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speaking up for change

## **Malnutrition in the community and hospital setting**

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In association with YouGov

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## Executive Summary

There is a lack of awareness amongst patients regarding the issue of malnutrition, whether they are at risk, how they can prevent malnutrition from developing and where to seek help and advice.

- At any point in time more than 3 million people in the UK are either malnourished or at risk of malnutrition.
- The NHS has been charged with making £20 billion of efficiency savings by 2014 but malnutrition costs the UK in excess of £13 billion a year. Tackling malnutrition could make substantial savings to the NHS.
- This is the largest survey of its kind carried out in the UK on the issue of malnutrition in the community and hospital setting (5,018 adults aged 18 or over living in England, Scotland and Wales).
- 'Good nutrition' was primarily associated with a balanced diet (62 % of all respondents).
- Alarming, only 7 % of respondents identified maintaining a regular weight as a sign of good nutrition.
- Regular weight loss is one of the key physical measures of malnutrition. Although the public make the connection between good nutrition and eating a balanced diet they do not take this association a step further and make the link between good nutrition and maintaining a regular weight.
- Monitoring weight is a very valuable quantifiable measure by which the public and carers can keep a proper record to check if they are at risk of malnutrition. Weighing oneself is one of the easiest forms of self assessment and is an inexpensive way for patients to monitor their nutritional status.
- By promoting the simple message that monitoring weight helps identify those at risk of malnutrition, the Department of Health could help the public identify those at risk and take action to prevent them from developing malnutrition.

- Older people were more likely than others to connect malnutrition to unexpected weight loss but were less likely to associate malnutrition with an increase in time taken to recover from illness and an increased likelihood of becoming ill.
- Those who had previously sought information about malnutrition were especially likely to associate it with mental changes, the time taken to recover from illness and slow wound healing, suggesting they have learnt this from the information provided or from their own experience of malnutrition.
- People in the oldest age group (65 and over) were most likely to have gained information from their GP on malnutrition. In addition, 31 % had contact with a Dietitian, but few had consulted a Pharmacist and there was little evidence of information or advice from support groups, charities, the media or family and friends.
- Those who sought out information in the past, were more interested than others in local services and support groups, suggesting there is a gap between what they were able to access last time and what they might ideally want information on.
- Around half of those who had searched for information did so via the internet, which highlights the need for regulation of websites that provide medical information to the public.
- Only 31 % of inpatients surveyed recalled having been screened for malnutrition – despite screening for malnutrition being a key clinical priority set out in NICE Guideline 32.
- A fifth of respondents (17 %) were unaware of any of the nutritional treatments or actions for malnutrition and only 1 in 5 of the 65 and over age group were aware that sip feeds were available on prescription, as were a quarter of Carers.
- Only 13% of Carers had sought out information about malnutrition in the past suggesting that the issue has only been a high priority for relatively few of them.
- In terms of information, half of Carers wanted to know who to go to for help if they had concerns and around a third were interested in community support services.
- Nine out of ten Carers check on the weight and diet of the person they care for, but very few have used the formal method of keeping a food diary and only 16% had weighed the person they care for. Those who had previously sought information on malnutrition were significantly more likely to weigh the person and to check that their clothes fit well.
- Given the context of low awareness and knowledge, it was worrying that as many as half of Carers had concerns about the person's weight and diet and that only quarter of that group had

looked for information about malnutrition. Only 50% had turned to a GP for help, but 55% took action on their own to try to resolve the issues.

- Of all those respondents with a friend or relative in a care home, a many as 68 % were unaware how often their diet and weight was monitored.
- Recognising that patients and carers want to be educated about the issues of malnutrition so that they can be empowered to identify the signs and symptoms of malnutrition and seek help, the Patients Association has produced a leaflet 'Malnutrition – signs and symptoms, where to go for help and what to expect from treatment'.
- This leaflet should be provided by GP surgeries and healthcare professionals to patients and carers who may be vulnerable or at risk of malnutrition.

## Calls to Action:

- The Department of Health must provide information on basic nutrition and the importance of monitoring weight loss as an early warning sign of malnutrition to patients and healthcare professionals
- GP consortia need to ensure information on malnutrition is tailored to local services and covers the whole 'malnutrition journey' from diagnosis to nutritional treatments that can be prescribed by the GP and also following up and monitoring in the community
- GP consortia and Local Authorities must ring-fence funding for community-based dietetics services and treatment options if clinically required
- GPs and GP consortia need to be educated as to the cost benefits of treating malnutrition
- The Department of Health must make nutritional screening across all health and social care settings mandatory and healthcare professionals must be educated and trained to use a nutritional guide to the social risk factors associated with malnutrition and nutritional screening questions to ask on these factors
- The new Public Health Directors who will sit within the Local Authority must have a role in promoting prevention of malnutrition and must see this as one of their public health duties
- The role of the community pharmacist in promoting good nutrition and screening for malnutrition must be considered by the Public Health Director
- The Patients Association's leaflet 'Malnutrition – signs and symptoms, where to go for help and what to expect from treatment' should be provided by GP surgeries and healthcare professionals to patients and carers who may be vulnerable or at risk of malnutrition

## Foreword



“The Patients Association has been campaigning on the issue of malnutrition for years. It is unbelievable that in the UK today there are more than 3 million people either malnourished or at risk of malnutrition in hospitals and in the community.

It is now almost a year since the Coalition Government announced its plans to reform the NHS, but we are no clearer as to how these reforms will tackle the issue of malnutrition. This is a huge oversight - malnutrition not only affects patients, their families and carers but it costs the NHS over £13 billion a year. With the NHS asked to save £20 billion by 2014, tackling malnutrition would not only benefit individual patients but would go a long way to helping the NHS achieve these financial savings.

One of the Government’s key policies forming the backbone of the Health and Social Care Bill is to introduce ‘local democracy in health’. It hopes to achieve this by moving health care from central to local control, with health care and public health to be the responsibility of Local Authorities and commissioning to move to GPs, with PCTs to be abolished.

But what do these changes mean for patients with malnutrition and those at risk of malnutrition? Our report shows that patients – particularly the elderly - rely on their GP for providing information and support but that very few have obtained information about local services and are unsure about the patient pathway for those suffering from malnutrition. Time and time again we hear from patients phoning our Helpline telling us that once they have been discharged from hospital they feel abandoned without adequate community support. Local Authorities must ensure that health and social care is properly integrated and that vulnerable patients are not discharged from hospital and left to fend for themselves.

Public Health Directors - which will be created at the Local Authority level - need to think outside the box and be looking at malnutrition as a public health issue. They need to make sure that dietetics services that were commissioned by Primary Care Trusts are not allowed to drop by the wayside. Community dietetic services are essential and Local Authorities and GP consortia must ensure they work together to make sure these essential services are still provided to patients by ring-fencing funding for these services and nutritional treatments.

We also need to be questioning why only 31% of inpatients are being screened for malnutrition when it clearly states in the NICE guidelines this is a clinical priority for ALL inpatients. Screening should not just be about height and weight. Guidance needs to be given to healthcare professionals for screening for social factors that may put a patient at risk, for example finding out if a patient lives on their own or if they struggle to get to the shops.

Malnutrition is a huge issue within our hospitals and communities, effecting millions of people and costing billions of pounds to treat, but it is not being given the attention it needs. Action needs to be taken now, to ensure that during these uncertain times for the NHS, this issue is not pushed further by the wayside.

A handwritten signature in black ink that reads "Katherine Murphy". The signature is written in a cursive, flowing style.

Katherine Murphy, Chief Executive, Patients Association

# Background

## Malnutrition

Malnutrition is a general term that refers to both under-nutrition and over-nutrition. Under-nutrition is due to inadequate food intake, dietary imbalances, deficiencies of specific nutrients and over-nutrition due to excess food consumption<sup>1</sup>. The National Institute for Health and Clinical Excellence (NICE) Guideline 32 defines malnutrition as ‘a state in which a deficiency of energy, protein, vitamins and minerals causes measurable adverse effects on body composition, function or clinical outcome’<sup>2</sup>.

Under-nutrition can have a severe effect on a patient’s health and wellbeing and general quality of life. Patients may have a reduced ability to fight infection, develop apathy and depression, and have impaired wound healing ability and reduced muscle strength and fatigue. Wider health and wellbeing effects may include a reduced quality of life and a reduced ability to work, shop, cook and self-care. Patients who are under-nourished also use more NHS resources with more GP visits and hospital admissions as well as longer stays in hospital<sup>3</sup>.

Malnutrition is both a cause and a consequence of ill-health. It is surprisingly common in the UK, especially in those who are unwell and is termed, ‘Disease-related Malnutrition’ (DRM). At any point in time more than 3 million people in the UK are either malnourished or at risk of malnutrition<sup>4</sup>. DRM has not only significant impact on the health of the individual patient and it is estimated to cost the UK in excess of £13billion a year<sup>4</sup>.

Many older people and those with any long-term medical or psycho-social problems are chronically underweight and so are vulnerable to acute illness. Even people who are well-nourished eat and drink less if they are ill or injured and although this may only be short-lived as part of an acute problem, if it persists the person can become undernourished to an extent that may impair recovery or precipitate other medical conditions<sup>2</sup>.

## Clinical factors resulting in malnutrition

DRM may develop due to several reasons;

- decreased dietary intake due to loss of appetite or physical impairment

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<sup>1</sup> Keller, H.H. Malnutrition in institutionalised elderly: how and why? *Journal of the American Geriatrics Society*; 41: 11, 1212-1218. 1993

<sup>2</sup> National Institute for Health and Clinical Excellence (2006) *Nutrition Support in Adults: Oral Nutrition Support, Enteral Tube Feeding and Parenteral Nutrition*. Guideline 32

<sup>3</sup> Guest, J.F. et al (2011) Health economic impact of managing patients following a community-based diagnosis of malnutrition in the UK. *Clinical Nutrition*, doi:10.1016/j.clnu.2011.02.002

<sup>4</sup> Elia M, Russell C. *Combating Malnutrition: Recommendations for Action*. Report from the advisory group on malnutrition, led by BAPEN. 2009



- impaired gastrointestinal function, which can reduce digestion, absorption and increase nutrient losses from the gut
- altered metabolism, which changes the utilisation and disposal of nutrients
- treatment of the disease, for example due to chemotherapy, radiotherapy

## Malnutrition in the Community

At any point in time more than 3 million people in the UK are either malnourished or at risk of malnutrition and the majority (93%) of these individuals live in the community<sup>4</sup>. Community settings include the patient's own home, as well as nursing homes, residential homes, community hospitals, district nursing, GP clinic, sheltered housing and free living elderly.

The charity, British Association for Parenteral and Enteral Nutrition (BAPEN)<sup>5</sup> established the Nutrition Screening Week (NSW) in 2007. The aim of this project is to collect data on malnutrition risk in adults on admission to hospitals, mental health trusts and care homes across the UK. Additional information is also collected on nutrition policy and practice. Four Screening Weeks were planned across all four seasons to evaluate any seasonal variations in malnutrition risk. Data from all 4 surveys will then be amalgamated to give a fuller picture of the prevalence of malnutrition across the UK. BAPEN have so far collected data for Summer and Autumn and most recently released their data for the Winter Screening week. Healthcare professionals at all hospitals, Mental Health Trusts and care homes are encouraged to sign up to take part in all NSWs to ensure that enough data are collected, but to also receive back their own data which can then be compared against the national picture. The Winter Screening week found that<sup>5</sup>:

- 1 in 3 of the 6865 patients surveyed on admission into hospital from their own homes during the 3 days of BAPEN's Winter Nutrition Screening Week at risk of malnutrition.
- 1 in 3 of the 337 residents surveyed on recent admission into care homes from their own homes during the previous 6 months at risk of malnutrition.
- The latest figures record a higher percentage of malnutrition in those admitted into hospital from their own homes than in previous surveys (Summer and Autumn)

BAPEN's report confirms that malnutrition is prevalent in the community and that seasonal variation in malnutrition is a real concern, with more patients suffering in the winter months<sup>5</sup>.

The causes of malnutrition in the community are several-fold and include many interacting factors. The most at risk groups in the community are often those who are housebound or who have limited mobility and do not have a social support network in place to assist with tasks such as food shopping and cooking. This includes people who are sick with long-standing diseases as well as the elderly.

Reasons for the high prevalence of malnutrition in the community include inadequate or poorly co-ordinated services – particularly for those patients that have been discharged from hospital. There can often be a breakdown in the continuity of care between the hospital setting and the community when

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<sup>5</sup> Combating Malnutrition: Recommendations for Action, BAPEN 2009

the care a patient needs becomes more dependent on social care support. Patients may 'fall through the gaps' and miss out on key support services such as home help and meals on wheels. Patients can end up being discharged from hospital and can be left isolated with no social care support.

The population is aging – over the last 25 years the number of over 65s increased from 15% per cent in 1984 to 16 per cent in 2009, an increase of 1.7 million. By 2034, it is projected that 23% of the population will be aged 65 and over.<sup>6</sup> Many charities and experts, including the European Nutrition for Health Alliance (ENHA) recognise that the problem of malnutrition is already endemic in the community, hospitals and homes for the elderly and with an aging population, the number of malnourished people will grow. The ENHA has stated that care providers need to do more work on identifying and treating those most at risk.

### Malnutrition in Hospitals

The Patients Association hear from patients, phoning our Helpline, of shocking incidences of malnutrition. Too many callers tell us of cases where healthcare professionals in hospital settings have failed to identify malnutrition and where crucial delays in this diagnosis have had detrimental impacts on patient outcomes. The issue of malnutrition in hospital patients featured heavily in our report in 2009, *'Patients...not numbers, People...not statistics'* and in our follow up report in 2010, *'Listen to Patients, Speak up for Change'*. In both reports we highlighted 16-17 patient cases of truly shocking care of elderly patients in hospitals throughout the UK. Issues with feeding and malnutrition featured in several of these cases and include examples such as:

*"{In hospital}...sometimes several days went by without any records at all.....there was no recognition of her decline, and when her weight loss became critical, no action was taken"*

*"I again mentioned his weight loss but again they didn't seem concerned.....He was finally given a build up drink after days of losing weight and not being able to eat properly. We wish it hadn't been left until he was nearing the end of his life when it was apparent to everyone he could not take solids and was losing weight rapidly."*

There is a wealth of published data on the issue of malnutrition in hospitals. The ENHA has estimated that up to 40% of patients are malnourished on hospital admission and many go undiagnosed due to inadequate screening<sup>7</sup>. As stated previously, a report from BAPEN's winter screening week suggests 1 in 3 patients are at risk of malnutrition on admission to hospital from their own homes.<sup>5</sup>

The issue of malnutrition in hospital has been the focus of many hard hitting campaigns including Age UK's *Hungry to be Heard* and also *Still Hungry to be Heard*. This campaign has highlighted that patients are becoming malnourished in hospital because they either don't get food they can eat or the help they need to eat it. Healthcare professionals are also concerned about the issue of malnutrition in hospitals

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<sup>6</sup> <http://www.statistics.gov.uk/cci/nugget.asp?ID=949>

<sup>7</sup> European Nutrition for Health Alliance (2008) Malnutrition. London: ENHA

and one in three nurses are not confident that malnourishment would be noticed if a relative was admitted to hospital<sup>8</sup>.

Age UK have developed seven steps to end malnutrition which include; listening to patients food preferences, hospital staff becoming food aware, assessing patients for malnourishment on admission to hospital, introducing protected mealtimes where assistance is give to those who need help eating, using a red tray system to identify those who need assistance with eating and the 'Hungry to Help' campaign using trained volunteers to provide additional help and support at mealtimes.

Age UK are calling for all hospital wards to implement the seven steps to end malnutrition and the Government to introduce compulsory monitoring of malnutrition in hospitals. Furthermore, they wish to see the Care Quality Commission (CQC) to undertake a comprehensive review of hospital mealtimes.

As part of our *Listen to Patients, Speak up for Change* campaign, the Patients Association called on the Government to introduce independent Matrons who would have an absolute commitment to patient care and would demand answers from hospital managers if nurses are being overstretched and raise issues with ward managers if they notice problems with standards on wards, such as patients not being fed. However, the Governments response was to announce 100 random inspections of hospitals to be carried out by the CQC in a 3 month period starting from the 7<sup>th</sup> March 2011. This would form part of the CQC's Dignity and Nutrition programme. The Patients Association sits on the steering committee for the planned inspections however we do have concerns with the approach. Hospitals are not usually 'good' or 'bad', with either a complete absence of these problems or scandalous failings. The reality is hospitals are patchy with good and bad wards, even good and bad shifts. If NHS leadership was effective there would not be this variation within a hospital. There is a real danger that the 'inspection' based approach may miss out on this complexity.

The CQC recently reported on the first 12 results of these 100 random inspections, stating that three hospitals had failed to meet legal standards for giving patients enough food and drink and treating them in a dignified way and also raised concerns about three other NHS hospitals. All six hospitals about which concerns were raised must now say how and when they will improve.

The Parliamentary and Health Services Ombudsman also raised the issue of malnutrition in her first annual report in February 2011. The report highlighted 10 cases in which patients suffered unnecessary pain, indignity and distress while being looked after in hospital or by GPs<sup>9</sup>. In her introduction to the report, the Ombudsman specifically references that '*<patients> were transformed from alert and able individuals to people who were dehydrated, malnourished or unable to communicate*'. Furthermore, the Ombudsman goes on to state that her office received 9,000 complaints received in 2010, of which 18%

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<sup>8</sup> Still Hungry to Be Heard. The scandal of people in later life becoming malnourished in hospital, Age UK, 2010.

<sup>9</sup> Care and compassion? Report of the Health Service Ombudsman on ten investigations into NHS care of older people. Parliamentary and Health Service Ombudsman, February 2011.

were related to the care of elderly patients. Of those cases that feature elderly patients, the Ombudsmen notes that a significant number highlight the issue of poor nutrition.

Half of the people featured in the report did not consume adequate food or water during their time in hospital. The Ombudsman states that she continues to receive complaints in which food is removed uneaten and drinks or call bells are placed out of reach. She states that arrangements such as protected meal times, intended to ensure a focus on nutrition and nurses have time to support those who need assistance with eating, have been distorted. Carers or members of the family who might wish to help the patient eat and drink are not permitted to do so, and help with eating is not forthcoming from nursing staff.

The Royal College of Nursing has also recognised the issue of malnutrition with their campaign Nutrition Now, which aims to raise the standards of nutrition and hydration in hospitals and the community. The campaign gives nurses the practical tools, support and evidence they need to make nutrition a priority in the area where they work<sup>10</sup>.

### Preventing and treating malnutrition

NICE guidelines recommend that if a person becomes unwell, the provision of normal food and drink along with physical help to eat will often be all that is necessary to ensure they do not become malnourished<sup>2</sup>.

However, if this is not sufficient, NICE guidelines recommend that nutrition support may be required. This support may be in a variety of formats including, either alone or in combination: extra oral intake such as extra food and nutritionally complete sip feeds; feeding via a tube into the gastro-intestinal tract (enteral tube feeding - ETF); or giving nutrients intravenously (parenteral nutrition - PN).

NICE guidelines recognise that choosing the most effective and safest route is essential, yet current knowledge of nutrition support amongst most UK health professionals and patients is poor.

There are many methods suggested for improving the identification and treatment of malnutrition<sup>11</sup>;

- Use of a valid, reliable screening tool to identify high-risk patients on admission to hospital or upon contact in primary care settings
- Prompt referral of high-risk patients to the dietitian for further detailed assessment
- Referral to occupational therapist and/or physiotherapist of disabled individuals who require aids/postural supports for eating
- Referral to speech and language therapist of individuals with dysphagia
- Documenting all nutritional assessments and weekly monitoring data in the nursing care plans
- Consulting with patients about individual preferences for foods, portion sizes, textures and flavours, ensuring ethnic/religious needs are met

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<sup>10</sup> <http://www.rcn.org.uk/newsevents/campaigns/nutritionnow>

<sup>11</sup> <http://www.nursingtimes.net/nursing-practice-clinical-research/disease-related-malnutrition-in-hospital-and-the-community/1958371.article>

- Provision of skilled assistance at mealtimes to disabled individuals; use of feeding protocols can markedly improve intakes in dementia<sup>12</sup>
- Provision of an environment in institutional settings that has adequate lighting, decor, seating choice and comfort, dining surfaces that provide easy access for the disabled and handwashing facilities<sup>13</sup>

Furthermore it has been suggested that specific roles for healthcare professionals to prevent and manage malnutrition should include<sup>11</sup>:

- Use of fortified meals and snacks that combine increased energy and nutrient density with small and/or normal portion sizes, particularly helpful where appetites are affected by illness<sup>14,15</sup>
- Monitoring of therapeutic diets
- Attending to food presentation, delivery, serving and accessibility of meals, for example using a decentralised, bulk food portioning approach, offering direct choice from a trolley<sup>16</sup>
- Development of local management policies for nutritional care, including the inception of multidisciplinary nutrition support teams
- Achieving best practice in nutrition support through the development and implementation of evidence-based guidelines for screening, assessment and management developed by multidisciplinary consensus – leadership and education are needed to implement these effectively

Current guidelines from NICE recommend that all health care settings, including GP surgeries, screen for malnutrition<sup>17</sup>. With the majority of patients with malnutrition based in the community, and GPs the focal point of community healthcare, it is essential that GPs carry out screening procedures. Furthermore, there is also a role for community nurses and community pharmacists to be aware of the signs and symptoms of malnutrition, carry out screening where appropriate and to advise patients at risk.

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<sup>12</sup> Simmons, S.F. et al (2001) Improving food intake in nursing home residents with feeding assistance: a staffing analysis. *Journal of Gerontology*; 56A: 12, M790-794.

<sup>13</sup> Sidenvall, B. et al (1996) Cultural perspectives of meals expressed by patients in geriatric care-intentions and experiences. *Journal of Advanced Nursing*; 20: 613-621.

<sup>14</sup> Gall, M.J. et al (1998) Effects of providing fortified meals and between meal snacks on energy and protein intakes of hospital patients. *Clinical Nutrition* 17: 259-264.

<sup>15</sup> Barton, A.D. et al (2000) A recipe for improving food intakes in elderly hospital patients. *Clinical Nutrition* 19: 445-449.

<sup>16</sup> Shatenstein, B., Ferland, G. (2000) Absence of nutritional or clinical consequences of decentralised bulk food portioning in elderly nursing home residents with dementia in Montreal. *Journal of the American Dietetic Association*; 100: 11, 1354-1360.

<sup>17</sup> NHS National Institute for health and Clinical Excellence (NICE). Nutrition support in adults: oral nutrition support, enteral tube feeding and parental nutrition (Clinical Guideline 32). 2006.

The ENHA on Routine Nutritional Status and Risk Screening across Europe recommend that<sup>18</sup>:

- EU Member States are encouraged to include routine and systematic nutritional status and risk screening and follow up nutritional care in their national public health, health care and social care programs.
- Routine and systematic nutritional status and risk screening should be included in all relevant EU public health programs, in EU chronic disease management as well as in Joint Programmes.
- All relevant public health, health care and social care professional societies at EU and national levels are encouraged to support and actively participate in the implementation and monitoring of the following recommendations

Screening tools for healthcare professionals are already available and the Malnutrition Universal Screening Tool 'MUST' launched by the British Association for Parenteral and Enteral Nutrition (BAPEN) in 2003, the most commonly used screening tool in the UK<sup>19</sup>. This is a five-step screening tool to identify adults, who are malnourished, at risk of malnutrition (undernutrition), or obese. It also includes management guidelines which can be used to develop a care plan. It is for use in hospitals, community and other care settings and can be used by all care workers.

However, self-assessment tools for patients are not currently available and there is also a lack of awareness amongst patients as to the issue of malnutrition, whether they are at risk, how they can prevent malnutrition from developing and where to seek help and advice.

### Financial costs associated with malnutrition

As stated in a previous section, the consequences of malnutrition are wide ranging and include vulnerability to infection, delayed wound healing, impaired function of the heart and lungs and decreased muscle strength and depression<sup>2</sup>. Patients with malnutrition rely on NHS resources more than patients without malnutrition and cost the NHS approximately £1000 per patient over a 6 month period<sup>20</sup>, due to increased use of healthcare resources, including:

- Malnourished patients visit their GP twice as often as those who are well nourished (regardless of co-morbidities)
- Malnourished patients are 3 x more likely to be admitted to hospital
- Length of stay in hospital is increased by 3 days where patients are malnourished
- Two thirds of people with malnutrition receive no treatment

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<sup>18</sup> [http://drf.nu/nyhetsfiler/ENHA\\_recommendation\\_EP\\_18.05.11\\_FINAL.pdf](http://drf.nu/nyhetsfiler/ENHA_recommendation_EP_18.05.11_FINAL.pdf)

<sup>19</sup> Elia M, Russell C.A. (2009) Screening for malnutrition in sheltered housing 2009. A report by BAPEN on behalf of The Group on Nutrition and Sheltered Housing (GNASH).

<sup>20</sup> Guest, J.F. et al (2011) Health economic impact of managing patients following a community-based diagnosis of malnutrition in the UK. *Clinical Nutrition*, doi:10.1016/j.clnu.2011.02.002

NICE guidelines include the need for systematic screening and assessment and treatment of malnutrition<sup>2</sup>. If guidelines were implemented it would result in better nourished patients which would lead to a reduction in complications such as secondary chest infections, pressure ulcers, wound abscesses and cardiac failure. This would reduce admissions to hospitals, length of stay for admitted patients, reduced demand for GP appointments and out patients' appointments. By implementing the NICE guidelines described in the previous section, it has been estimated that the average PCT with an adult population of 100,000 could save £28,472 each year<sup>21</sup>

As well as implementing screening for malnutrition to identify patients at risk or suffering from malnutrition, NICE also recommend that nutritional support should be provided if the provision of normal food and drink along with physical help to eat if necessary does not suffice. The ENHA has recently published a summary of the clinical benefits of oral nutritional supplements (ONS) when compared to standard care<sup>22</sup>. Evidence shows that ONS use leads to patients gaining weight and prevents weight loss in patients who are malnourished or 'at-risk' of malnutrition in hospital and community settings. ONS use is shown to be consistently linked to lower mortality rates and complications rates compared to standard care as well as fewer readmissions to hospital and improved rehabilitation.

Worryingly, the Patients Association has heard from patients contacting our Helpline that were admitted to hospital but were not screened for malnutrition or were diagnosed with malnutrition but their healthcare provider did not discuss any nutritional treatments including the option of ONS with them or set any nutritional treatment goals to manage their condition.

## NHS reforms

The NHS White Paper 'Equity and excellence: Liberating the NHS' and the subsequent Health and Social Care Bill, sets out a new era for the NHS in which GP commissioning groups or consortia will commission the majority of NHS services on behalf of patients including elective hospital care and rehabilitative care, urgent and emergency care (including out-of-hours services), most community health services, and mental health and learning disability services.

The intention of the proposed reforms is to create an NHS which is much more responsive to patients, and attains better outcomes. However there is a lack of detail and clarity as to how moving towards GP commissioning will help to achieve this. Although GPs have greater interaction with patients than patients have with PCTs, it does not necessarily follow that GPs are better placed to represent the patients' viewpoint or understand the complex needs of patients in relation to healthcare. Furthermore,

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<sup>21</sup> National Institute for Clinical Excellence. Nutrition support in adults: oral nutrition support, enteral tube feeding and parenteral nutrition CG32: Costing Report. Implementing NICE guidance in England. 2006  
<http://www.nice.org.uk/usingguidance/benefitsofimplementation/costsavingguidance.jsp>

<sup>22</sup> Tackling Malnutrition: Oral Nutritional Supplements as an integrated part of patient and disease management in the hospital and in the community – A summary of the evidence base. MNI. European Nutrition for Health Alliance, online at <http://www.european-nutrition.org/record.jsp?type=publication&ID=32>

GPs will be responsible for commissioning a wide range of services – from mental health to malnutrition - and it will be an extremely difficult task for GPs to understand and reflect the needs of patients with such varying conditions and requirements, in the breadth of services they commission<sup>23</sup>.

There is very little detail within the NHS White Paper regarding the role of community pharmacists and community nurses within the new NHS structure. However, it does state that the community pharmacy contract, through payment for performance, will incentivise and support high quality and efficient services, including better value in the use of medicines through better informed and more involved patients. Pharmacists, working with doctors and other health professionals, have an important and expanding role in optimising the use of medicines and in supporting better health. The Patient Association recently attended a Community Pharmacy workshop to discuss how the role of community pharmacists must adapt in light of the proposed changes outlined in the NHS White Paper. The workshop was organised by NHS Employers and attended by pharmacists from hospital and community settings, general practitioners, bodies representing pharmacies, the Department of Health, the Pharmaceutical Services Negotiating Committee and NHS Employers. During this meeting it was agreed that community pharmacists must adapt and work proactively with other members of the health care profession, in particular it was highlighted the need for joined up working with GPs, consistency of messaging and also to develop a more hands-on approach to public health and wellbeing. The role of the community pharmacist may therefore become more essential in raising awareness of malnutrition within the community, potentially offering screening services and educating patients.

With this new responsibility over services, it is essential that GPs are aware of the issue of malnutrition and how it affects their local community. GPs do not operate in silos and it is important that other healthcare professionals within the community are also engaged with the issues. Results from The Patients Association survey of patients regarding the White Paper showed that an overwhelming 79% of survey respondents believe that it should not just be the responsibility of GPs to commission services but that other community healthcare professionals - such as community pharmacists and practice-based nurses – should be involved as well.

The recent report from the Health Select Committee on GP commissioning<sup>24</sup> stated that GP consortia must not be led solely by GPs but must include input from other healthcare professionals. If this recommendation is taken on board by the Government, there is potential for community nurses and pharmacists as well as providers of secondary care to input into the commissioning of GP services.

Furthermore, the Government pledged their commitment to public health and recently carried out a public consultation (March 2011). This proposed the creation of a new Public Health Service, which will integrate and streamline existing health improvement and protection bodies and functions, including an increased emphasis on research, analysis and evaluation. It will be responsible for vaccination and screening programmes. PCT responsibilities for public health will transfer to local authorities, who will

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<sup>23</sup> Equity and excellence: Liberating the NHS, Department of Health, July 2010

<sup>24</sup> <http://www.publications.parliament.uk/pa/cm201011/cmselect/cmhealth/513/51302.htm>



employ the Director of Public Health jointly appointed with the Public Health Service. The Department of Health will create a ring-fenced public health budget and, within this, local Directors of Public Health will be responsible for health improvement funds allocated according to relative population health need. The allocation formula for those funds will include a new “health premium” designed to promote action to improve population-wide health and reduce health inequalities<sup>25</sup>.

Although a focus on local public health issues is welcomed, it is not clear how ‘local need’ will be determined and how malnutrition will feature in this agenda. Cancer screening and vaccination programmes are well established, in the public eye and at the forefront of public health plans. However, issues such as malnutrition, which do not always receive as much attention, may not be given the resources or focus that is required. It will be essential to engage with Directors of Public Health at a local level to ensure funding for malnutrition awareness programmes – both for community healthcare professionals and patients – is prioritised.

The Government has proposed moving the control of health care to the local authority. It is hoped that by having health and social care within the remit of local Government, a more integrated service can be provided to patients. Whilst greater coordination between health and social care services is welcomed, there is real concern that local authorities will not have the skills or the budget to be able to provide this service. Local authorities are going to be under huge financial pressures and there is a risk that services such as Meals on Wheels will be cut. Numerous charities, including BAPEN, Mencap and Age UK have spoken out about the importance of Meals on Wheels for patients who are unable to purchase or cook their own meals.

BAPEN chairman, Dr Mike Stroud, said: 'Clearly it's a false economy to be making cuts out in the community that are going to make people more vulnerable to malnutrition, with them ending up in hospitals where it costs a fortune to look after them, even for a short stay.'

Michelle Mitchell, Charity Director at Age UK, said: 'Preparing meals can become difficult for some older people, particularly those living with illness and disability. We know that up to 1 million older people living in the community are malnourished. 'Lunch clubs and "meals on wheels" services help ensure many vulnerable people get a hot nutritious meal, helping them to stay healthy and live at home independently for longer. Lunch clubs also provide an opportunity to get out and socialise, preventing isolation and loneliness as well as giving carers much needed respite. Age UK is warning that cutting these relatively low cost services today could store up problems in the future, with deteriorating health leading to, increased hospital admissions and demand for care home places as people become unable to cope at home independently.'<sup>26</sup>

The information reported in the literature, coupled with the cases we hear on our Helpline, raises serious concerns about the public's perception of malnutrition and the level of support for patients,

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<sup>25</sup> Equity and excellence: Liberating the NHS, Department of Health, July 2010

<sup>26</sup> <http://www.ageuk.org.uk/latest-news/archive/third-of-patients-at-risk-of-malnutrition/>

carers and their families regarding this issue. This survey was carried out to try and establish the current level of understanding of malnutrition from the perspective of patients, carers and their families, and the effectiveness of the support, nutritional treatment and help currently available within hospitals, the community and care homes.

## Methodology

This research report is based on the findings of a UK wide survey of adults about awareness, knowledge and experiences of the issues around malnutrition. It was conducted by YouGov through an online survey with responses from 5,018 adults aged 18 or over living in England, Scotland and Wales, between March 29th and April 6th 2011. Respondents were drawn from YouGov's panel of 330,000 individuals, sampled and weighted to be nationally representative by age, gender, and socio-economic classification.

Within the total sample of 5,018, we specifically focused on boosting responses from three specific sub-groups who answered tailored sections of the questionnaire. Each sub-group was selected because of their specific experiences of malnutrition as an issue. The groups were:

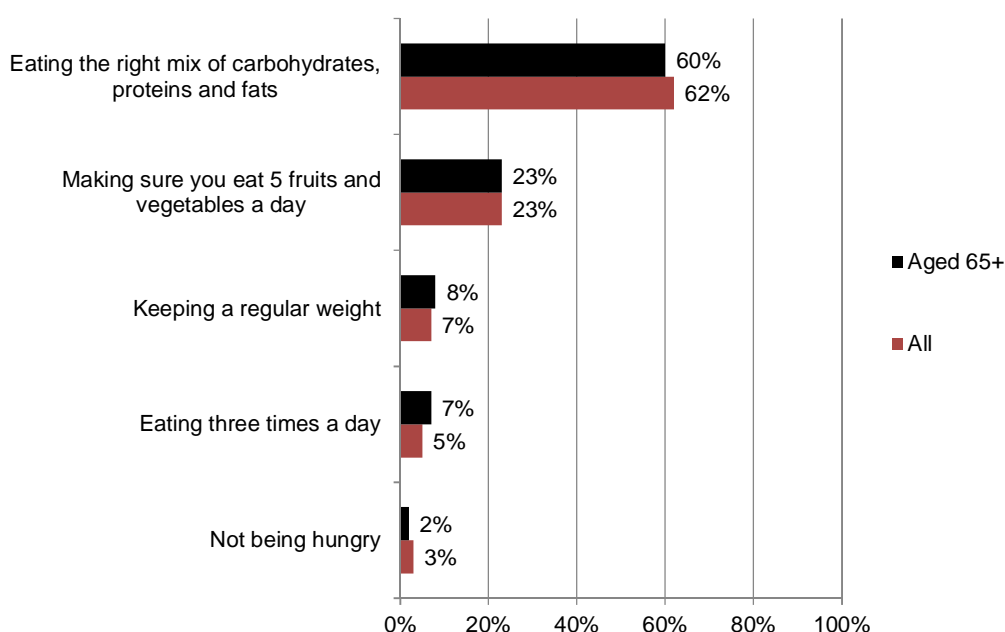
- Those who had been hospital inpatients in the last 12 months (1,311 responses)
- Those with a close friend or relative living in a residential care or nursing home (1,511)
- Those who are Carers to family members or friends (1,883)

Where this report refers to differences between sub-groups, based on age or gender for example, these have been checked and confirmed as statistically significant using the Column proportions (z-tests) at the 95% confidence level.

## Results

### What do you think 'good nutrition' means? (Please rank these in order of importance for good nutrition)

Figure 1: What does 'good nutrition' mean to you?



Base: all (5,018); 65+ (1,136)

When asked what 'good nutrition' meant to them, 62 % of those surveyed related it to 'eating the right mix of carbohydrates, proteins and fats' (Figure 1). Nearly a quarter believed that it was primarily about eating "five a day" – a message about fruit and vegetables that has been heavily promoted over the last decade. This belief was stronger among women than men with 26 % of women relating nutrition to "five a day" compared to 20 % of men. In comparison men (64 %), were more likely than women (61 %) to relate it to the 'mix of carbohydrates, proteins and fats.'

Among social grades C2DE there was a greater focus on 'eating three times a day', when compared to ABC1s<sup>27</sup>. In contrast those in the ABC1 group tended to focus on having the 'right mix of carbohydrates, proteins and fats.'

<sup>27</sup> National Readership Survey social grades: A (upper middle), B (middle), C1 (lower middle), C2 (skilled working), D (working), E (lowest). These are defined as: A: Higher managerial, administrative or professional. B: Intermediate managerial, administrative or professional. C1: Supervisory or clerical and junior managerial, administrative or

In contrast few felt that it was about 'keeping a regular weight' or 'eating three times a day.' Opinion did not vary significantly with age. It is alarming that one of the key physical measures of malnutrition – whether someone is keeping a regular weight – is not associated with good nutrition. It seems that the public make the connection between good nutrition and eating a balanced diet but do not take this association a step further and make the link between good nutrition and a regular weight.

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professional. C2: Skilled manual workers. D: Semi and unskilled manual workers. E: Casual or lowest grade workers, pensioners and others who depend on the welfare state for their income.

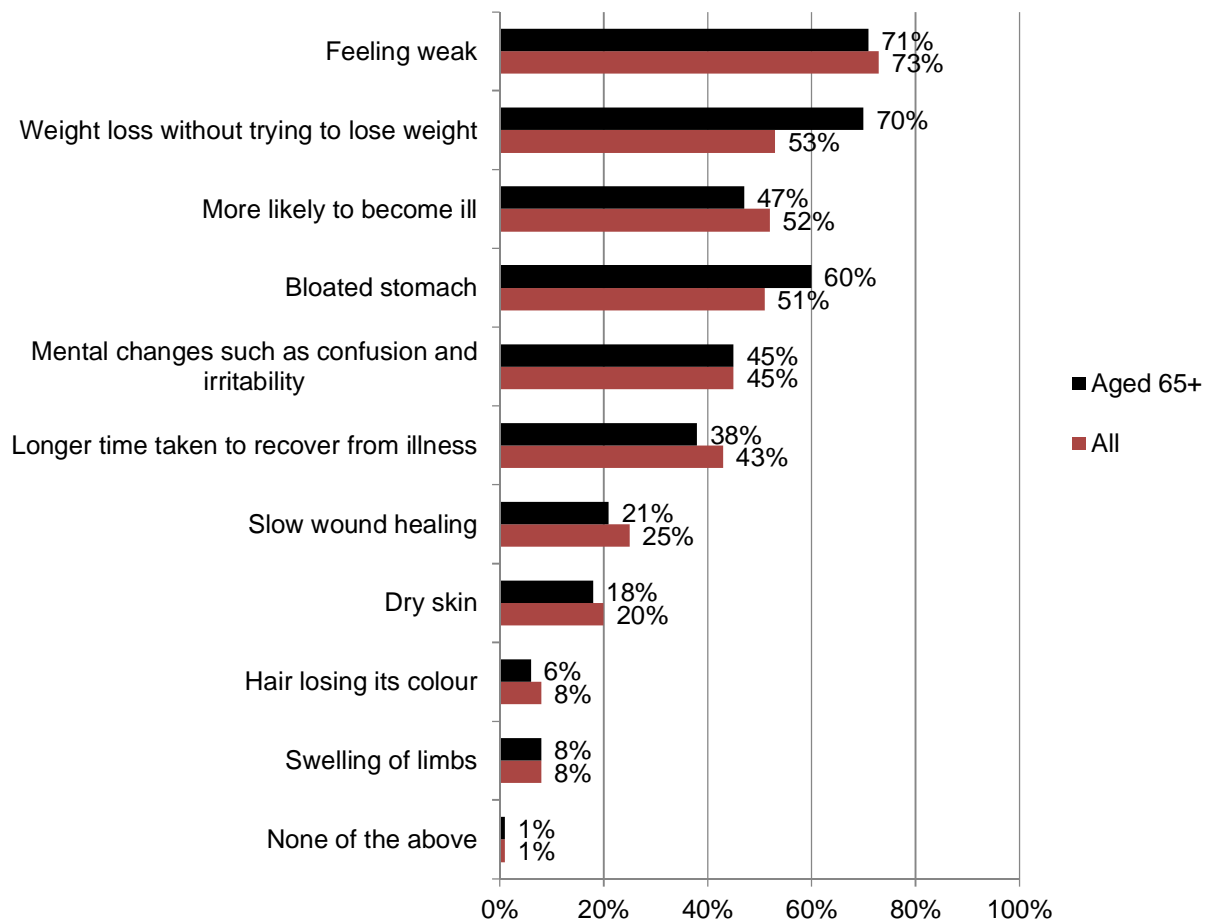


*"Feeling hungry, looking thin, depression, weakness, vulnerability to disease."*

The majority of the over 65 age group associate weight loss with under-nutrition although very few associate keeping a regular weight with good nutrition (8 % - previous question), suggesting there is an issue with messaging. Greater emphasis on preventative messages on how good nutrition can help avoid malnutrition and monitoring to assess whether an individual maintains a regular weight, may be needed.

## Which of the following, if any, do you think are the key signs of malnutrition?

Figure 3: Which of the following, if any, do you think are the key signs of malnutrition? You can choose up to four.



Base: all (5,018); 65+ (1,136)

When prompted with a list of symptoms, feeling weak and weight loss were the signs most often associated with malnutrition (Figure 33). An increased susceptibility to illness, the time taken to recover from illness, a bloated stomach and mental changes were also felt to be key signs of malnutrition. In contrast, swelling of the limbs and hair discoloration did not feature prominently.

Older people were much more likely to identify malnutrition with unexpected weight loss. Of the 65 plus age group, 70 % did so, compared to just 53 % of adults as a whole. However, they were less likely than others to make the connection with vulnerability to other illnesses (47% compared with 52% of all adults) and the time taken to recover from illness (38% compared with 43%). Likewise fewer of the 65



and over age group associated malnutrition with slow wound healing (21 % compared with 25% of all adults).

Carers tended to associate malnutrition with mental changes (50 %), more so than the general public as whole (45 %). They were also more likely to relate it to weight loss (56 %), compared to 50 % of all adults.

There were many significant differences between men and women when it came to the identification of symptoms. Men tended to focus on feeling weak (76 %) and weight loss (55 %), whereas women picked on the symptoms of 'bloated stomach' (53 %), dry skin (24 %) and slow wound healing (28 %) and mental changes (49 %).

Importantly, those who were identified as having sought information about malnutrition were significantly more likely than others to associate it with mental changes (53 % against 44 %), the time taken to recover from illness (48 % compared to 42 %) and especially slow wound healing (32 % against 24 % without any information). This suggests that these particular messages have come through strongly from the information and advice received. Conversely those who had not sought information tended to associate malnutrition with a bloated stomach (52 % compared to 38 % with information). They also focused on feeling weak (74 % against 66 %) and weight loss (54 % versus 48 %).

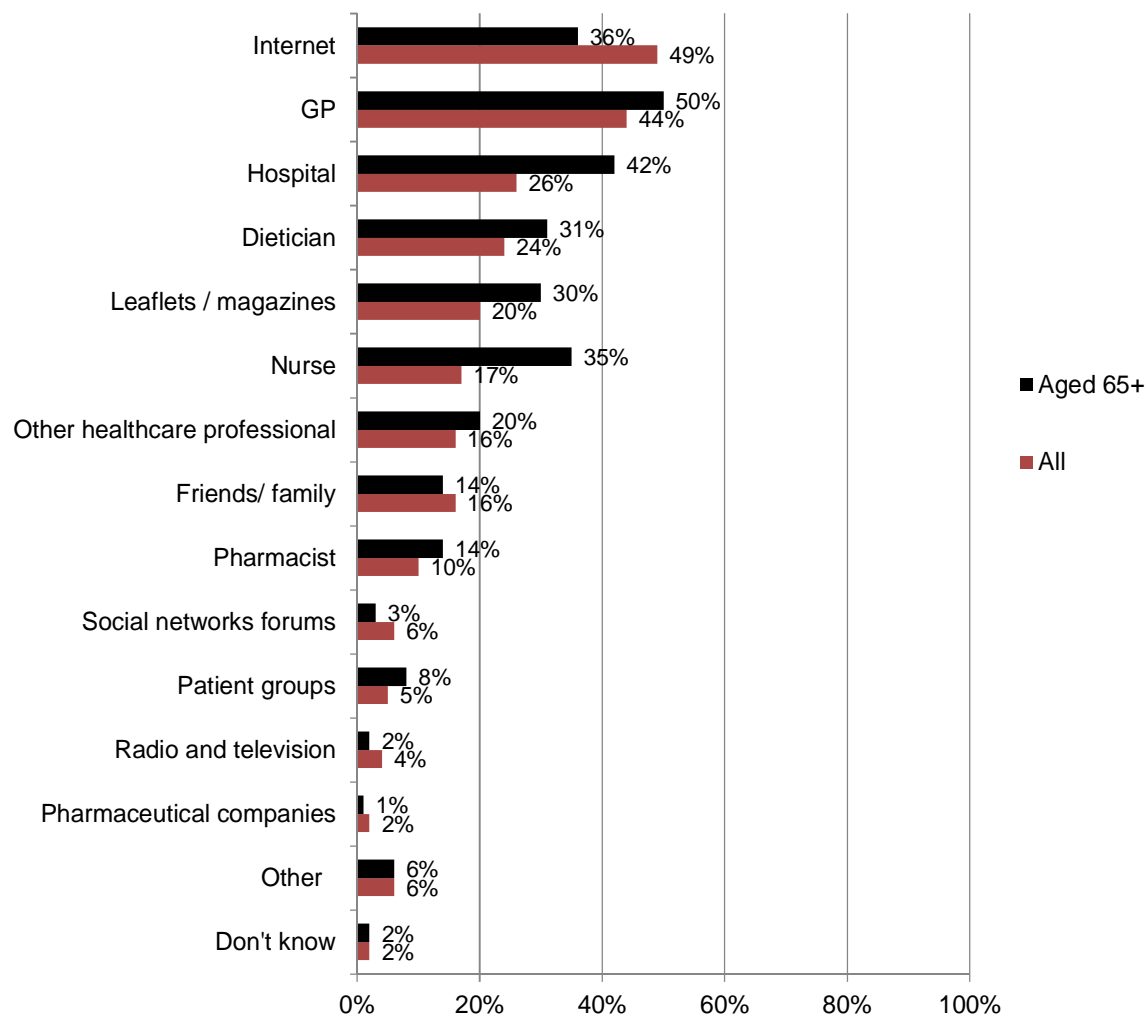
## **Have you ever needed to find information about malnutrition either for yourself or a friend or family member?**

Of all those surveyed, 11 % (542 respondents) had sought out information on malnutrition in the past with 5 % seeking information for themselves and 7 % for a relative or friend. Women were more likely to have sought information than men.

Of the Carers surveyed, only 13 % per cent of them had sought out information on the issue of malnutrition, suggesting this was not been a high priority for them.

## Where did you go for information on malnutrition? (sources listed)

Figure 4: Where did you go for information on malnutrition? (multiple choice)



Base: all who searched for information (542); people aged 65+ who searched for information (92)

Nearly half of those who had sought information did so via the internet (49 %) rather than healthcare professionals such as GPs or Pharmacists (44%, 10% respectively, Figure 4). However for the oldest age group (65 plus), GPs were the most popular source of information (50 %), as were hospitals (42 %), nurses (35 %) and dietitians (31 %). The 65 and over group were significantly less likely to seek information via the internet.

The differences between the oldest age group and others, including those who have caring responsibilities, is that their personal experiences have led them into contact with healthcare professionals who have in turn delivered information about malnutrition. In contrast, Carers under the age of 65 tended to have sought information indirectly, through the internet and family and friends in particular.

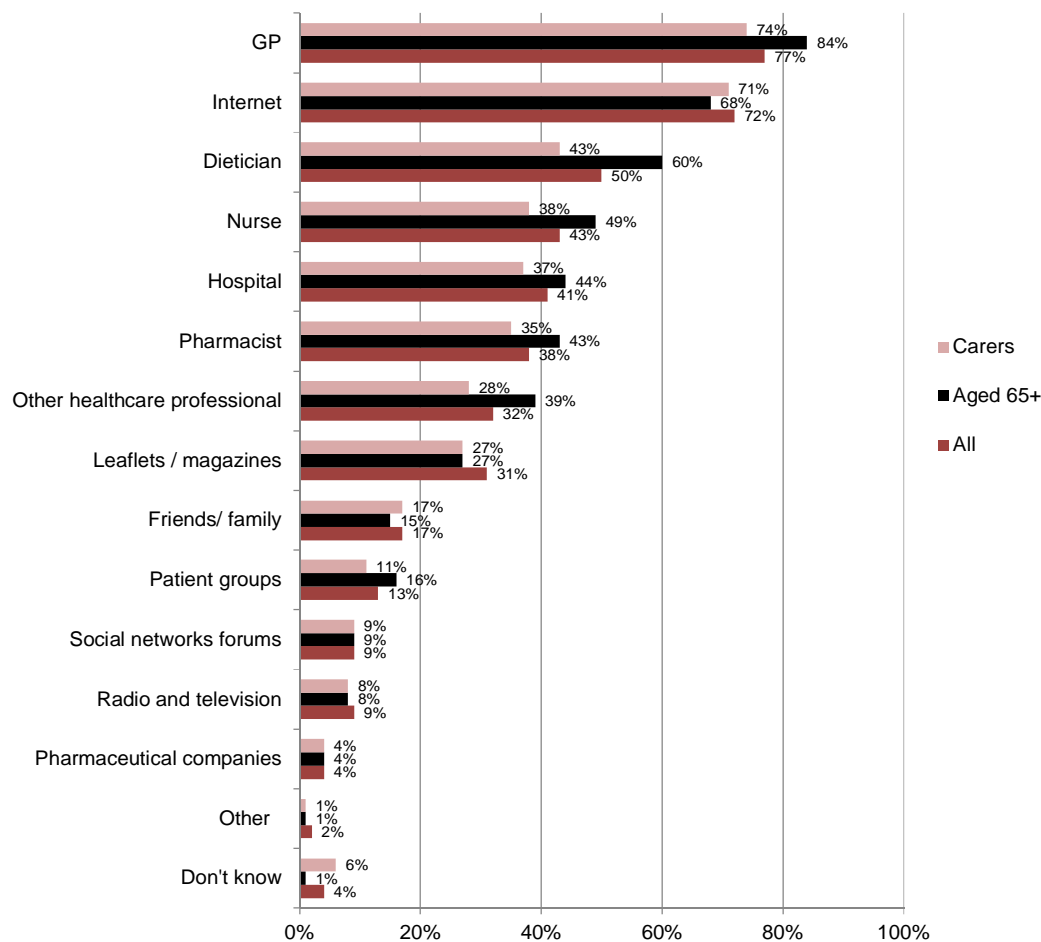
With more individuals turning to the internet (49%) of all respondents in total, it is essential that the information provided by medical websites is regulated so that patients feel confident that the information they receive is evidence-based, safe and approved. The Department of Health has introduced the Information Standard, to help the public identify trustworthy health and social care information. The Standard is accredited only to those organisations that produce evidence-based health or social care information, and includes charities, local authorities and NHS Trusts<sup>28</sup>. The Information Standard needs support and publicising for it to be adopted across the UK by information providers and for patients to be aware of its existence.

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<sup>28</sup> <http://www.theinformationstandard.org/>

## And where would you want to find information on malnutrition? (sources listed)

Figure 5: And where would you want to find information on malnutrition? (multiple choice)



Base: all (5,018); 65+ (1,136); Carers (1,883)

In contrast to where respondent did go for information, there was an expectation that healthcare professionals would be the main source of advice if required in the future (Figure 5). GPs were cited as the most popular source for all respondents if they required information, with the internet being the second most popular source of information for all respondents, including Carers and those aged over 65. Only 14 % of the 65 and over age group had gone to a Pharmacist for advice, but it is notable that 43 % have an expectation of going to this source for information if required. The same was similar for

dietitians, with only 31 % of over 65s who needed to find information had consulted a dietitian, but 60 % of the same age group thought that they might do so if required in the future.

The internet was expected to be an especially strong source of information for ABC1s, with 76 % expecting to use this as a source compared to 68 % of C2DEs, who in turn thought that they would favour information from hospitals (43 %), compared to ABC1s (39 %). Women thought that that they might use multiple sources of information and so were more likely to want to use all sources compared to men, except GPs and hospitals which were evenly distributed between men and women.

It is of interest that patients want to receive information on malnutrition from their healthcare professionals – especially GPs – but in practice they are using other sources. This suggests that the public still view healthcare professionals as the most trustworthy or easily accessible source of information. However, although 84% of respondents would go to their GP for information, in practice only 44% of those that have obtained information did go to their GP. This suggests there are barriers in terms of accessing information from this source.

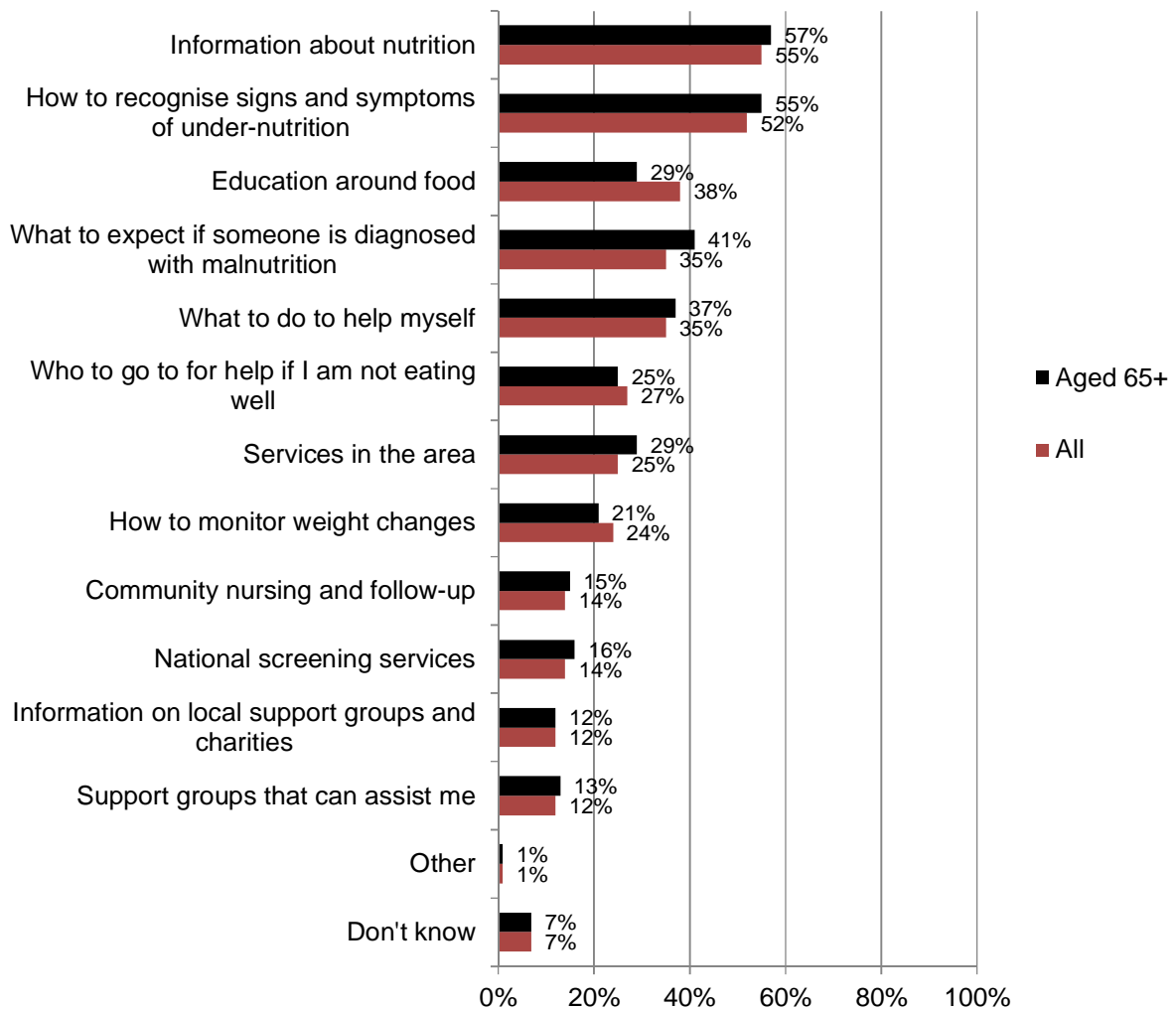
## **To what extent would you be interested in knowing more about nutrition for yourself or to help another person?**

Of those aged 65 and over, three-quarters were interested in knowing more about malnutrition, with 11 % stating that they were interested to 'a great extent,' more were interested to 'a little' (32 %) or 'some extent' (33 %). Carers of all ages were especially interested (81 %), but again only 16 % were interested to 'a great extent.' Likewise those with a friend or relative in a care home were significantly more likely to be interested (80 %) but with only 15 % to 'a great extent'.

It is not surprising that those with a more personal connection to healthcare – i.e. older patients, carers or respondents with a friend or relative in a care home – are more interested in accessing information on a medical issue such as malnutrition.

## What sorts of information would you be interested in knowing? Please tick as many as apply

Figure 6: What sorts of information would you be interested in knowing? (multiple choice)



Base: all those interested in finding out more (3,740); those aged 65+ who were interested in finding out more (863)

Respondents were interested in finding out about information on nutrition in general (55 %) and also information specific to the signs and symptoms of malnutrition (52 %) (Figure 6). There was also interest for information on what to expect if someone was diagnosed with malnutrition (35 %) and about how to help themselves (35 %). There was less demand for information about support groups, community nursing, charities and local services – although women were often more open to these sources of information than men. There were two key differences for the oldest age group (65 and over) who were



particularly interested in what to expect if someone is diagnosed and less concerned in knowing about food.

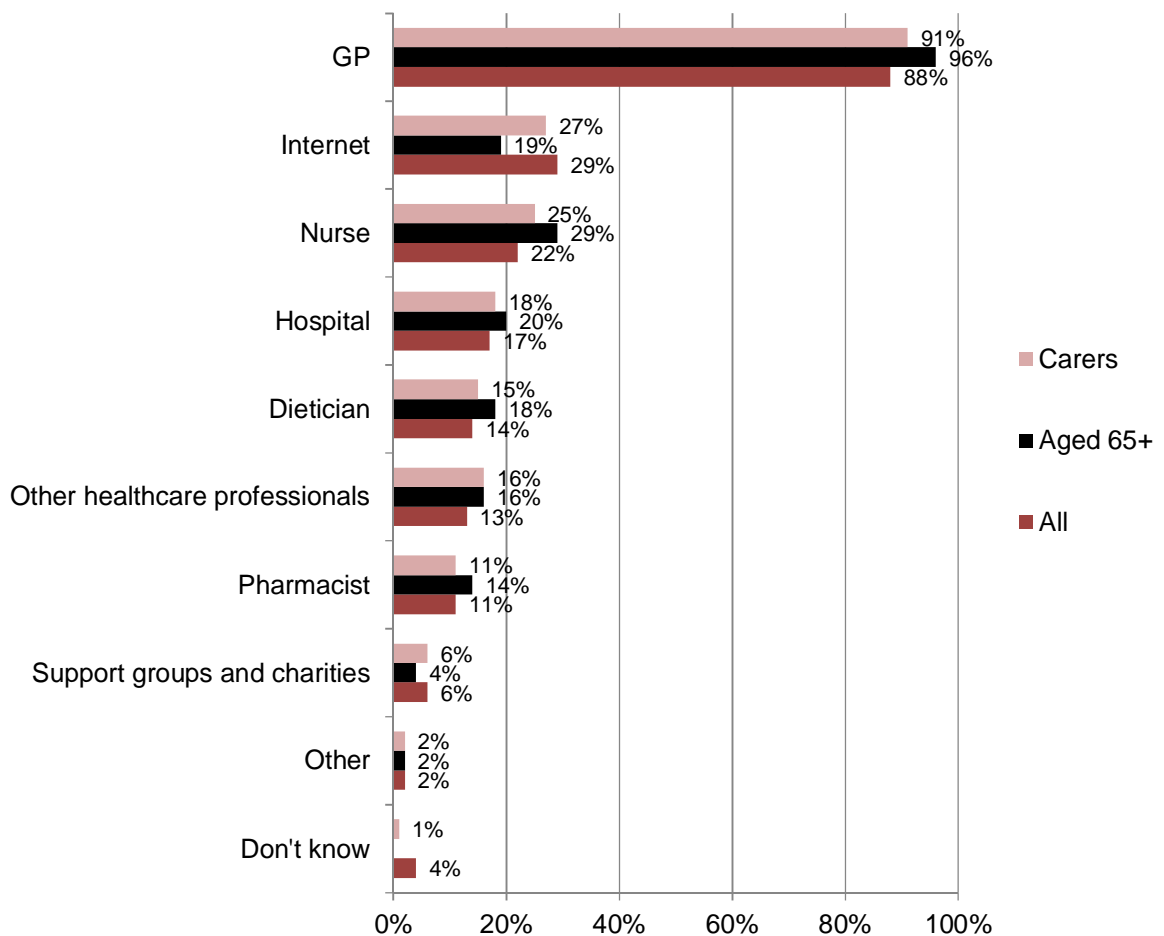
Those who had been recent hospital in-patients were significantly more likely than others to be interested in information that would help them to help themselves. This was the case for over two-fifths (41 %) compared to 35 % of all adults.

Those who have needed to find information about malnutrition in the past were significantly more likely to be interested in local services, support groups and community nursing. This suggests a gap between what they found when they sought information in the past and what they would be interested in finding out in the future. They were also interested in who to go to for help if not eating well, what to expect if someone was diagnosed and how to monitor weight changes.

It is interesting that those who previously sought help are still requiring information that is local to them i.e. local services, support groups and community nursing. It suggests that current information provision is not tailored to the local community and needs of local people. The Coalition Government outlined in the Health and Social Care Bill<sup>23</sup> currently before parliament, a focus on a move to local control of the NHS as well as an information revolution to empower patients. However, it is clear from this report, that the Local Authority and GP consortia - who will take on local responsibility for health - will need to address the issue of providing tailored information that outlines services and support for people in the local area as this is clearly an unmet need.

## If you, or someone you care for, lost weight unexpectedly and you were concerned, who would you turn to for help? Please tick as many as apply

Figure 7: If you, or someone you care for, lost weight unexpectedly and you were concerned, who would you turn to for help? (multiple choice)



Base: all (5,018); 65+ (1,136); Carers

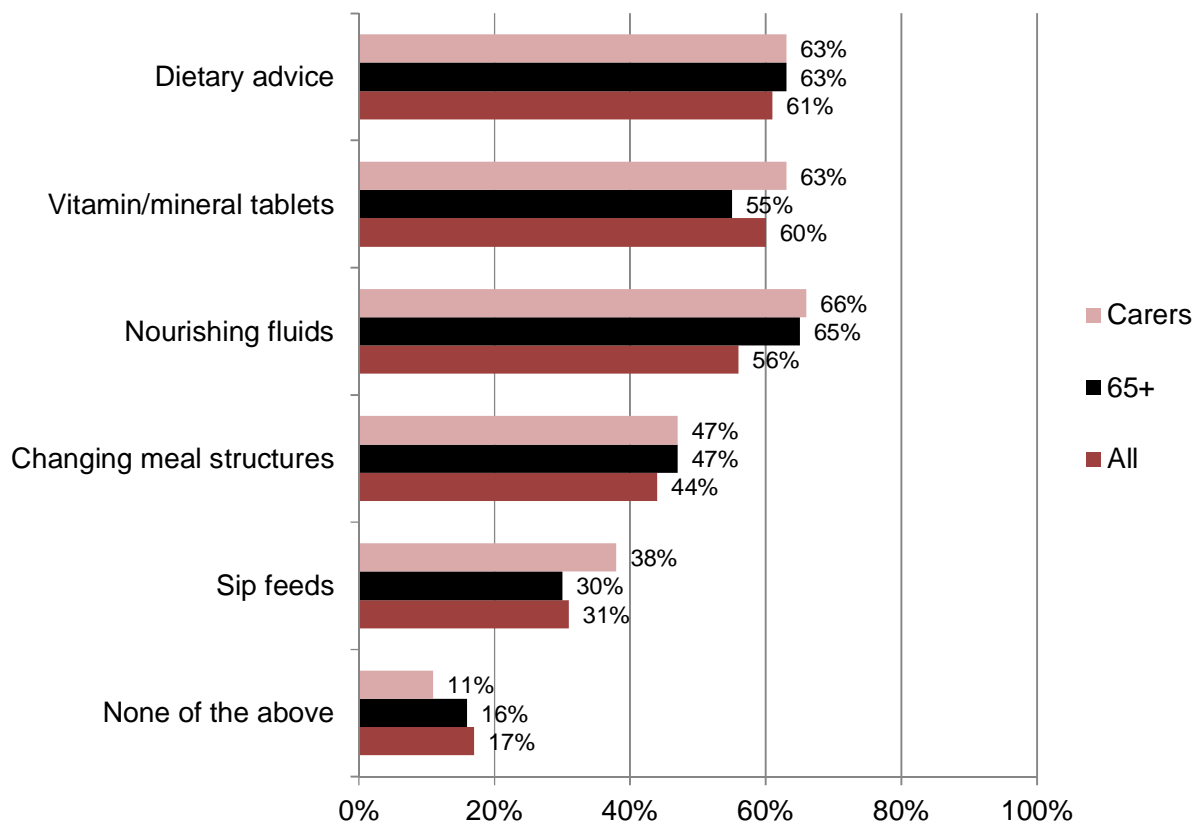
Nearly nine out of ten (88 %) of all adults and 96 % of the 65 and over age group would go to a GP if they themselves or someone they care for lost weight unexpectedly (Figure 7). This was also the case for 91 % of Carers. The internet would be used by 29 % of all respondents for information, but this was significantly lower among the oldest age group (19 %).

There was a notable difference on the basis of socio-economic group with ABC1s more likely than C2DE to consult a GP, who in contrast were more likely to head straight to hospital. This was also the case for men, 19 % of whom felt they would turn to hospitals for help, compared to 15 % of women. Relatively few felt that there was a role for Pharmacists (11 % of all respondents and 14 % of the 65 and over group).

Again, this response highlights the great emphasis patients place on GPs for providing information and support in terms of help and support around the issue of malnutrition. The GP is the focal point from where patients may access other services such as those of the community dietitian. With the move to GP commissioning there is confusion as to how dietetics services will be commissioned. Presently, dietitians may be hospital based or commissioned by Primary Care Trusts (PCTs) and offer services in the community. Community dietitians may offer appointments at clinics in various health centres, GP practices, in nursing homes, special schools and at home. With the abolition of PCTs and a move to GP commissioning, it is possible that services such as dietetics may 'slip through the gap'. It is essential that those commissioning services at GP consortia are aware of the prevalence of malnutrition in the community and the financial cost to treat malnutrition if it is untreated and the importance of commissioning community dietitians.

## Before this survey which, if any, of the following treatments for malnutrition were you aware of?

Figure 8: Before this survey which, if any, of the following treatments for malnutrition were you aware of? (multiple choice)



Base: all (5,018); 65+ (1,136); Carers (1,883)

As part of this question, the type of treatments for nutrition were defined as follows: Dietary advice, for example to add ingredients high in energy and/or protein such as butter, cream, milk, sugar to meals; Nourishing fluids, for example milky drinks, fruit juices and smoothies; Changing meal structures, for example to eat 3 meals plus snacks; Sip feeds, a type of oral nutritional supplement in liquid form such as soups or milkshakes.

Nearly one in five of all adults (17 %) were unaware of any of the treatments for malnutrition that were listed in the survey. This figure was significantly lower for Carers (11 %) but similar for the older age group (16 %). Awareness was highest for the availability of treatments such as dietary advice. However, the use of vitamins and minerals were stated by around three-fifths of all adults as a treatment for malnutrition. This is alarming as vitamins and minerals are not a treatment for malnutrition in isolation.

Carers were significantly more likely to be aware of all possible treatments, including nourishing fluids and sip feeds. Those in the oldest age group (aged 65 and over) were particularly likely to know about nourishing fluids (Figure).

Women and those within socio-economic group ABC1 were significantly more likely to be aware of all the treatments listed. A fifth of C2DEs were unaware of any of the treatments listed as were 14 % of ABC1s. The gap between social groups was largest for nourishing fluids with 61 % of ABC1s aware compared to 51 % of C2DEs. There was also a gap of nine percentage points for dietary advice, but small differences of five points for sip feeds. Compared to men, women were substantially more aware of nourishing fluids (63 % compared to 49 %) and sip feeds (38 % compared to 23 %).

It is alarming that 1 in 5 of the general public do not know of any treatment for malnutrition, including basic treatments such as dietary advice. Nutritional supplements such as sip feeds (also known as oral nutritional supplements) were only known by 31 % of the population, and alarmingly by only 38 % of carers. Sip feeds can help patients gain weight and are identified as a key clinical priority in NICE guideline CG32:

*“Healthcare professionals should consider using oral, enteral or parenteral nutrition support, alone or in combination, for people who are either malnourished or at risk of malnutrition”<sup>29</sup>*

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<sup>29</sup>CG32 Nutrition support in adults: NICE guideline, pg 7,

## **Before this survey were you aware that you can get sip feeds from your GP on prescription?**

Less than a fifth (18 %) of all adults knew that you could get sip feeds on prescription from a GP. A quarter of all Carers and 22 % of those with a friend or relative in a care home also knew that sip feeds were available. Awareness varied with age, with 23 % of the 50 to 64 year olds knowing and 20 % of those aged 65 and over. Again this was substantially higher for women (23 %) than men (13 %).

Awareness needs to be raised that sip feeds are prescribed by GPs. Sip feeds are stated in NICE guidelines as a key clinical priority for use both within hospitals and the community.<sup>17</sup>

## **Have you or someone you care for been on sip feeds prescribed by your GP in the last 12 months?**

In the last 12 months, 7 % of respondents had either a sip feed prescription for themselves or someone that they care for. This was most common for the 50 to 64 year old age group, which will be connected to their status as Carers<sup>30</sup>, 14 % of whom reported that they knew about a prescription.

## **If you / someone you care for have been on sip feeds, was the prescription withdrawn in the 12 months?**

Of those who knew about a prescription, either for themselves or another person, 31 % reported that the prescription was withdrawn within the last 12 months. This was less likely to be the case for those aged 65 or over (24 %). The reasons given for ending the prescription varied considerably and many related to either patient recovery following nutritional treatment via sip feeds, with improved health, weight and being able to eat normally after the support provided:

*“Gained weight and went into full time care.”*

*“Did not need it any more as the person had been rehydrated and was eating well.”*

Some mentioned prescriptions being issued in hospital but stopped by their GP because of the patient recovering.

Alarming a few did not know why they had stopped or were simply told it was no longer necessary. Patients were not given information as to why the sip feed was stopped, information on how to maintain weight or provide any details about future monitoring.

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<sup>30</sup> 36% of Carers in the survey were aged 50-64 – the largest proportion within the age groups analysed.

*"Was not given any reason, a dietitian prescribed the sip feeds and GP (not our own GP) stopped the prescription"*

Only a few specifically referred to the costs of sip feeds or other prescribing difficulties:

*"[healthcare professional] said patient did not need them and they are expensive."*

*"Given as a short term solution to [treat] weight loss. When needed again told by GP that they can no longer prescribe and would have to be referred to dietitian of which there was a long waiting list."*

*"GP said he wanted evidence that she had lost weight ... and she had lost a stone. Tried to put it down to a dietitian's responsibility."*

A few had been advised by their GP about dietary changes or alternatives instead of continuing with sip feeds, others had struggled with compliance:

*"Advised fortified diet would be appropriate."*

*"Mother's prescription was changed to alternative diet."*

*"They did not like the taste of them and with me providing good proper food and encouragement they put on weight again."*

*"My wife was unable to stomach the flavours and she felt she had little or no benefit from them. I must confess I felt they were very unappetising and would not like to take them myself."*

It is concerning that only 18 % of respondents are aware that sip feeds are prescribed by the NHS. The NHS Constitution states that:

*"You have the right to drugs and treatments that have been recommended by NICE for use in the NHS"<sup>31</sup>*

Patients also have a right to:

*"...be given information about your proposed treatment in advance, including any significant risks and any alternative treatment which may be available...."*

It is concerning that patients who are at risk of malnutrition or have malnutrition may not be informed about the availability of sip feeds by their Healthcare professional. It is a patients right, as outlined in the NHS Constitution to be made aware of available treatments on the NHS, and it is detailed in NICE Guideline 32 that ONS, such as sip feeds, are an appropriate treatment for malnutrition. The financial benefits of treating malnutrition are clear, with the cost of treating a patient with malnutrition costing the NHS £1,000 over a 6 month period<sup>20</sup>. Healthcare professionals need to be educated as to the long-term financial savings of prescribing nutritional treatments to patients at risk of malnutrition or for those patients suffering from malnutrition.

## Experiences as an inpatient

The sub-group of hospital inpatients (1,311) were asked a series of questions about whether and how issues of their weight and diet were handled when they were in hospital. The average age of an inpatient was 49 and the median number of nights spent in hospital was two. In this section, ages above the average of 49 years (i.e. 50 and over) have been taken as reference point and those who stayed in hospital for more than two nights are used as a comparison against those who stayed for a shorter period of time.

### Were you asked questions about your diet and weight?

Of all inpatients surveyed, only 31 % could recall having been asked questions about their diet and weight. Of those who were in hospital for more than two nights, 38 % were asked questions about their weight and diet. In comparison, 26 % who were in hospital for one or two nights were asked these types of questions. Those over the age of 50 were no more likely to have been asked questions about their diet and weight than those under 50. Men were significantly more likely to report having been asked such questions than women (37 % compared to 26 %).

NICE Guideline 32 has screening as a key clinical priority:

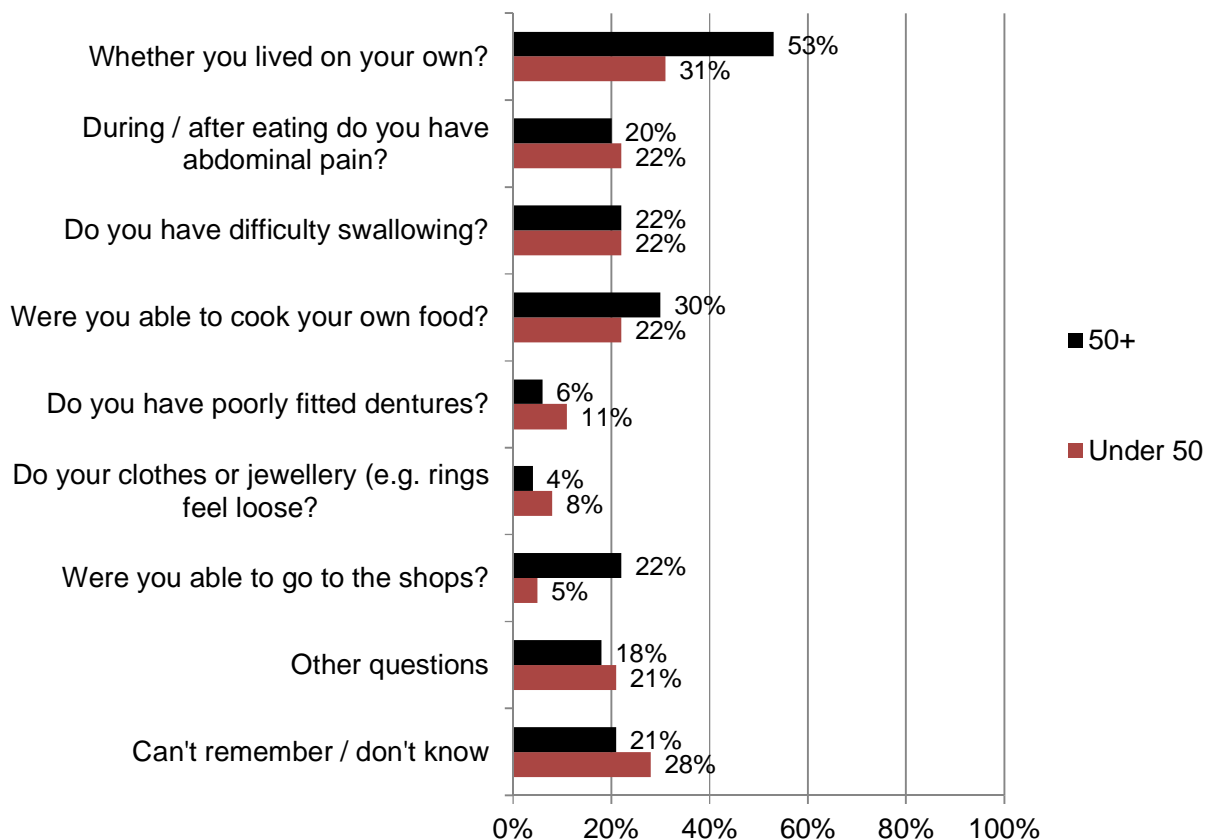
*“All hospital inpatients on admission and all outpatients at their first clinic appointment should be screened. Screening should be repeated weekly for inpatients and when there is clinical concern for outpatients. People in care homes should be screened on admission and when there is clinical concern.”*

It is therefore alarming that only 26% of patients who were in hospital for one or two nights were screened as this should be a requirement for all inpatients, irrespective of length of stay.



## Which of the following questions, if any, were you asked about your diet and weight?

Figure 1: Which of the following questions, if any, were you asked? (multiple choice)



Base: In-patients who could recall having been asked questions about their diet and weight, under 50s (153); 50+ (247).

Over half of those aged 50 or over (53 %) were asked whether they lived alone, a figure that rose to 57 % for those in hospital for more than two nights (Figure 9). In addition, 30 % were asked whether they were able to cook their own food. Few (4 %) were asked about the fit of their clothes or jewellery. The key differences on the basis of age were whether the question of whether the patient was able to go to the shops themselves (22% of over-50s compared to 5 % of under-50s) and whether they lived on their own (53 % of over-50s compared to 31 % of under-50s).

Within NICE Guideline CG32 there is no detail around the type of questions the healthcare professional carrying out the screening should ask. The guideline only states that:

*“Screening should assess body mass index (BMI) and percentage unintentional weight loss and should also consider the time over which nutrient intake has been unintentionally reduced and/or the likelihood of future impaired nutrient intake. The Malnutrition Universal Screening Tool (MUST), for example, may be used to do this”*

‘MUST’ is focused on determining if a patient is at risk of malnutrition or is malnourished. However, the tool only uses measures of height and weight to assess risk and does not look at social factors such as whether a patient is able to go to the shops. There is potential for trying to widen the scope of the questions that a healthcare professional asks patients when screening, to include an assessment of social factors.

## **Can you remember who asked you those questions about diet and weight? If more than one person did so, please tick as many as apply**

Two-thirds reported that these questions came from Nursing staff, with 46 % recalling the involvement of a Doctor. In fact, doctors were less likely to have asked questions of those aged 50 or over (39 %, compared to 47 % of the under 50s). Thirteen per cent of the oldest patients (12 per cent of all) reported having spoken to a Dietitian about their weight and diet, but only 3 % could remember having done so with a nutrition specialist.

Among those who had stayed for more than two nights, a Dietitian had become involved in 18 % of cases and Doctors were more likely to have asked questions (50 %) and Nurses less so, suggesting that Doctors have a more prominent role in a longer term hospital stay.

Within the NICE Guideline CG32 there is no specific detail on which healthcare professional should perform screening but that it should be *“carried out by healthcare professionals with appropriate skills and training.”*

## **Was any action taken?**

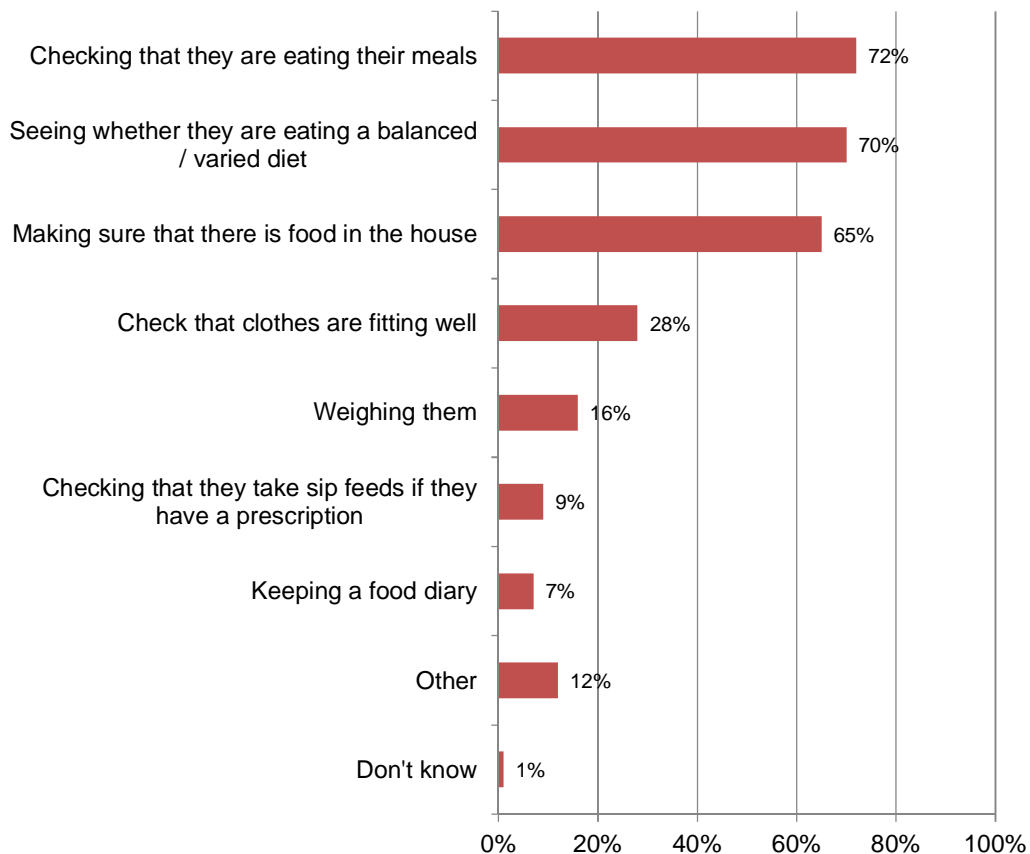
No action on diet or weight was taken in the cases of 62 % of inpatients (64 % of those aged 50 and over). Of those aged 50 and over (who were in hospital for more than two nights) 12 % were weighed regularly, and 11 % reported that their food and drink intake was monitored. Only 4 % were put on a special diet and 2 % had to have help to eat and drink.

## Experiences of Carers

The survey captured the experiences of a substantial sub-group of 1,883 Carers who were identified using the standard definition of adult caring responsibility. The average age of a Carer was 55. Nearly nine out of ten (89 %, 1,690 respondents) reported that they check that the person they care for is eating well. Women were more likely than men (91 % compared to 87 %) to report that they check how the person is eating.

### How do you assess the person you are caring for is eating well? Please tick as many as apply.

Figure 10: How do you assess the person to check that they are eating well? (multiple choice)



Base: Carers who check that the person they care for is eating well (1,690).

This checking process tended to be informal with 72 % simply monitoring whether the person they care for is eating their meals and 70 % trying to ensure a balanced diet (Figure 10). Two-thirds of Carers (65 %) also check that there is enough food in the house. Only 16 % report weighing the person, but a higher proportion (28 %) have checked that the person's clothes fit well. Only 7 % had used the formal method of keeping a food diary and 9 % had experience of ensuring that the person took prescribed sip feeds.

Female carers were more likely than men to have taken action across nearly all the listed methods of monitoring.

There is real concern that without using a formal method such as weighing them (16%) or keeping a food diary (7%), malnutrition may not be recognised by carers. Interestingly, those who had sought information on malnutrition in the past were significantly more likely to weigh the person they care for (22 %, compared with 15 % who have not previously sought information), keep a food diary (10 % versus 6 %), to check that their clothes fit well (37 % against 26 %) and ensure that any prescriptions for sip feeds are taken (18 % compared to 7 %). This provides evidence of the positive effects of seeking information but also that these actions were only triggered by having had cause to find out more about malnutrition.

## **Have you ever used a formal method (like a checklist) of assessing the person's nutrition?**

Only 8 % of carers had used more formal methods to assess the nutrition of the person they care for, but this rises to 26 % of those who have in the past had cause to seek out information on malnutrition. Again, this is worryingly low. Without carrying out formal assessment methods, carers may not notice weight loss in patients they are seeing on a regular basis.

## **Before this survey had you heard of the 'MUST' tool ('Malnutrition Universal Screening Tool')?**

Only 5 % had heard of 'MUST' (Malnutrition Universal Screening Tool), although again this rises to 14 % for those who have looked for information about malnutrition.

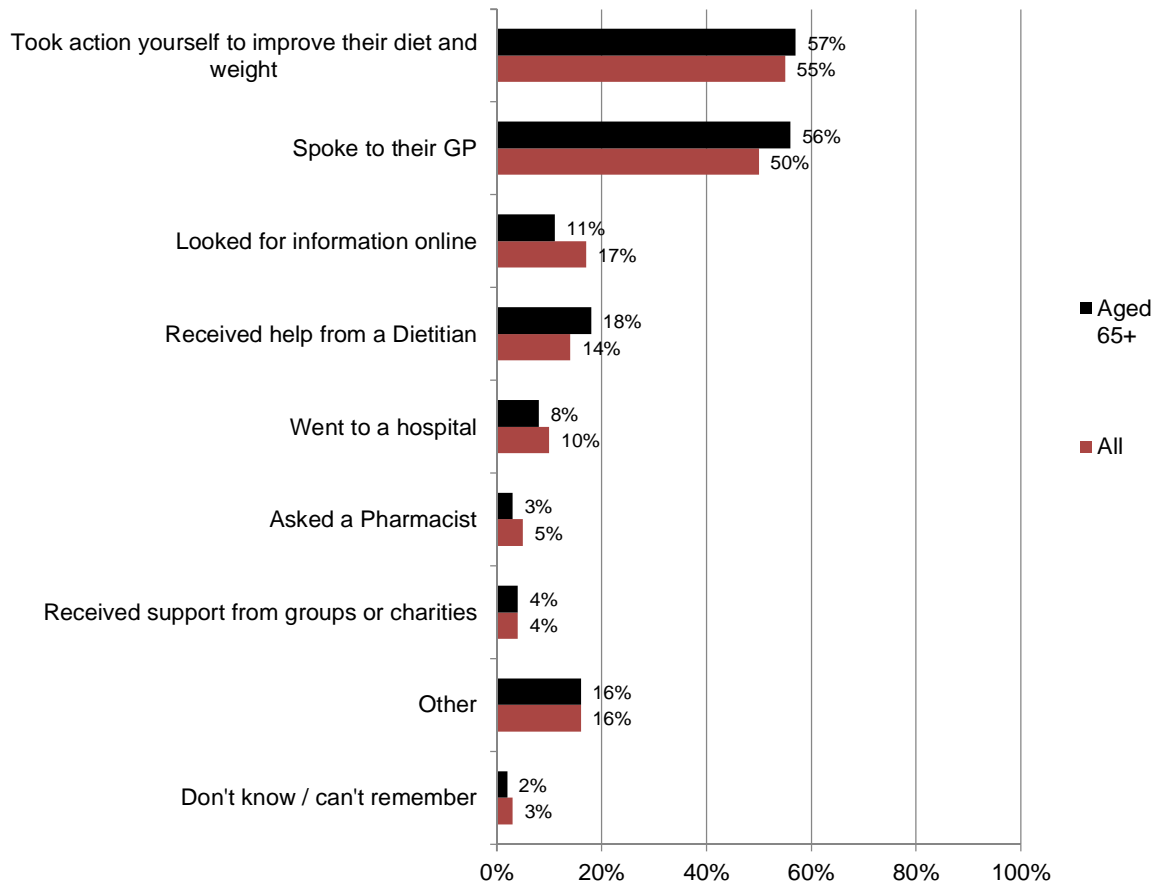
## **In the past have you ever had concerns about the person's diet and weight?**

Half of all Carers stated that they have had concerns about the diet and weight of the person they care for. Women (53 %) were more likely than men (47 %) to have had concerns. Those in socio-economic group ABC1 (54 %), were more likely to have had concerns compared to 45 % of C2DEs. Carers aged 65 or over were less likely than their younger counterparts to have had concerns about weight and diet in past. This was the case for 42 %, compared to 53 % of Carers aged 50 to 64 and 56 % aged 35 to 49.

It is concerning that over 50 % of carers have concerns about the weight of someone they care for but only 8 % had used formal assessment methods in the past.

## What did you do about those diet and weight concerns? Please tick as many as apply.

Figure 2: What did you do about those diet and weight concerns? (multiple choices)



Base: Carers who have had concerns about the weight and diet of the person they care for.

All (960); 65+ (203).

Only 26 % of those who have had concerns have sought out information about malnutrition in the past. Having done so made them more likely to take a range of possible responses that were presented in this survey. They were particularly more likely to have received help from a Dietitian – 21 %, compared to 12 % of those who had not needed to find information.

The most common course of action for all Carers with concerns in the past was to take direct action themselves that improved the person's diet and weight (55 %) or speak to a GP (50 %). Very few asked a Pharmacist (5 %) and just 4 % had received help from any support groups or charities (Figure 11).

Older carers (aged 65 and over) were more likely than others to consult a GP on behalf of the person they care for (56 %) and less likely to have used the internet or visited a Pharmacist for advice. Again women were significantly more likely than men to have taken action themselves that would help improve matters – 59 % had done so, compared to 49 % of men.

### **If you did have concerns about their diet and weight in the future, which of the following, if any, might you do?**

When asked what single thing they might do if they had future concerns, taking direct action yourself was a less popular response than it had been (18 %). Those Carers with previous experience of weight and diet concerns were significantly more likely to have the confidence to proceed on their own (21 %, compared to 16 % with no prior experience). Women were significantly more likely than men to feel confident in taking action themselves – 21 % thought that they would do so, compared to 16 % of men.

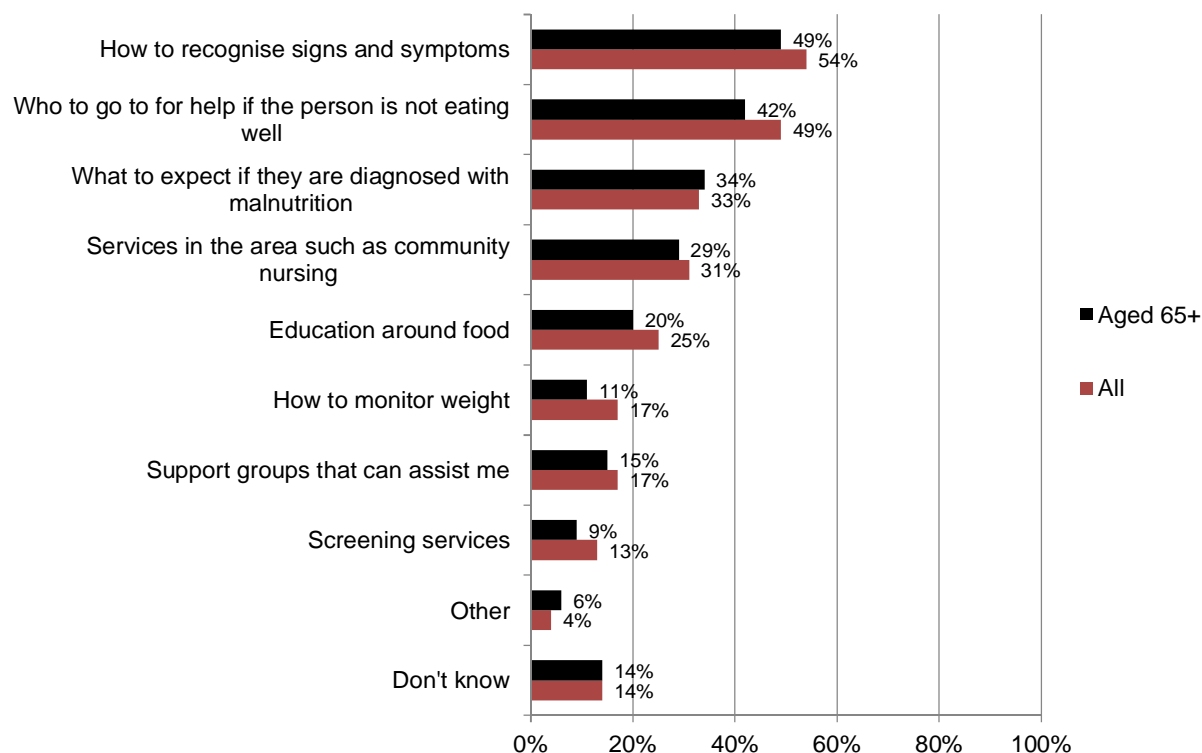
Speaking to a GP remained the most likely course of action (44 %), especially for those Carers aged 65 and over and those with no previous history of weight and diet concerns (52 % against 37 % of those who had). As many as 13 % of those with prior experience thought that this time they would go straight to a Dietitian for help.

Older Carers were again less likely to look for information online (just 7 % of the 65 and over age group) and to ask a Pharmacist – a first option for just 1 % of those surveys.



## What information would help you as a Carer?

Figure 3: As someone who cares for that person, what information about nutrition and malnutrition would you be interested in?



Base: All carers (1,883), carers aged 65 and over (455)

Over half of Carers (54 %) requested more information on how to recognise the signs and symptoms of malnutrition (Figure 12). Just under half (49 %) wanted to know who they could go to for help and around a third were interested in community services and information about what to expect if someone was diagnosed with malnutrition. Carers aged 65 and over though that they would be less likely to seek information across the range of sources, suggesting a lower degree of awareness and engagement on this issue than younger carers.

Again women were more interested than men in finding out information – as were those from an ABC1 background, compared to C2DEs. Thirty-six per cent of female Carers stated that they would like information about what to expect in the case of diagnosis, compared to 30 % of men. Fifty-one per cent of women wanted to know who to go to for help, compared to 46 % of men.

## Those with friends or relatives in a care home

A sub-group of 1,511 people had close friends or relatives in a residential care home.

Of all those with a friend or relative in a care home, as many as 68 % were unaware how often their diet and weight was monitored. Eleven % felt that it was done at least once a month with just a small proportion (3 %) believing that it was done less often than once a month.

Of those that were aware their friend or relatives diet was monitored in a care home, 50% did not know how often. 28% thought it was every week, 18% every month, 3% every 2 or 3 months and < 1 % less often than that.

If we specifically consider carers, 23 % believed that the care home assessed their friend or relative's weight and diet every week, but 55 % did not know how often it was done.

## Conclusions

### *Understanding of Malnutrition*

The majority of respondents aged 65 plus identified good nutrition as eating a balanced diet (60 %), but it is concerning that they did not associate keeping a regular weight (8 %) with good nutrition. In contrast, many older respondents (65 plus) associated weight loss as a sign of malnutrition (70 %).

This suggests that for many patients monitoring their weight regularly is not seen as a tool to check that they are adequately nourished. This is concerning as monitoring weight is a very valuable quantifiable measure by which the public and carers can keep a proper record to check if they are at risk of malnutrition. Weighing oneself is one of the easiest forms of self assessment and is an inexpensive way for patients to monitor their nutritional status.

The NHS has also been charged with making £20 billion of efficiency savings by 2014 but malnutrition costs the UK in excess of £13 billion a year<sup>4</sup>. By promoting the simple message that monitoring weight helps identify those at risk of malnutrition, the Department of Health could help the public identify those at risk and take action to prevent them from developing malnutrition. The new Public Health Directors who will sit within the Local Authority will also have a role in promoting prevention of malnutrition and must see this as one of their public health duties.

### *Information provision*

Of those who have sought information on malnutrition, they are more aware of signs of malnutrition such as mental changes, longer recovery time from illness and slow wound healing compared to the more commonly perceived signs of bloated stomach, feeling weak and weight loss. This suggests that seeking out this information has helped inform and educate individuals about the signs and symptoms.

However, the majority of respondents would like to receive more information about nutrition suggesting that provision of healthcare information in this area is lacking. Specifically respondents require information on general nutrition, education around food as well as the signs and symptoms of undernutrition and what to expect if someone is diagnosed with malnutrition. Again, health information promotion around this area falls to the Department of Health as well as the Public Health Directors.

However, there appears to be an information gap regarding local information. Those respondents who had previously sought information were more likely to require further information specifically on local services such as support groups and community nursing. This suggests that there is a gap in tailored, information or that those who had originally sought information had progressed to a stage in their condition where they now required additional, specialist services. Either way, information is clearly needed about local, specialist services.

### *Support and Help*

GPs and the internet were the most popular source of information for patients who had previously sought information on malnutrition, although the internet was not as popular for those patients aged over 65. In contrast patients may want to find information in the future would go to healthcare professionals for information on malnutrition as well as the internet (in order of popularity GP, internet, Dietitian, Nurse, Hospital, Pharmacist). In addition, GPs and the internet would be the areas that patients would turn to for help if they or someone they knew started to lose weight unexpectedly.

This suggests there is a barrier in terms of where patients want to receive information such as from healthcare professionals and where they end up seeking information from i.e. the internet. This may reflect that it is easier for many patients to simply go on line rather than obtain an appointment with a healthcare professional.

If this is the case it may be easier for patients to access services at their local pharmacies. There is certainly a role for community pharmacists in helping to screen for malnutrition and promoting good nutrition. NICE guidelines do not specify which healthcare professional in the community should screen for malnutrition and it may be this is a role that can be partly fulfilled by community pharmacists which are often more easy to access than GPs. The role of the community pharmacist in promoting good nutrition and screening for malnutrition must be considered by the Public Health Director.

With so many patients seeking information from medical websites it is essential that these websites are subject to regulation. Patients need to feel confident that the information they are receiving is evidence based and trustworthy. The Department of Health's Information Standard accreditation may be one method of ensuring this.

### *Screening*

Only 31 % of inpatients were asked questions about their weight and diet when in hospital. This is alarming as all inpatients should be screened for malnutrition according to NICE Guideline 32. Screening is defined by NICE Guideline 32 as checking body mass index, weight loss over time and the likelihood of future impaired nutrient intake. It also suggests using a tool such as 'MUST'. However, there needs to be clearer guidance for healthcare professional on how to assess 'the likelihood of future impaired nutrient intake'. Healthcare professionals must check social factors that could contribute to patients not being able to obtain enough nutrients, such as whether a patient can get to the shops or is able to cook for themselves. Of the 26 % who were asked screening questions, only 53 % of those aged 50 plus were asked if they live on their own and only 30 % of the 50 plus were asked if they were able to cook their own food.

Of those patients over 50 who were in hospital for over two nights, only 12 % were weighed regularly. It is recommended that screening should be carried out weekly in hospital but without knowing the total length of hospital stay it is difficult to analyse the figure of 12 %.

## Nutritional Treatments

NICE guidelines<sup>2</sup> state that

*“The provision of normal food and drink along with physical help to eat if necessary, when unwell will often suffice. However, if this fails, is impractical or is unsafe, measures to provide nutrition support may be indicated”.*

However, one in five respondents was unaware of even the basic treatments for malnutrition such as dietary advice and changing meal structures. Carers were more likely to be aware of all treatments, but alarmingly, only 38 % of carers and 30 % of the 65 plus group were aware of treatments including Oral Nutritional Supplements (ONS), also known as sip feeds. Furthermore, only 25 % of carers and 20 % of the 65 plus group knew they could get sip feeds on prescription from their doctor.

Seven percent of the respondents or someone that they cared for had been prescribed a sip feed in the last 12 months however, 31 % reported that the prescription had been withdrawn in the last 12 months. The reasons for this included the patient recovering, prescribing difficulties, cost or patients struggling with the compliance.

It is a huge concern that awareness is low amongst patients regarding their entitlement to treatments from their GP. The NHS Constitution clearly states that:

*“You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.”<sup>31</sup>*

However, patients need to be made aware not only that they have a right to these treatments from their GP but that these treatments exist. Over 50 % of carers had previously had concerns about the diet and weight of the person they were caring for, to rectify this 55 % of carers took action themselves to improve diet and weight of the person they cared for and 50 % sought advice from their GP. However, only 25 % of carers knew that they could get a prescription for sip feeds from their GP, suggesting that the majority who approached their GP would not have asked for this type of nutritional support.

Patients who are at risk of malnutrition or have malnutrition must be informed about the nutritional treatment options, by their Healthcare professional, as it is outlined in the NHS Constitution that patients have a right to be made aware of treatments that are available on the NHS, that are clinically appropriate for them. Evidence shows that ONS use is consistently linked to lower mortality rates and complications rates compared to standard care as well as fewer readmissions to hospital and improved rehabilitation in the treatment of malnutrition<sup>32</sup>. NICE Guidance 32 states that ONS, such as sip feeds are

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<sup>31</sup> The NHS Constitution: the NHS belongs to us all, March 2010

<sup>32</sup> Tackling Malnutrition: Oral Nutritional Supplements as an integrated part of patient and disease management in the hospital and in the community – A summary of the evidence base. European Nutrition for Health Alliance, online at <http://www.european-nutrition.org/record.jsp?type=publication&ID=32>

an appropriate treatment for malnutrition. Treating malnutrition has the potential to offer real financial savings for the NHS. Malnutrition costs the NHS over £13 billion a year<sup>4</sup> with the cost of treating an individual patient with malnutrition £1,000 over a 6 month period<sup>20</sup>. With the NHS having to make £20 billion of efficiency savings by 2014, treating malnutrition would have a huge impact on achieving this target. Healthcare professionals need to be educated as to the long-term financial savings of treating malnutrition and how prescribing nutritional treatments may help to treat malnutrition.

### *Carers*

Only 16 % of carers weigh the person they are caring for and only 8% use formal methods such as check lists. This is alarming – formal method of monitoring weight could alert carers to any early risks of malnutrition and enable action to be taken early and help to be sought. However, if carers had previously sought out information on malnutrition they were more likely to adopt formal monitoring methods, suggesting that information is having some success in communicating this message.

Half of all carers have had concerns about the diet and weight of the person they were caring for. To address this, over half took action themselves to improve the weight and diet of the person and also half sought help from their GP. Very few went to their pharmacist or received help from a dietitian.

With the move to GP commissioning the role of other healthcare professionals is under debate. It has been proposed that consortia are not just made up of GPs but also include other healthcare professionals such as nurses and community pharmacists.

## Calls to Action

- The Department of Health must provide information on basic nutrition and the importance of monitoring weight loss as an early warning sign of malnutrition to patients and healthcare professionals
- GP consortia need to ensure information on malnutrition is tailored to local services and covers the whole 'malnutrition journey' from diagnosis to nutritional treatments that can be prescribed by the GP and also following up and monitoring in the community
- GP consortia and Local Authorities must ring-fence funding for community-based dietetics services and treatment options if clinically required
- GPs and GP consortia need to be educated as to the cost benefits of treating malnutrition
- The Department of Health must make nutritional screening across all health and social care settings mandatory and healthcare professionals must be educated and trained to use a nutritional guide to the social risk factors associated with malnutrition and nutritional screening questions to ask on these factors
- The new Public Health Directors who will sit within the Local Authority must have a role in promoting prevention of malnutrition and must see this as one of their public health duties
- The role of the community pharmacist in promoting good nutrition and screening for malnutrition must be considered by the Public Health Director
- The Patients Association's leaflet 'Malnutrition – signs and symptoms, where to go for help and what to expect from treatment' should be provided by GP surgeries and healthcare professionals to patients and carers who may be vulnerable or at risk of malnutrition