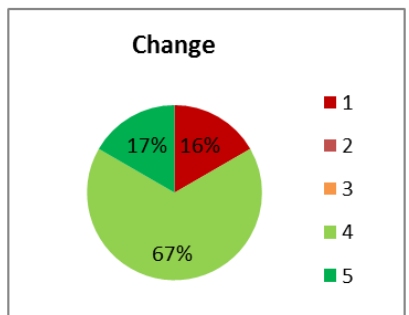
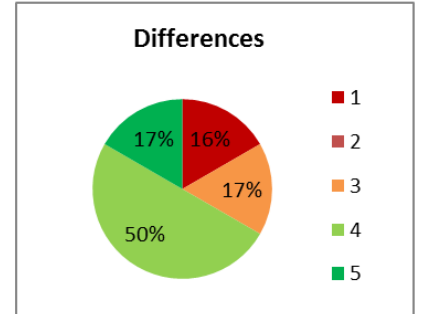
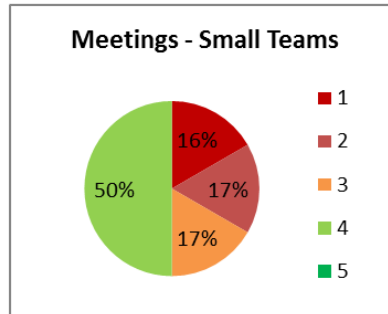
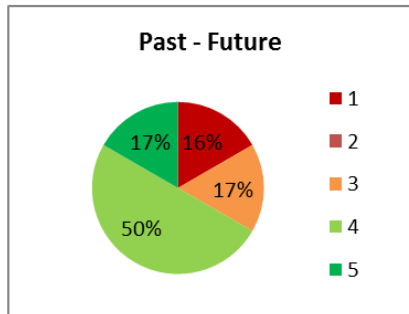
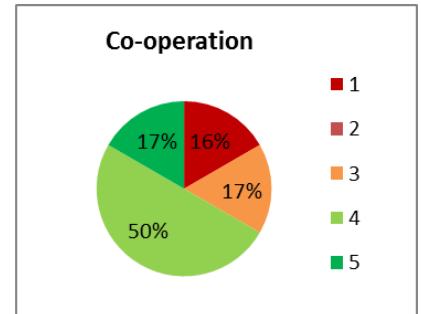
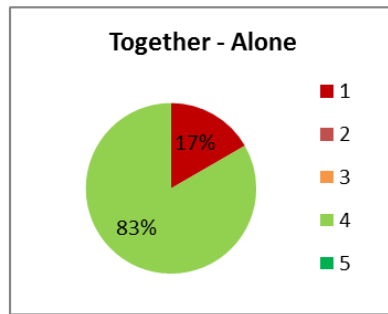
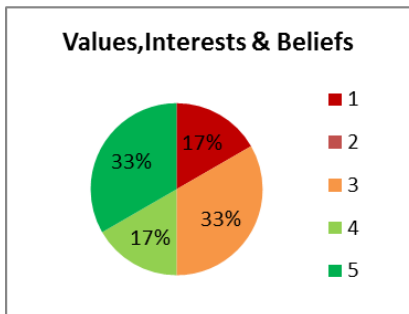
Appendix 2a: Results of team culture questionnaire

Positive scores Green, negative scores Red.

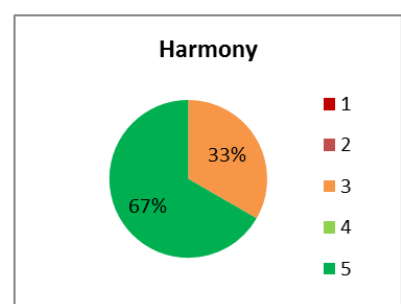
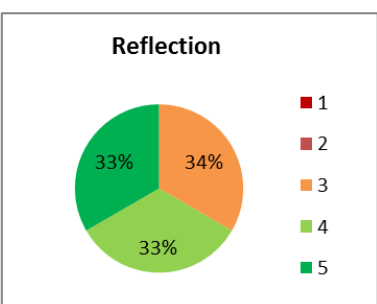
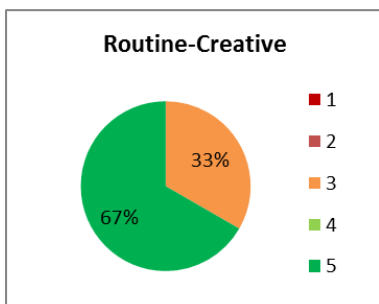
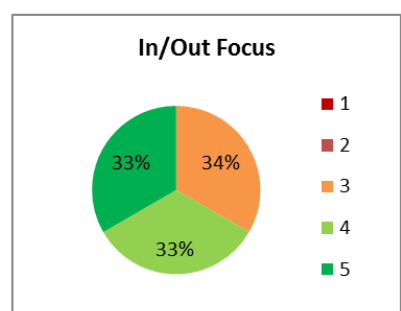
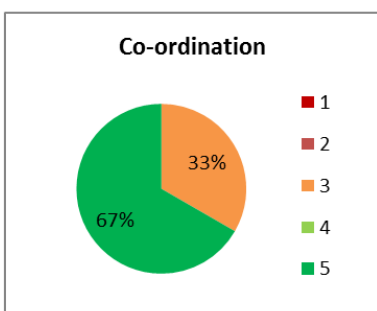
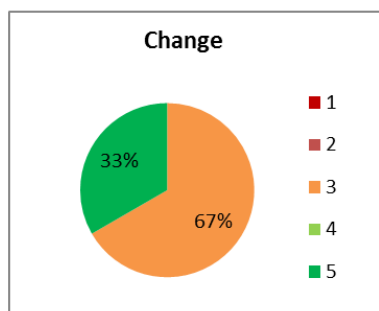
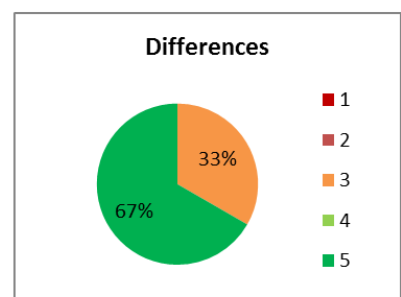
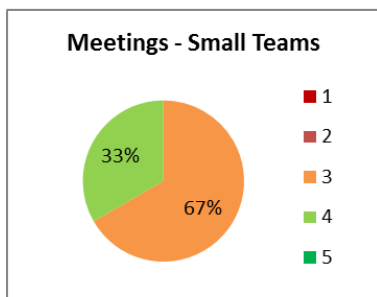
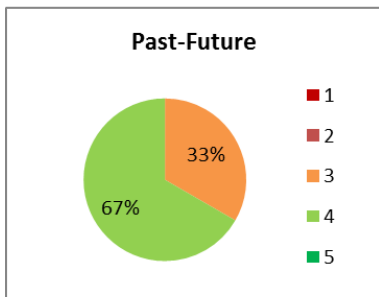
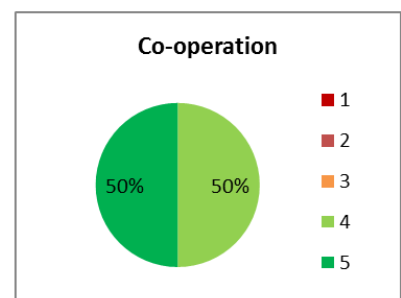
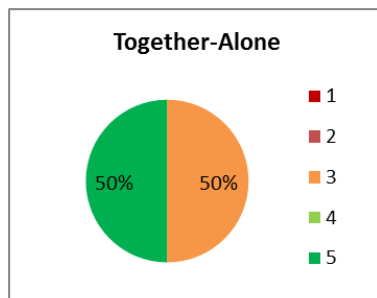
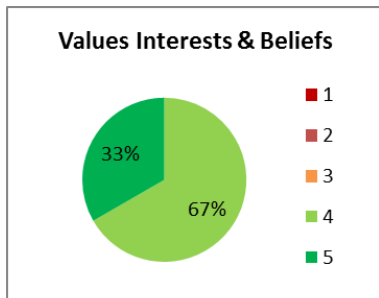
IPU (n=16)



DPU (n=6)



DPU Volunteers (n=3)



Kitchen Staff (n=4)



Appendix 3: Summary of minutes of Nutritional Steering Group

1st meeting: March 2014

At the beginning of the meeting, the group was asked to complete their individual values and beliefs clarification questionnaire. This exercise aimed to establish individual views regarding nutrition in palliative care. These individual values and beliefs were then shared with the group and a joint mission statement in the form of a poster/visual aid was developed (see Appendix 1a and 1b for the results).

Poster: This approach facilitated the creation of a joint mission statement, building the group statement on the basis of the individuals' values and beliefs. It enabled the group to work together as a team and apply their own values in a joint vision.

After the meeting, the team leader, together with the project team and the FONS facilitator, reflected/evaluated the meeting using a 'claims and concerns' exercise: Through this it was found that:

Claims: The patient was contributing a lot to the overall discussion and the entire group was very passionate about the topic and its potential impact on the quality of life in terminal, or near terminal phase patients. The meeting was very well structured and attended.

Concerns: There were concerns that some members of the group withheld their voices and that generally the whole meeting needed more time.

Action plan: Due to lack of time the poster was not finished by the end of the session therefore project team aimed to create a visual aid of nutritional statement for the next meeting. It was decided that future steering group meeting would last an hour and a half. It was felt that each meeting should have a theme (food theme) which would encourage members to attend the meetings regularly. Each of steering group members should receive a thank you gift for attending the meetings at the end of the project.

2nd meeting: April 2014

At the beginning of the session, the posters were presented from the previous meeting's values, beliefs and clarification exercise by the project team. A claims and concerns exercise was utilised to structure the meeting.

The claims were:

- The group thought that the hospice was good at providing high quality food, that the in-house cooking/presentation of food was suitable and that the portion size was appropriate.
- The staff clearly displayed passion regarding the food and appropriate information resources available.
- Dietician input was very valuable in more complex cases,
- The hospice staff had a better understanding of the end of life illnesses and management e.g. bowel obstruction than those in acute hospitals
- We are good at focussing on both the patient's and carer's needs, while at the same time acknowledging their concerns.
- As a specialist palliative care facility it was also thought that we were generally better at addressing palliative symptom control issues in the end of life, compared with others primary and secondary NHS places of care.

The concerns were:

- Communication between patients and the kitchen, especially regarding the Inpatient Unit (IPU)
- Family's understanding of patients' needs
- Whether carers' needs are being met
- The group felt that our advice should be appropriate to the patients' nutritional needs in every stage of their palliative journey.

Action points from the meeting:

1. Introduce nutritional wellbeing workshops alongside the other topics already addressed.
2. Ensure existing 'Pall rehab courses address the needs of both patients and carers who attend.
3. In order to improve communication between patients, IPU staff and the kitchen the chefs could be introduced during a patient's admission to the IPU and, if necessary, come to see patient for any individual requests.
4. IPU/DPU could introduce charts for special-needs patients with 'likes' and 'dislikes', along with a visual menu for those with communication difficulties.
5. The group also felt that ongoing assessment of patients' nutritional needs would help raise the quality of care by responding to patients' current nutritional needs which should be adjusted if necessary. This would include community teams and the education across the board.
6. The dietician will update the hospice Nutritional Policy, including producing and sharing copies of the resource prepared by the patients about nutrition and diet in palliative care.

It was felt to be important that patient and carer's needs were the driving force behind any planned changes. To this end, the NSG decided to interview a number of patients and carers individually about their nutritional needs. These interviews would be recorded and listened to by the NSG in order to guide changes on practice. The project leader asked the group to discuss and approve the patient information leaflets produced in order to obtain informed consent for the interviews and participation in the project.

3rd meeting: June 2014

During our third meeting the group started analysing patients' stories. The first interview was with the IPU patient. It was clear that the patient was very positive about the nutrition and diet, stating that good quality food was served at flexible times with a good variety of choices. Sharing meals with the relatives was also appreciated by the patients.

The group found few concerns during the interview. A perceived lack of understanding about the reasons for patients reduced appetite, inability to eat food, linked with a lack of flexibility regarding advance meals booking.

As a direct result of these findings several questions were asked to address specifically how we might improve our patients lack of understanding and how those with small appetite could be provided with improved flexibility, choices and mealtime orders. It was decided that there is a need to educate patients and carers therefore information leaflets are now in preparation by the hospice dietician.

The steering group also identified that people involved with delivering food need appropriate education on end of life nutrition (new staff, yearly updates on nutrition, volunteers) and this needs to be supported by a continuing education programme. Discussion around flexibility and availability of different foods is also scheduled to be discussed with the kitchen staff (towards a more 'person-centred' care, incorporating daily food orders instead of advance ordering the day before). It was also agreed to invite the catering manager to future meetings as their contribution/co-operation would help to facilitate and support the implementation of changes identified in the patient interviews and recognised by the NSG.

At the end of this meeting we also discussed the current nutritional policy and there was a consensus that some adjustments should be made to the policy regarding re-feeding syndrome in palliative care. The dietician is to research this issue further as an outcome action.

4th meeting: Aug 2014

Listening to the interview with a patient and his wife in the community.

Claims:

- Good nutritional leaflet but supplemented by appropriate, individualised advice tailor made to the patient.
- Individual needs addressed
- Reassurance that loss of appetite is a normal process in this situation (though warning in advance that this might happen would be helpful and reassuring)
- Ideas on prevention of weight loss

Concerns:

- The patients' nutritional needs had not been addressed or assessed by anyone else over a 3 year period of intensive treatment
- Loss of appetite needs to be proactively discussed
- Our nutritional leaflets do not mention that this is a common experience
- Our nutritional leaflets do not mention the impact on the carer who may feel inadequate, unsure of what is normal or abnormal, be struggling with a change in role and whose own diet may be affected. The relationship between patient and carer may also be affected.

Action points:

1. Ensure that there is information in the nutritional leaflets about the impact on carers and the commonness of these symptoms.
2. Ensure the leaflets explain the relationship between cancer and weight loss.
3. Ensure nutritional leaflets are available for people to pick up in the hospice
4. When teaching about nutrition in palliative rehabilitation and carers' courses, ensure the needs of carers and the above points are highlighted
5. DPU and IPU staff to give out the leaflets to supplement oral advice so patients can take them home to their carers, especially on discharge.
6. Ensure the kitchen staff have access to the written information on nutrition on the P drive
7. Putting the carers' needs on the agenda of the DPU
8. Early intervention on appetite and nutrition – ensure this is one of the well being workshops in the future

5th Meeting: Sept 2014

Listening to the interview with a patient from DPU. Unfortunately, no kitchen staff could attend

Claims:

- Lovely salads
- different chefs bring new ideas and presentation
- Individual requests possible
- Enjoys plain food
- Options available if things are too salty or spicy due to taste changes
- Well cooked fish is enjoyed
- Social aspect of eating together is important
- Food and eating is natural , about well being
- Pre meal alcohol

Concerns:

- 7 day menus mean that those who come on the same day each week get the same food
- Supper choices rarely change
- Patients have little energy for cooking – we need to recognise this

- What about the social aspect of eating for patients in the IPU who normally eat alone in their room? Could a space be freed up for them to eat together?
- If the dining room is full it may not be welcoming

Action points:

1. teaching for kitchen staff especially new ones about patient needs, taste changes etc
2. catering team manager to be invited to the next meeting
3. gluten free food in the freezer so it is readily available
4. 8-10 day menu plan
5. see if productive ward could find space for communal eating
6. next interview to find someone with more problems with nutrition

6th Meeting: Oct 2014

This meeting focused on discussion with the kitchen staff and catering manager in order to address the practical issues within Dorothy House.

Claims:

- Freshly cooked meals that meet individual needs/wants – a bespoke service
- Professional trained kitchen staff, approachable, reactive to needs
- A good safe, social environment in the dining room, with kidney shaped tables for those with wheelchairs, the ability to eat in isolation if the patient wishes.
- Food vending service for families
- Alcohol available if desired

Concerns:

- Limited choice at times
- Catering staff and volunteers serve too large a portion for those with small appetites, assuming they need to feed them up
- Catering staff do not know the patients
- New legislation re allergies and food labelling mean a lot of extra work and that the nursing and kitchen staff need to know about a patient 's allergies
- Menu rotation still 7 day
- Patients are more frail than in the past, so eating is more difficult
- Need for more choice in finger foods (especially useful for those with dementia or poor appetites)

Action points:

1. A 13 day menu was introduced and was a great success especially with the DPU patients
2. The kitchen will explore getting colour coded portion spoons to ensure that all staff know how small a 'small' portion is
3. A new menu sheet for the IPU will include advice on allergies, special diets, portion size
4. Volunteer hosts on the IPU will be responsible for serving meals and clearing away dishes. They will liaise directly with the nurse in charge of each patient and the kitchen staff to ensure that each patient gets the type of food, size of portion etc that they need.

7th meeting: Dec 2014

This was a small meeting attended by the core members of the NSG. Progress so far was discussed and reviewed and the team were encouraged by the enthusiasm of the kitchen staff to meet patient needs, the dietician's desire to ensure the nutrition information leaflets met the needs of patients and carers and the ward staff's hope that the group would be able to develop an appropriate assessment tool.

A meeting with the director of nursing was planned to consider how to introduce and implement a new assessment tool.

8th meeting: Feb 2015

Staff shortages, heavy workload and internal changes meant that little had moved forward since the last meeting. The nurses working on the project and the dietician had met together with the Director of nursing at Dorothy House. It was decided that the MUST tool was a screening tool to ascertain those at risk of malnutrition which should then lead to a full assessment of the patient's nutritional needs. However, it was felt by the group that in the light of the research, all of our patients should be considered to be at risk of malnutrition and therefore an assessment of each patient is warranted.

The NSG considered a number of assessment tools in the light of the needs expressed by our patients and carers. It was noted that none of the tools expressly dealt with carers' concerns although much the research quoted above and experience in the community had demonstrated the extent of their needs. The NSG felt that the assessment tool developed by Macmillan for palliative care patients (Macmillan 2007) most closely met the needs of our patients but that it should be amended to include information about dietary needs, allergies and special diets and should assess the needs of carers.

9th meeting: March 2015

The kitchen staff reported to the NSG the developments that they had made.

- The new menu cards have worked well, the kitchen feel much more connected to the patients and are enthusiastic about being about to meet their needs directly.
- DPU staff report that 2 patients with very specific dietary needs have met directly with the catering staff and this has enabled their needs to be met and for them to feel confident to attend DPU and stay for lunch
- The volunteer hosts for the IPU have been trained and this appears to be working well, the staff feel that patients' needs are being met more appropriately and they are more aware of the patients' difficulties with nutrition.

The catering staff sounded very enthusiastic and fully engaged in the project.

Two members of the NSG had attended the nurse forum at Dorothy House and presented a paper on nutritional assessment (appendix 8)

This had been well received but the forum had decided that, in the light of an imminent CQC inspection, the implementation of an unverified assessment tool was too great a risk. Despite the disappointment, the NSG decided to continue with their work and, using the Macmillan tool and its algorithms as a basis, developed the tool and algorithms. The dietician had a subsequent meeting with the director of nursing and it was agreed that the PLANC tool would be audited against MUST with 10 patients assigned to each tool. At the end of the audit, the dietician will evaluate to assess how well the tools resulted in an appropriate care plan and actions compared to the dietetic assessment. If the PLANC proves to be as effective as MUST in determining appropriate care planning, then the nursing staff must decide which tool to use – this will be done by discussion with the IPU staff using a questionnaire and focus group approach. This proved effective originally to discover the staff's views concerning MUST. It will also be important to ask patients and carers for their views on whether PLANC assessed their needs adequately and the method of doing this is yet to be decided.

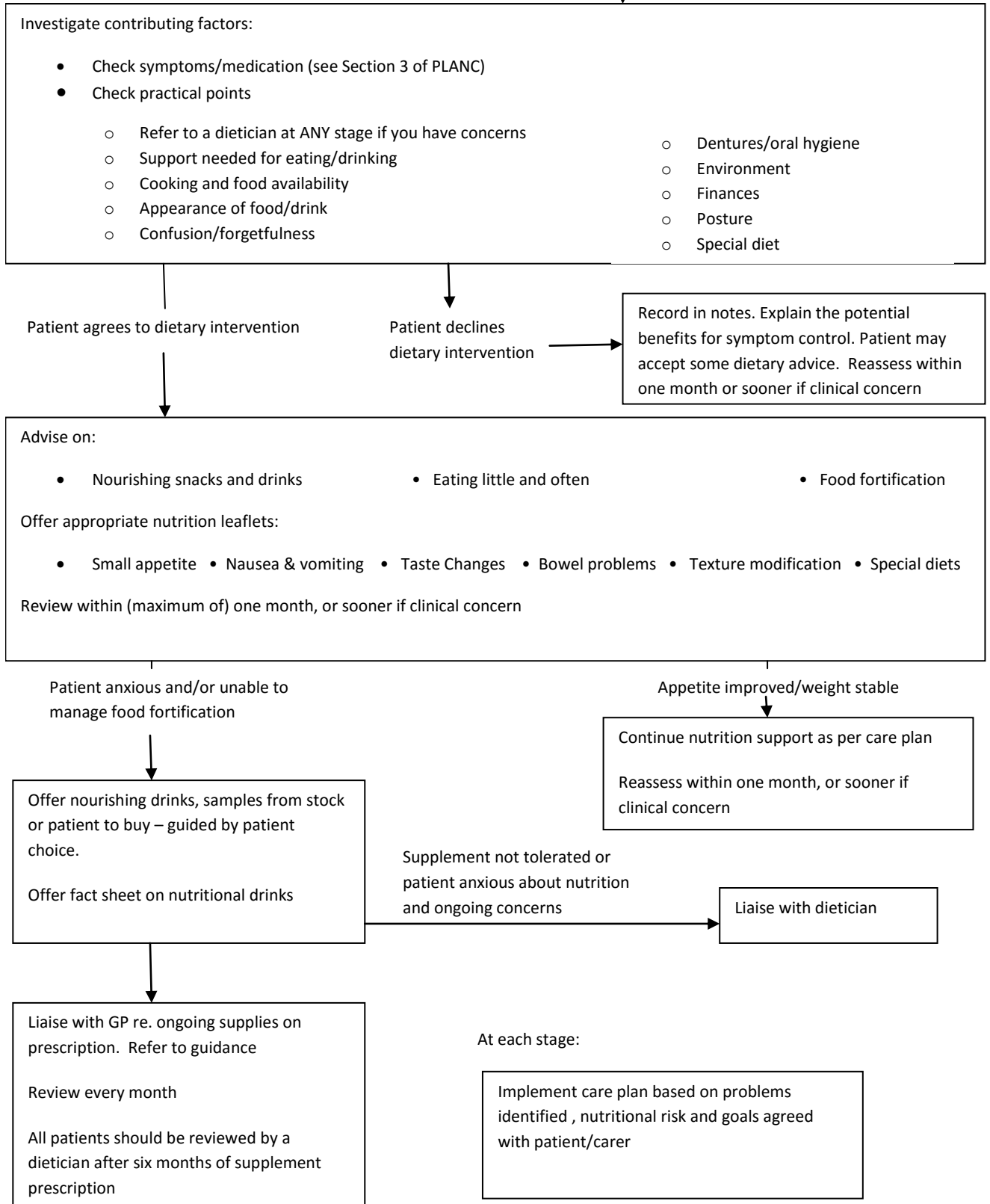
February 2016

It had taken much longer than expected for the dietician to do the audit, she had a new nutritional assistant and there had been many staff changes. However, the audit was finally done and the team met informally over the period to encourage each other. The team are about to work on an electronic version of PLANC and to embed its use across the hospice.

Dietary Algorithm 1

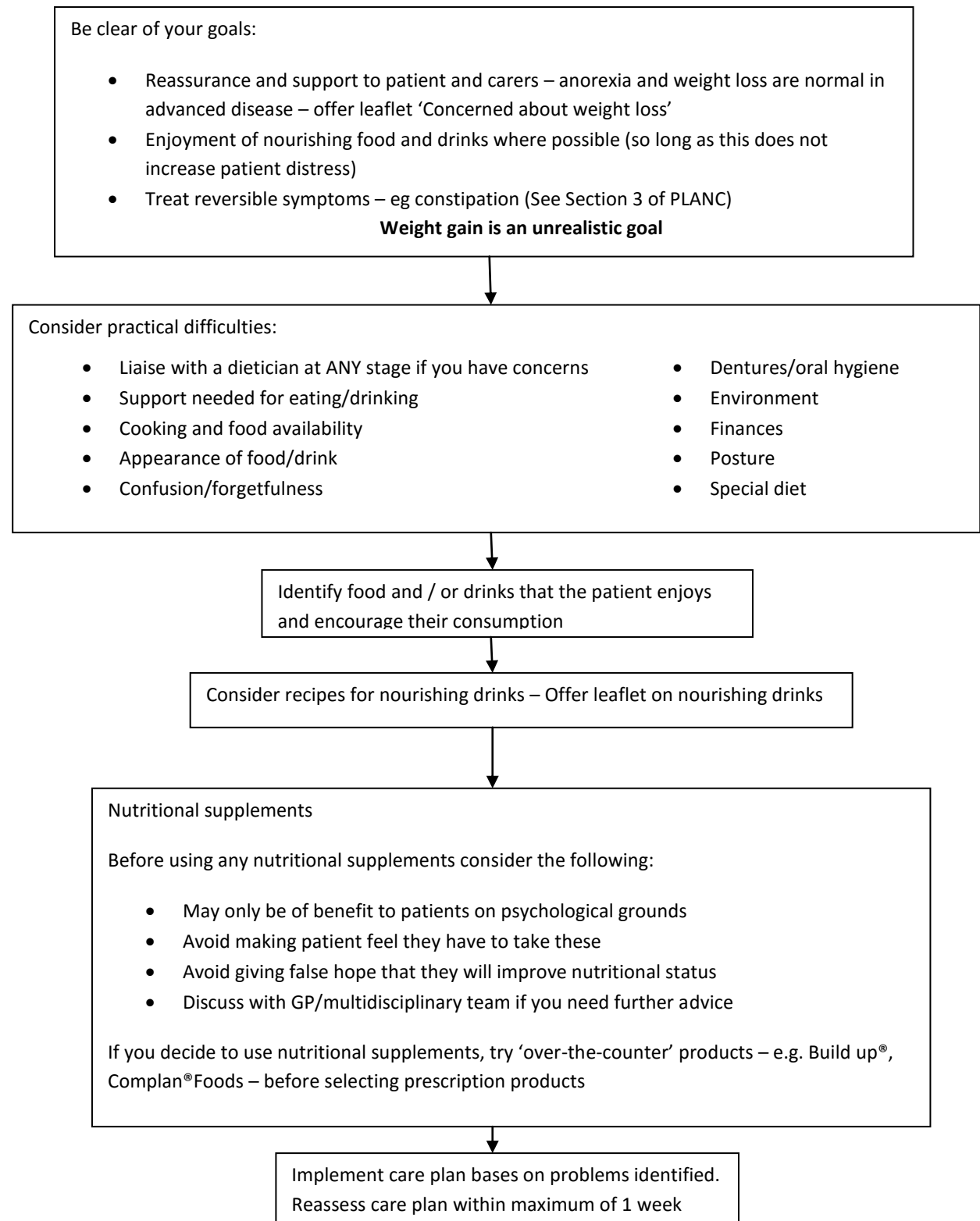
Weight loss and/or reduced appetite in early palliative care when nutrition can make a difference to well being.

(Use **Dietary Algorithm 2** for patients at late palliative care stages)



Dietary Algorithm 2 – Patients at late palliative care stages

N. B. This algorithm is intended for use with patients who are too unwell to manage meals, rather than for patients who have difficulties swallowing



Seek advice from/refer to a dietician if there are concerns/queries that you cannot answer

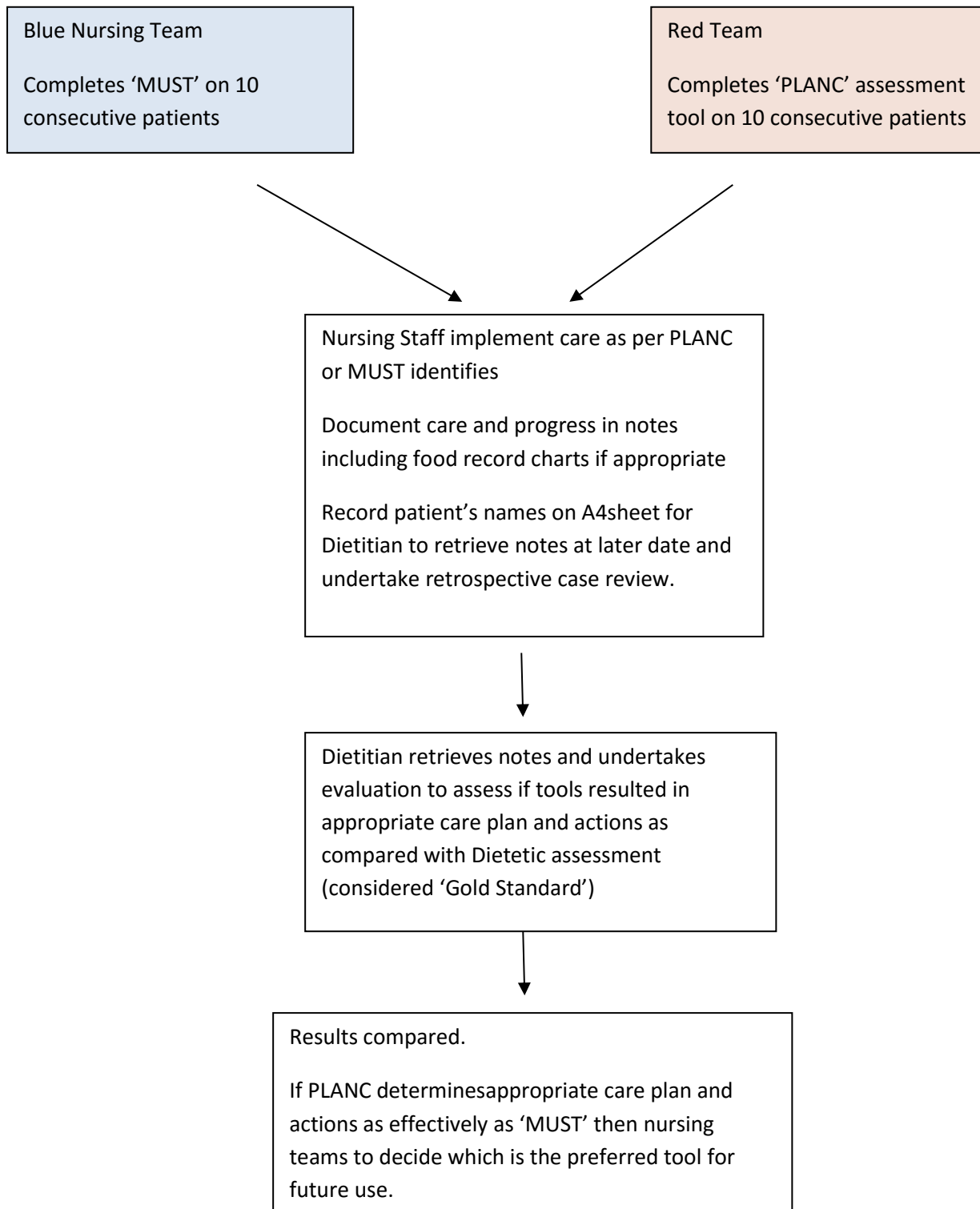
Seek advice from the patient’s clinical nurse specialist/specialist palliative care team for treatment of symptoms that you are not able to manage.

Appendix 5 Nutrition Audit – April 2015

Aim: To evaluate the use of 'PLANC' vs. 'MUST'

Venue : IPU

Outline of Audit Ward Level



Appendix 6: Patient Information Leaflet

Project title: A Holistic Approach to Nutrition and Diet in Palliative Care.

Participant Information Leaflet

Dorothy House is continually seeking to improve the services it provides for patients and carers. Therefore we would like to invite you to take part in an evaluation of the assessment, advice and support you have received from the Dorothy House Hospice Team with regard to food and nutrition.

What is the purpose of the Project?

The overall aim is to learn more about the patient experience of food and nutrition and the care that is offered by the Hospice.

What are we trying to find out and why?

Through undertaking this evaluation we hope to find out more about your experience of living with your condition, how it affects your nutrition and the current assessment, advice and support that we provide in practice for our patients and their carers.

What does the study mean for me?

The Principal Investigator, Agata Czerwinska (IPU nurse) and the nursing team: Jill Souter (Clinical Nurse Specialist) Community Outreach Centre and Sarah Cooley (DPU nurse) will interview you and ask you to tell your story. This interview (40 minutes maximum) will be recorded and transcribed for the sole purpose of the service evaluation. The recording will be destroyed afterwards.

Do I have to take part in the project?

No, it is up to you. You do not have to agree to take part.

How will I be treated if I do not take part?

You will not be treated differently if you do not take part in the study. The standard of care you receive will not be affected.

What are the benefits of taking part?

There will be no direct benefits to you from this project. However, the information gained from this evaluation will help us to improve our service in the future.

What will happen if I don't want to carry on with the project?

You can choose to withdraw from the project at any time. If you decide to withdraw from the project you can do so by informing the Investigator (Agata, IPU) or the nursing team.

What will happen to the results of the project?

The findings from the project will enable us better address the nutritional needs of the patients under the care of our hospice. Additionally the results of the project will be published so that others can learn from what we find out. All published data will remain anonymous.

Who is organising and funding the evaluation?

The project is being funded by the Foundation of Nursing Studies, a registered charity that is dedicated to working with nurses and healthcare teams to develop and share innovative ways of improving practice. This project is a multidisciplinary initiative.

Who has reviewed the study?

The service evaluation has been reviewed within Dorothy House and has been approved by the Clinical Governance Committee as per Dorothy House policy.

What if I do have any questions or concerns?

You can contact us during working hours by ringing the phone number below or by writing by e-mail. We will be happy to answer any questions or address any concerns that you have. If you wish to complain, or have any concerns about any aspect of the way you have been treated during the course of this project then you should immediately inform the Investigator. Dorothy House Hospice has a complaints procedure which is also available to you

Thank you for taking time to read this information leaflet

Contact numbers: via Dorothy House main reception 01225 722988

- Agata Czerwinska (IPU), Winsley
- Sarah Cooley (DPU), Winsley
- Jill Souter (Community Outreach Centre), Peasedown

agata.czerwinska@dorothyhouse-hospice.org.uk

PATIENT CONSENT FORM

Name of Patient	
Date	

Title of Programme	A Holistic Approach to Nutrition and Diets in Palliative Care
Organisation and/or Publication	Dorothy House Hospice Care, Winsley
Purpose of interview	Verbal information regarding patients/carers views around nutrition in Palliative Care
	Description of story or context in which it will be used

I give permission for interview to be undertaken/taken by the organisation mentioned above	Yes	No
I understand that interview may be used for the purpose detailed below	Yes	No
A member of Dorothy House Hospice has explained to me that the quotes taken/given may be used for any publicity that the Dorothy House feels is appropriate. I understand that this may include being used on notice boards, in publications, on the Internet/Intranet, in local or national newspapers or magazines and agree that my quotes may be used for these purposes.	Yes	No
Signature of patient		

The rest of this form should be completed by a member of the nutritional project.

I have explained to the patient/relative signing this form that recording / interview may be used for the purposes outlined above.

Counter signature of staff member	
Print Name	

Please ensure that this form has been completed fully and return the signed and dated hard copy [a tape of relevant footage if available] to: Dorothy House Hospice, Winsley, Bradford on Avon, Wiltshire BA15 2LE

Thank you
Agata Czerwinska

Appendix 8

Nutritional Screening, Nutritional Assessment and Planning Nutritional Care:

Notes for the Nurse Forum Mtg 19th March

- It is recommended that a validated screening tool is used in all care settings to identify patients at risk of malnutrition (NICE CG32 2006, NICE QS24 2012).
- The Malnutrition Universal Screening Tool 'MUST' (BAPEN) is the most widely used validated screening tool in the UK (BAPEN Nutrition Screening week data 2014).
- 'MUST' has previously been adopted by Dorothy House to identify those at risk of malnutrition including subsequent guidance on further assessing and treating dietary problems.

Disadvantages of 'MUST'

- 'MUST' relies on objective measures such as weight, height, BMI and weight loss over time to determine nutritional risk.
- Due to the anxiety around weight loss in palliative patients and the psychological challenges of not being able to prevent or reverse weight loss, clinicians and staff have raised concerns about the use of monitoring body weight and therefore 'MUST' amongst palliative patients.
- In 2012 it was concluded by the Nutrition Steering Group that the use of Mid Arm Circumference (MAC) be incorporated in place of weight to avoid the need to weigh patients (Nutrition Policy 2012). MAC however is not a sensitive tool to measure changes in weight.
- In addition many clients cared for at Dorothy House Hospice (IPU and outreach) experience cachexia (loss of lean tissue due to solid tumours and an incurable long term disease) and sarcopenia (muscle wasting associated with ageing). Both these factors result in muscle wasting and therefore measuring MAC may reflect the underlying disease effects rather than the effectiveness of any nutritional or dietary intervention. The use of MAC as a surrogate measure for Body Mass Index has not been validated in palliative care population. And nor is MAC suitable as a short term measure, therefore changes in MAC measurements are unlikely to be captured over the time our patients are cared for particularly in the IPU.
- Local research at Dorothy House surveying attitudes amongst nurses towards the use of 'MUST' and in particular the use of objective measures highlighted concerns on the appropriateness of the MUST.
- Nor is MUST appropriate for end of life care.
- Clinical experience and clinical literature illustrates that many if not all of the clients under the care of Dorothy House are either at risk for malnutrition, have malnutrition and/or have eating difficulties.
- Work with patients and carers and staff undertaken by the Nutrition Steering group highlighted the need to revisit the need and appropriateness of 'MUST'. As ALL patients are considered at nutritional risk a malnutrition screen such as 'MUST' can be considered superfluous. The Nutrition Steering Group believe ALL patients should be assessed and factors contributing to diet issues should be evaluated and treated or managed where possible. Consequently we have evaluated tools available and believe a nutrition assessment based on the Durham Cachexia assessment is more suitable for our client groups. Underlying factors impairing nutritional intake or causing symptoms are identified through a series of prompts in the Durham cachexia tool and issues identified subsequently guide care and enable an appropriate nutritional care plan to be designed in agreement with patients and carers.

Benefits of the Durham Cachexia Approach

- The Durham Cachexia Assessment tool and accompanying resources offer the advantage of an assessment rather than a screen, the assessment guides appropriate nutritional care taking into account the stage in the patient's journey with a focus on quality of life, enjoyment of food and symptom relief.
- It is a patient-focussed symptom led approach.
- Aims to relieve symptoms through dietary management.
- Incorporates an assessment of Body Mass Index and weight loss but outcome measures are not necessarily focussed on weight unless appropriate.
- Assumes all patients are 'at risk' of malnutrition but treat according to staging of underlying disease therefore also suitable for those approaching end of life who benefit from symptom relief.
- To support and / or educate patients/carers/family members appropriate leaflets from the Nutrition and dietetic resources available in hard copy at each Dorothy House Hospice site or online: DH Public folder > Nutrition> Diet resources for patients & carers) can guide the care. For malnutrition visit: www.malnutritionpathway.co.uk

Appendix 9

PLANC has been adapted by our in patient unit to incorporate some of the information that they need routinely on admission. They do not include information on fatigue as this is covered in another area of their assessment.

Nutrition and Diet Patient Information

PLANC - Patient Led Assessment of Nutritional Care



Name: NHS Number:
Date completed: By whom:

Symptoms

What is your approximate current: Weight Height:
During the past month my weight has: Decreased Increased Not changed
Approximate weight 1 month ago:
Approximate weight 6 months ago: %weight loss:

If unsure of weight and weight history or weight loss, note any signs of recent weight loss (e.g. loose clothes, dentures, jewellery):

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Food Intake

Compared with my normal intake, I would rate my food intake during the past month as:
Unchanged More than usual Less than usual

I am currently eating:
Normal food Little solid food Only liquids Only nutritional supplements/nourishing drinks
Very little of anything Tube feeding : indicate PEG RIG

Special Dietary Needs:

Include information on allergies/intolerances/cultural or religious requirements

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.....

Are swallowing problems present? Yes No

If Yes, has a Speech and Language Therapy assessment been done? Yes No

Have you been advised to follow a texture modified diet? – tick which
A B C D E
Soft mashable Pureed Thin Liquids Thickened liquids

#whenitmattersmost

dorothyhouse.org.uk

Registered Charity No. 275745

Name: NHS Number:
 Date completed: By whom:

Symptoms

Do you have any of the following problems that have kept you from eating enough during the past few weeks (tick all that apply)

No problem eating <input type="checkbox"/>	Nausea <input type="checkbox"/>	Food tasting different/ having no taste <input type="checkbox"/>
No appetite, do not feel like eating <input type="checkbox"/>	Diarrhoea <input type="checkbox"/>	Feeling full quickly <input type="checkbox"/>
Constipation <input type="checkbox"/>	Dry Mouth <input type="checkbox"/>	Breathlessness <input type="checkbox"/>
Mouth sores <input type="checkbox"/>	Smells bother me <input type="checkbox"/>	Pain <input type="checkbox"/> Where? <input type="text"/>
Vomiting <input type="checkbox"/>	Other <input type="checkbox"/> <input type="text"/>	

Examples: fatigue, anxiety, depression, financial concerns, dental problems.

Do you have any concerns about nutrition and diet?

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.....

Assistance

Do you require assistance with

Meal Preparation <input type="checkbox"/>	Positioning for eating <input type="checkbox"/>	
Shopping <input type="checkbox"/>	Equipment <input type="checkbox"/>	Please tick any need for:
Eating a meal <input type="checkbox"/>		Plate Guard <input type="checkbox"/> Utensils <input type="checkbox"/>
Specialised beaker <input type="checkbox"/> What type? <input type="text"/>		Slip mat <input type="checkbox"/> Non-return valve straw <input type="checkbox"/>
Other <input type="checkbox"/> <input type="text"/>		

Carer Assessment

What concerns (if any) do you have about nutrition and diet?
 How have concerns about nutrition and diet affected you?
 Are there any issues regarding nutrition and diet that you would like more information or advice about?

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