



BAPEN

*Putting patients at the centre
of good nutritional care*



PINNT

A SUPPORT GROUP FOR PEOPLE
RECEIVING ARTIFICIAL NUTRITION

Nutritional Care and the Patient Voice

Are we being listened to?

M Elia and C Wheatley

on behalf of BAPEN and collaborating partners

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Preface

In 2008 a roundtable discussion about nutritional care in the UK took place between patients, carers and their representatives from 18 organisations. The report that emerged from the discussion¹ concluded that nutritional care could be improved substantially by taking greater account of patient perspectives, including patient choices, and being more sensitive to patient dignity and respect. It also concluded that malnutrition was often unrecognised and untreated, particularly in vulnerable populations and patient groups. Patients, carers and their advocates felt it was not only necessary to address these issues, but also to improve the process by which this is achieved because it would enable a more flexible and compassionate approach to patient care. It was recommended that healthcare workers should be trained to support vulnerable children and adults with verbal and physical and/or cognitive impairment who are unaware or unable to express their needs and fulfil their nutrition and hydration requirements. To facilitate implementation of its key messages, the report provided separate recommendations to government and policy makers, healthcare professionals, public health professionals and all stakeholders.

Since 2008, many other reports have been published about patient and carer involvement in health and social care, often focusing on decision-making and self-care. The statement “no decision about me without me” made in the Secretary of State for Health’s speech to the National Clinical Assessment Service conference (5th November 2010) was echoed in the White Paper, *Equity and excellence: Liberating the NHS* (2010)² as well as a subsequent consultation paper with proposals for securing shared decision-making³. Recently, patient reported outcome measures (PROMS) have been used to assess clinical outcomes⁴, some of which involved assessments of quality of life by patients before and after surgical operations such as hip replacements, knee replacements and varicose vein surgery. In addition, data based on Patient-Led Assessments of the Care Environment (PLACE) has been gathered (replacing those obtained from Patient Environment Team (PEAT) inspections⁵).

However, many of the reports and many of the new proposals about patient involvement have not focused on nutritional care as a central theme. Furthermore, little attention has been paid to the methodology for evaluating complex nutritional problems, such as those experienced by patients receiving home enteral or parenteral nutrition. A particularly important problem concerns the reported differences in opinions expressed by patients and healthcare workers in audits involving the same or similar topic. For example, a discrepancy has been highlighted in a recent analysis of food provision in hospitals. NHS staff rated 98% of patient meals as ‘good’ + ‘excellent’ compared to a survey of more than 64,000 patients which showed that only 55% of patients rated the food as ‘good’⁶, implying that almost half of the patients had concerns about the adequacy of the food and did not match the responses of NHS staff. This mirrored discrepancies between views expressed by healthcare workers and patients about help with eating⁷. These observations suggest healthcare workers need to have a better understanding of patient perspectives (and vice versa) on nutritional issues so that the problems can be addressed together by both parties in a partnership.

Many new initiatives attempting to implement a patient-centred agenda have been suggested both by governmental and non-governmental organisations. These have been variously described as ‘patient power’⁸, ‘patient-powered health’⁹, ‘partnering with patients’^{10,11}, ‘the patient revolution’¹², and the ‘the patient-centred revolution’¹³, as well as ‘time to listen in NHS hospitals’ and ‘time to listen in care homes’, the latter two representing the titles of reports emerging from the Dignity and Nutrition Inspections (DANI) which were carried out by the Care Quality Commission^{14,15}. These colourful descriptions reflect the need to make changes to the current system of care, for example, from the traditional paternalism of the healthcare profession to a partnership with patients, from power held by healthcare professionals to empowerment of patients, and from decisions made by healthcare professionals on behalf of patients to joint decision-making. However, if the ‘patient revolution’ is to progress in a constructive way so that patient partnerships can become the norm rather than the exception, as suggested by a government report¹⁶, it is necessary to consider the evidence on which the proposed changes would be based.

Most importantly, despite the publication of many new reports, policies and reviews (e.g. the Keogh review¹⁷) and the ongoing reorganisation of the health service which aims to improve patient care and partnerships with patients, there remains uncertainty about how much real progress has been made on the ground. There continue to be many touching stories told by patients, their carers, families and friends, raising concerns about important societal issues that need to be addressed. Our current report brings out some of these issues and suggests that a lot of work still needs to be done. It is hoped that the patient voice on nutritional issues will join other voices concerned with other healthcare issues to form a choir of voices that are loud, harmonious and difficult to ignore.

Marinos Elia and Carolyn Wheatley

Joint Chairs

Nutritional Care and the Patient Voice: Are we being listened to?

Executive summary

- Despite the publication of many new reports, policies and reviews, and the ongoing reorganisation of the health service to improve patient care, there remains uncertainty as to how much real progress has been made.
- The Nutritional Care and the Patient Voice report suggests that there is still a lot to be done in relation to the fundamental issue of nutritional care.
- The nine organisations that have collaborated in the compilation of this report agree that more needs to be done to improve management of patients with nutrition and hydration problems, and if the messages it contains are heeded many aspects of patient care could be improved.
- The content of the report has been compiled via the completion of questionnaires, a workshop of participating organisations and feedback on draft versions.
- Measurement of patient involvement and satisfaction with their care must be conducted robustly and shared with all parties.
- Patients, families, carers and patient organisations represented in this report stand ready to be involved directly in improving patient care, stating that they are ‘a valuable resource’ with whom closer interaction can benefit healthcare organisations.
- Patients, families and carers can contribute to improving continuity of care if they are involved and included in a meaningful way, particularly in reducing emergencies and where patients are in transition between services.
- Patients as reported here wish to be seen as a person first and foremost, not only a problem to be ‘solved’.
- Priorities may not be the same for healthcare professionals and patients and should therefore be discussed and agreed at an early stage of treatment and advice.
- Communications between the parties should be clear and double checked as to how messages have been received and interpreted.
- Confidence of patients, families and carers in the healthcare services provided will be boosted by their involvement at all stages of care.
- Achieving these changes requires a culture change, some of which can be readily achieved and implemented through a better understanding of and respect for patients and their needs. Some changes are more difficult to achieve requiring extra training, time and effort by staff, and an evaluation of the outcomes that can be achieved through such commitments.

Key messages/recommendations to improve nutritional care

Although this report provides four separate recommendations for organisations and individuals involved in providing and receiving care, they reflect the aspirational changes that are needed to provide high quality care to all. Similarly, although the recommendations emerged from consideration of nutritional care, they also reflect issues that require changes in other fields of health and social care.

For Government, Department of Health and Policy-makers

- STOP any more reorganisations!
- There must be 'real' patient involvement: this cannot be a 'tick box' exercise.
- Patient and family experience of health services must be measured effectively: evaluations based on asking healthcare staff and patients whether they would recommend their friends and family to attend a given hospital are not enough.
- The outcomes of these measurements must be shared not only between health and social care workers but also with patients, so that all learn and benefit from each other.
- Patient and population group organisations are ready to work in partnership – “help us to help you”.
- Ask patient and population group organisations to work with care workers – “we are a valuable resource”.
- Patient and population groups are willing to be involved in their care – “we will contribute to our care”.
- Clearer communication and signposting of services are needed centrally.
- The standard inspections by the Care Quality Commission are not enough – a carefully considered 'secret shopper' element would help.

For Health Trusts Care Organisations and Social Care

Show us:

- Real engagement with patients.
- Real integration between departments and settings.
- Real collaboration between sectors and integrated standards of care.

- The seamless care that is needed to ensure effective continuity of care within and between care settings, and to help avoid emergencies.
- The effective transition between paediatric and adult services, which is urgently required. A poor start can lead to longer-term problems, often associated with poor ongoing relationships.

Healthcare Professionals

- See us as a person, not only as a problem.
- Ask us what is important to us.
- Let's discuss and agree on the goals of our treatment – we may not have the same priorities as you.
- We will contribute to our care if we are allowed to.
- Check our understanding of what you have told us – we may be embarrassed to ask again or not want to seem a nuisance.
- Communicate with us clearly at the right time – this is essential.

Patients/Families

- We can contribute to our care.
- We can be better patients by preparing for our appointments by writing down our questions/queries and making sure they are clear.
- 'Attitude costs nothing' – we must make sure our attitude is positive, respectful and open so that it can contribute to a better experience.
- With appropriate support we may be able to manage some elements of our treatment ourselves, including monitoring our weight.
- Our confidence in you and ourselves will increase over time so please support us, particularly in the early stages.

Abbreviations

BAPEN: British Association for Parenteral and Enteral Nutrition

BLT: British Liver Trust

CQC: Care Quality Commission

DANI: Dignity and Nutrition Inspection

GP: General Practice (or General Practitioner)

HEN: Home Enteral Nutrition

HPN: Home Parenteral Nutrition

MENCAP: The Royal MENCAP Society

MTF: Malnutrition Task Force

NICE: National Institute of Health and Care Excellence

NNNG: National Nurses Nutrition Group

PA: Patients Association

PINNT: Patients on Intravenous and Nasogastric Nutrition Therapy

UCLH: University College London Hospital

WWL: Wrightington, Wigan and Leigh NHS Foundation Trust

Introduction

During the last five years many reports^{1,14,15,18-21} have been published about the need to take greater account of patient perspectives in health and social care, so that patient satisfaction, choices, dignity and respect can all be improved. To achieve this, it is necessary to have a partnership between patients and families/carers on the one hand, and health and social care workers on the other.

However, only one report, which emerged from a roundtable discussion about five years ago, has specifically focused on nutritional care, including specialised forms of nutritional care such as enteral and parenteral nutrition¹. Since then, the National Institute for Health and Care Excellence (NICE) issued a specific guideline document about improving the experience of people using adult NHS services. The document provided recommendations on general aspects of nutritional support in the context of other considerations, such as shared decision-making, tailoring of healthcare services to the patients' needs, and continuity of care²². In November 2012 NICE also issued a quality standard on nutrition support in adults, which provided high quality standards relevant to patients receiving long-term tube feeding and parenteral nutrition²³. An accompanying document for patients was also provided²⁴. Several of the above developments reflect, at least to some extent, the accumulated concerns of patients and carers over many years. For example, in 2001 the Bristol inquiry into the inadequate care of children undergoing cardiac surgery concluded that the patient must be at the centre of everything the NHS does and that patient perspectives must be included in policy, planning, and delivery of services²⁵. The General Medical Council has traditionally encouraged doctors to comply with the old motto "make your patient your first concern". However, behavioural and institutionalised changes based on socio-cultural modifications, can take a long time to implement and embed in routine practice. Therefore, despite the above reports, such changes have been doggedly resistant to becoming implemented and embedded in routine care.

A change in culture was also a central recommendation of the Francis Report²⁶⁻²⁸, which was set up to examine the estimated 400–1200 excess deaths between 2005 and 2008 in a relatively small trust in mid-Staffordshire. Politicians, healthcare professionals and patients all hoped that the tragic outcomes summarised by the Francis Report would be rare, but numerous reports involving a wide range of trusts have raised similar concerns to those recognised in the Francis Report. Furthermore, following the Francis Report another 14 hospitals were identified for detailed investigations. The Francis Report itself raised specific concerns about nutrition and hydration which echoed other issues related to personal hygiene, dignity and respect. Implementation of the recommendations of the Francis Report would need a culture change based on leadership, training and information to improve patient experience and safety (emphasised in the Berwick Report²⁹, which also drew attention to the importance of patient dignity and involvement).

However, it is essential to consider how these issues are viewed from the patient's and carer's perspectives. Some of the problems are complex and not easily solved by a single approach. In addition, shared decision-making can sometimes create its own problems.

Shared decision-making is relevant to many types of choice, including whether or not to undertake a screening test, take medication, and undergo long-term lifestyle changes. The process is not simply about providing information, but also about aiding and encouraging people to think about their values and future well-being. A report published by the Royal Pharmaceutical Society²⁰ on patient involvement and decisions concerning medicines raised a number of challenging questions: What if there is doubt about the capacity of patients to represent themselves effectively? What if patients do not want to be involved in particular ways? What if attempts to involve patients cause them anxiety or distress? What if actions or interventions to promote involvement undermine the trust patients have in clinicians or the comfort and reassurance the clinicians can offer? What if 'involved' patients make choices that are harmful to themselves or others, or damage the public realm more generally (for example, because they are very expensive or otherwise adversely affect public health)?

Some of these problems can be difficult and they need to be explored carefully, taking into account whether or not patients wish to participate actively in decisions about their treatment and whether their attitudes might change over time. For example, a systematic review issued in 2012³⁰ found that in 63% of articles published before 1990 the majority of patients preferred to be actively involved in decisions about their treatment (shared or autonomous decision-making). The proportion between 1990 and 1999 was 51% of articles and this increased to 71% of those published after 1999 (85% in the case of cancer).

If a new infrastructure is to be built to involve patients, carers and their advocates more appropriately, it is necessary to establish strong foundations that include the evidence base underpinning the new approaches. This may include the use of patient decision aids³¹. A Cochrane systematic review³² examined the value of implementing international patient decision aids, such as pamphlets and videos designed to assist people in understanding their options in order to help them make decisions. It found that the introduction of these aids resulted in significantly greater knowledge, lower decisional conflict about being uninformed, lower decisional conflict about personal values, a reduction in the proportion of people who were passive in decision-making, and a lower proportion remaining undecided. One of the reported outcomes of implementing such aids in particular groups of surgical patients was a reduction in the rate of elective invasive surgery and an increase in conservative management. Another Cochrane systematic review found that specific outcomes may vary depending on the patient group and the method of implementation. For example, the effect of patient involvement on consultation time ranged from a reduction of 8 minutes to an increase of 23 minutes (median increase 2.5 minutes)³³ (nine studies). However, decision aids should not be considered in isolation since a range of associated activities, such as training of health and social care workers, also need to be taken into account.

Despite all these developments, a number of questions about patient and carer perspectives remain unanswered. For example, has there been a substantial improvement in patient care in England over the last few years? Have the strategies outlined in many of the reports been implemented effectively with favourable outcomes in patients and carers? Are there continuing concerns about issues raised in a previous BAPEN report regarding patients' and carers' anxieties about nutritional problems? And has the recent

reorganisation of the health service resulted in greater clarity and improvement in healthcare or a deterioration, which may have arisen from increased confusion, competition and privatisation? During the last five years there have been many specific activities related to nutrition and hydration, several of which have been accompanied by inspections and recommendations. However, it is still unclear whether patients and carers feel satisfied that progress has been made. Some may even feel that there has been a recent deterioration in care, in which case the underlying factors would need to be identified and addressed. Previous concerns have been raised about the lack of integration of health and social care services, but it is unclear whether patients, families and carers feel that the services have managed to work together effectively to meet their needs.

This report on patient/carer perspectives on nutritional care aimed to address three main issues. The first is whether adequate priority has been given to nutrition and hydration services and whether they have improved in the last few years; the second is whether or not the patient experience associated with nutritional support has improved; the third is whether or not inequities in nutritional care have been adequately addressed.

Methods

A questionnaire was devised (Appendix 1) to obtain the views and insights of patients/carers on three areas of health and social care, with a specific focus on nutrition and hydration:

- Nutrition and hydration services: priorities and trends over time
- Patient experience
- Inequalities.

Thirty organisations were contacted to scope the issues concerned, with the view to organise an in-depth facilitated discussion using a qualitative approach. This discussion by a focus group was based on the nine questionnaires returned before the roundtable discussion meeting on 25th April 2013 (see list of organisations and attendees at the back of this report). Two questionnaires were returned from NHS trusts which were recruited opportunistically. One of them was recruited via the Macmillan service which was involved in our previous roundtable discussion¹. The individual from this trust was also involved in the roundtable discussion whereas the one from the other NHS trust was not.

The meeting also aimed to extend the discussion on the issues raised in the questionnaire to consider two additional topics:

- The extent to which patients/carers share the same priorities as a group of health trusts in the process of establishing protocols for improving patient centred care.
- The potential value of self-screening in routine clinical care.

Issues raised during the consultation process, which included distribution of the draft report to various organisations, were taken into account before this report was finalised.

A qualitative summary with narrative description of the concerns raised by patients, carers and their representatives follows. Graphs are used to summarise the answers to the questions, and to distinguish between responses obtained from patients, carers and their representatives (non-governmental organisations) and those from two individuals working for NHS trusts (government organisations).

Results and discussion

1. Nutrition and hydration services: priorities and trends over time

1.1 Results of survey (Questions 1–4)

Question

1) How high a priority are nutrition services and malnutrition and dehydration issues:

- a) In your own organisation?**
- b) In government and policy circles?**
- c) Among the public?**

2) In the last 5 years have the delivery and experience of nutrition and hydration services improved or not?

3) Are nutrition and hydration services regulated and inspected appropriately?

4) In the last 5 years has there been a change in the priority given to nutrition services and the issues of malnutrition and hydration:

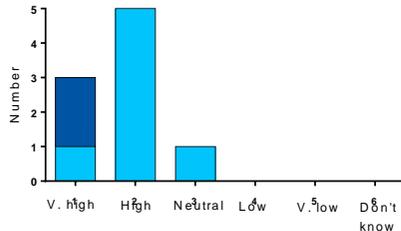
- a) In your own organisation**
- b) In government and policy circles**
- c) Among the public?**

The results to the above four questions (the questionnaire in Appendix 1 also indicates the options for answering) are shown **Figure 1**. In this figure the results obtained from those working in healthcare trusts (government-funded organisations; referred to as ‘government organisations’) are distinguished (darker blue colour) from those obtained from voluntary organisations not supported by government (lighter blue colour).

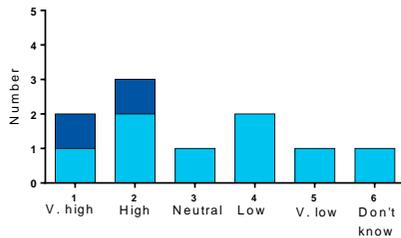
Nutrition/malnutrition issues were considered to currently have a ‘high’ or ‘very high’ priority by the respondents (8/9), who also considered that the public has a high priority. More variable responses were obtained when considering the perceived priorities given to nutrition/malnutrition by government (**Figure 1**; Question 1 (Q1)). With respect to

Q1. How high a priority are nutrition services and malnutrition?

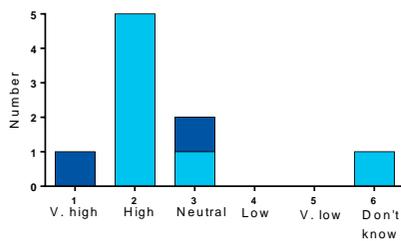
a) in your organisation



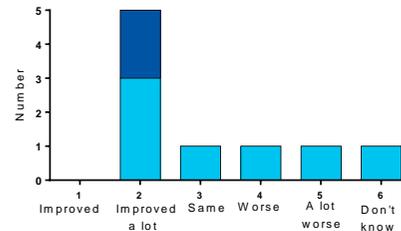
b) in government policy



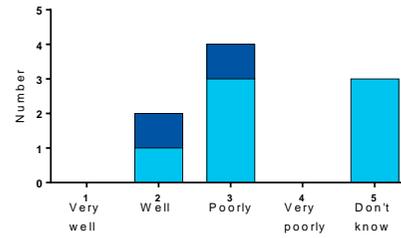
c) among the public



Q2. In the last 5 years have the delivery and experience of nutrition and hydration services improved or not?

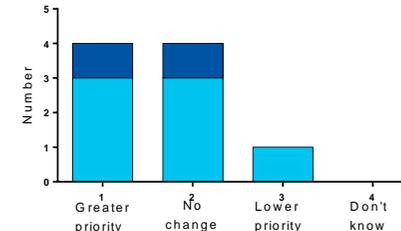


Q3. Are nutrition and hydration services regulated and inspected appropriately?

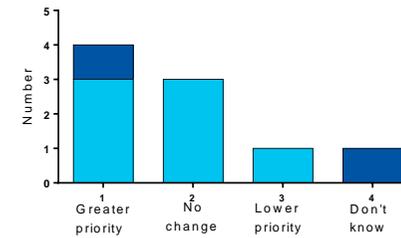


Q4. In the last 5 years has there been a change in the priority given to nutrition?

a) in your organisation



b) in government



a) among the public

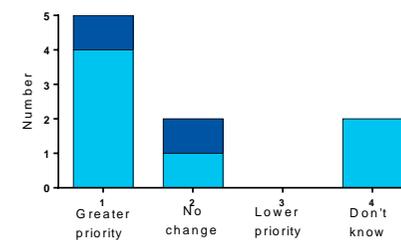


Figure 1 Responses to questions 1, 2, 3, and 4 (Q1, Q2, Q3, Q4) provided by individuals working for non-governmental (lighter blue) and governmental organisations (darker blue)

perceived priorities among the public, individuals from the two governmental organisations tended to give it a higher priority than those from non-governmental organisations. There was a wide variation in responses to questions about whether the services dealing with nutrition and hydration had improved over the last five years. Some reported an improvement, others a lot of deterioration, and yet others little or no change (**Figure 1**; question 2 (Q2)). Individuals working for the two governmental organisations gave the most favourable rating to Q1a and most favourable response to Q2. The responses from those working for non-governmental organisations were more variable (**Figure 1**; questions 1-3).

With respect to changes over the last five years, there were suggestions that the priority given to nutrition by organisations, government and the public had improved, but this was not consistent. Several responses indicated that there had been no change, and occasionally that it had been downgraded to a lower priority. There was also some uncertainty about whether the changes within government circles had improved or deteriorated (see **Figure 1**; question 4 (Q4)).

1.2 Roundtable discussion

a) Organisations

Question 1)

How high a priority are nutrition services and malnutrition and dehydration issues:

- a) In your own organisation?**
- b) In government and policy?**
- c) Among the public?**

At the meeting nutrition and hydration were rated highly in the ranking order of priorities. The **Patients Association (PA)** gave nutrition and hydration a very high priority, as these topics were among the most frequently raised by patients and their families on their helpline. Between 30 and 35% of all calls were currently reported to involve nutrition and hydration.

As a consequence a campaign by **PA** is looking at the barriers that prevent all patients receiving high quality nutrition and hydration care. The case study below (**Box 1**) and the increasing activity of the **PA** helpline with respect to nutrition and hydration issues in hospital (**Box 2**) highlight the importance of these issues.

The **British Liver Trust (BLT)** takes many calls mainly from patients, carers, family and friends regarding all forms of liver disease. Many of these are from people who are worried about either their own alcohol intake or that of someone they care about. They also take a significant number of calls from people who have been diagnosed with fatty liver, which is often due to poor nutrition. Consistent dietary advice based on healthy living can help prevent and help treat alcohol-related problems and fatty liver, as well as many other liver conditions. However, accessing such information is often difficult or

Box 1 Case Study (Come Dine with Me)

The catering team at the Heart of England NHS Foundation Trust has developed its own 'take' on the Channel 4 television programme 'Come Dine with Me' to help improve the image of the hospital food. A meal sampling initiative at the trust's three hospitals – Solihull Hospital, Good Hope Hospital in Sutton Coldfield and Birmingham Heartlands Hospital – invited the public and staff to eat exactly the same meals that patients received on that day. The aim was to tackle the perceived stigma attached to hospital food and the assumption by many that it is bad everywhere. The trust conducted this activity by using a ward-level regeneration trolley – filled with a selection of lunchtime meals prepared in the trust's Central Production Unit (CPU) – in a busy public area of the hospital where passers-by were offered a plate with some food.

Patients Association: CARE Report – Dec 2012

Box 2 Patients Association Helpline

Over the last three years the Patients Association has seen an increase in the number of people calling its helpline regarding nutrition and hydration in hospitals. Lack of suitable meal choices and inadequate help with eating and drinking have been highlighted as key issues.

impossible. General practitioners (GPs) appear to have low awareness of the importance of nutrition and hydration in the prevention and treatment of these conditions. Due to increasing volumes of enquiries via their helpline and website, **BLT** has given nutrition and hydration an increasingly high priority. **Box 3** indicates the activity of its helpline with respect to diet and nutrition.

Box 3 British Liver Trust Helpline

Over the last three years (up to March 2013) the British Liver Trust received 7491 medical enquiries via its helpline. Of these enquiries, 2241 (29.9%) were directly related to diet and nutrition.

People with a learning disability are supported by **MENCAP** (Royal MENCAP Society, formerly The Royal Society for Mentally Handicapped Children and Adults) which provides much needed advice about how to eat healthily. This has always been an issue for the charity and for their ‘customers’, particularly with regard to the steps they need to take to feed themselves appropriately using a restricted budget.

A major concern for **MENCAP** is how to implement this support to ensure that the health needs of people with a learning disability are met in the community and also when they are in hospital. Understanding of the impact of ‘malnutrition’ has increased in recent years within the organisation due to major reports and media coverage.

A case study involving two NHS trusts (**Box 4**) illustrates what can be done to improve communication with people with a learning disability using the ‘Patient passport’.

Box 4 Case Study (The Patient Passport)

Two organisations (Humber Mental Health Teaching NHS Trust and Hull and East Yorkshire Hospitals NHS Trust) have been working together to improve the care and treatment they give to people with a learning disability. They knew that when people with a learning disability were admitted to hospital staff were struggling to understand their needs, including their communication needs and the type of extra support they might need to keep safe.

To make things better, they set up a ‘**patient passport**’. This is available on a CD:Rom and holds an electronic database that records the full range of an individual’s needs. It also includes information from patients and their carers/families so that that staff working in acute trusts can access it quickly to ensure specific patient needs are met during hospitalisation. The patient passport provides information about patient status, including when they are considered to be well and can stop diagnostic overshadowing, and also highlights specific care needs, like help with eating or drinking.

MENCAP website: www.mencap.org.uk

Humber Mental Health Teaching NHS Trust and Hull and East Yorkshire Hospitals NHS Trust

Whilst artificial nutrition support is the main concern of **Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT)**, oral nutrition is also of some interest because it

is taken whenever possible, sometimes in only small amounts, to maintain gut function. Healthcare professionals should be aware of this need to ensure those on artificial nutrition therapy are given opportunities to eat, including being offered a menu when in hospital.

The **Malnutrition Task Force (MTF)** is focusing its efforts on older people in hospital, care homes and living in the community, making use of its experience on nutrition and hydration issues linked to information, support and treatment. The very existence of the **MTF** is a testament to the priority given to the topic. **MTF** felt that awareness of the vital need to improve implementation of best practice has definitely increased across all sectors. A case study concerned with improving the dietary intake of hospitalised patients illustrates what can be done (**Box 5**).

Box 5 Case Study (The Right meal, Right Time, Right Help)

The **Right Meal, Right Time, Right Help** project aimed to provide patient-focused meal times. The team agreed and collected baseline data using a measurement tool. They observed patient meal times for a week, talked to staff and patients to identify good practice and shared ideas for improvement. The team then introduced a series of changes. Meal mats were brought in to ensure areas were kept clear for the patient's meal tray and to ensure easy access to food. Patients were also offered a variety of drinks and snacks throughout the day. Visitors were encouraged to join patients at mealtimes and provide assistance when necessary. Staff encouraged the use of 'own foods' where appropriate to meet patient preferences. They also promoted the activity by displaying informative posters on the walls for residents and visitors.

MTF website: www.malnutritiontaskforce.org.uk

The **University College London Hospital (UCLH)** Dietetics Department Macmillan senior specialist dietitian reported at the meeting that amongst all staff working in the acute setting there is much heightened awareness of the importance of getting nutrition and hydration right.

Various responses were received when attendees were asked whether the service and experience improved over time, for example:

"This will vary across different groups of patients."

"There are serious variations in standards throughout the NHS."

Overall the meeting agreed that whilst activity had increased it was hard to quantify whether the service had improved to the extent that patients and their families could say they have had an improved experience.

Families reported to **MENCAP** that whilst 'red trays' for food have been introduced to flag up a patient's extra needs, there is very little active follow-up by staff. Families also reported that red trays are provided but often make no difference as they are taken away after 30 minutes with food untouched, with no help given with eating while the red trays are at the bedside.

Assumptions about the nutrition of adults and children with learning disability are still being made by staff, but these are not always correct. For example, it is often assumed that patients with a moderate to severe learning disability have dysphagia when they do not, meaning that staff are fearful of the problem and reluctant to offer nutrition when it is needed.

PINNT stated that their patient and family groups feel that the problem of variable practice and experience has not gone away.

UCLH stated from a professional perspective that their practice had definitely improved with regard to screening for malnutrition and the use of red trays and jugs for treating hydration and nutrition problems.

MENCAP's experience is that GPs will often fail to give adequate advice, let alone advise according to individual needs. Education of GPs must therefore be a priority. No one set of patients should be singled out to receive different care because they are more difficult or complex: everyone should receive the same high level of care.

The focus group not only considered the priorities given to nutrition and hydration, but also the value of regulation and inspection, complementing the findings of the survey. Although the results from the questionnaire indicated that inspection and regulation of nutrition services catering for malnutrition and dehydration problems were generally satisfactory, with responses rating the performance ranging from 'very high' to 'neutral' (**Figure 1**; Q2a), specific concerns were raised during the discussions. For example, the following statement was made about inspections by the Care Quality Commission (CQC) concerning nutrition and hydration:

"CQC Inspections need to be carried out in more depth."

A proposed new way of working has been announced by the CQC (**Box 6**).

Box 6 Care Quality Commission (CQC) Update

During 2013, the CQC launched a consultation, consolidated responses from a wide range of stakeholders and announced their proposed new way of working in the period 2013–2016. Key changes included the appointment of a new Chief Inspector of Hospitals (Professor Mike Richards), a focus on five key questions during inspections of services (are they safe, effective, caring, well led and responsive to peoples' needs?), and the appointment of specialist inspectors leading teams that include clinical experts and people with experience in providing care.

<http://www.cqc.org.uk/public/about-us/our-performance-and-plans/our-strategy-and-business-plan>

MENCAP commended the CQC's use of 'patients by experience' and 'experts by experience,' but it also expressed concern that those involved can sometimes be 'the usual suspects,' working with the CQC on other initiatives, including those with nutrition and hydration components. It was felt that inspection teams should give special attention to individuals with special needs, such as those with learning disability. Given that the inspections are primarily concerned with the 'lowest common denominator' (i.e. basic standards of care), perhaps the teams interacted with people with ordinary needs and not those with special or difficult needs during the recent rounds of inspection.

The key issue for the **MTF** regarding recent inspections was the lack of training received by the inspection teams. Did they really know what they were looking for and understand what they were seeing and hearing? This same issue has been of concern to other organisations, such as **BAPEN**, for some time. The concern has been expressed at meetings with the Task Group previously managing the Dignity and Nutrition Inspections (DANIs).

An extract from the DANI reports^{14 15}, illustrates that whilst some improvements appear to have occurred there is still some room for concern, for example with respect to people's privacy and the dignity of hospitalised patients (**Box 7**).

Box 7 Extract from the Dignity and Nutrition Inspection Reports

“CQC inspected 500 care homes and found 84% respected people’s privacy and dignity and 83% met people’s nutritional needs. This means that staff were aware of people’s likes and dislikes, so that they could target their support, for example in helping people with dementia to choose their food. However, there were also times when inspectors witnessed a failure to provide help with eating and drinking or to provide personal care while respecting personal privacy. The report also looked at the same issues as those covered in the 2011 report on respect, dignity and nutrition in NHS hospitals. It found improvements in the way people’s nutritional needs were met, with 88% of inspected hospitals visited providing help with eating and drinking compared to 83% in 2011. Whilst this is good progress there were also pockets of poor care.

Disappointingly, fewer hospitals were respecting people’s privacy and dignity, with 82% meeting people’s needs compared to 88% in 2011. CQC inspectors saw call bells left unanswered, which meant leaving people without help to get to the toilet and without support to address other needs.

Dignity and Nutrition Inspection Report (DANI) published -- March 2013

www.cqc.org.uk

b) Government and policy circles

Question 1b)

How high a priority are nutrition services and malnutrition and dehydration issues in government and policy circles?

Attendees at the meeting were aware that there had been considerable discussions on nutrition and hydration in government and policy circles, and this was interpreted as an improvement in understanding of the importance of nutrition and hydration. However, it was also felt these observations do not necessarily equate with improvements ‘on the ground’, or in the patient and family experience of healthcare.

MTF said that it has not always been made clear who is responsible for nutrition and hydration care, thus the buck has been passed from pillar to post. **MENCAP** noted that from their perspective there is evidence of ‘lip service’ being paid to nutrition and hydration. **BLT** added that these initiatives are not making an impact and the key issue of ‘affordability’ appears to be ignored. **PINNT** commented that the activity ‘looked good’ but again queried how much improvement had actually taken place ‘on the ground’. **ULCH** felt more emphasis was given to healthy living (prevention) than to treatment of specific problems, including under-nutrition

c) Public

Question 1c)

How high a priority are nutrition services and malnutrition and dehydration among the public?

“The public must be confused about nutrition information – there is so much conflicting ‘diet’ advice!”

The meeting agreed that public awareness and understanding of nutrition and hydration ‘spike’ after specific stories feature in the media. The stories have usually been critical of or uncomplimentary about the care provided to vulnerable people, both in hospital and outside hospital. After these stories have featured in the media, there is often heightened public anxiety, especially among groups where an individual, a relative, a neighbour or a friend is receiving or about to receive healthcare. This may drive people to access more information in order to help themselves and/or their relatives and friends. An example of a media article raising awareness about problems with nutrition and hydration is shown in **Box 8**.

Box 8 A newspaper report about nutrition and hydration

- Patients die of malnutrition and dehydration.
- For every patient who dies from malnutrition, four more have dehydration mentioned on their death certificate.
- In 2011, 43 patients starved to death and 291 died in a state of severe malnutrition.
- The Department of Health branded the figures 'unacceptable' and said the number of unannounced inspections will increase.

Source: article by Tara Brady, Daily Mail, 03/03/13

Overall, the meeting agreed that the public’s awareness of malnutrition and hydration issues had improved, and that it was now time to make use of this awareness by lobbying for improved and consistent nutrition and hydration services for all. Unfortunately, GPs, the first port of call for most, seemed to remain at best disinterested and at worst dismissive of this area of healthcare.

Key points emerging from the discussion on priorities in nutrition and hydration and the associated concerns and trends over time are summarised in **Box 9**.

Box 9 Key points (Priorities, trends over time and concerns)

1. Awareness of malnutrition and hydration problems among the public, government and healthcare providers appears to have increased in recent years.
2. New initiatives have been planned and started, and activity to address malnutrition and hydration problems has increased.
3. However at the meeting some concern was expressed that not enough improvement had been made to ensure a better and consistent experience for all.
4. There is still a disconnection between the vision of improved awareness on the one hand, and improved healthcare services and experience by patients and their families receiving the healthcare on the other. This gap needs to be closed.

2 Patient experience

2.1 Results of survey (Question 5a–5k)

Question 5)

- 5a) Are nutrition and hydration issues under-recognised and under-treated?**
- 5b) Are patients, their families/carers, sufficiently involved in making decisions about their nutritional treatment?**
- 5c) Are patients, their families/carers, aware that they have a right to expect to be involved in making decisions and choices regarding treatment options, where that treatment is delivered and over what timescale?**
- 5d) Do patients, their families/carers receive the right training, information and support to enable them to become fully involved in making decisions about their nutritional treatment?**
- 5e) Do patients receive nutritional treatment and care that is tailored to their own individual needs?**
- 5f) Do patients experience problems with continuity of care during their journey from one setting to another, e.g. hospital to home?**

5g) Do patients experience follow-up problems with those services catering for their needs?

5h) Can patients managing more complex treatments at home (such as parenteral nutrition, enteral feeding) access information and support from healthcare professionals out of usual working hours and at weekends?

5i) Do the healthcare professionals dealing with patients and families/carers have the right training, competence and confidence in delivering nutrition and hydration services?

5j) Do patients, their families/carers receive the right training, information and support to help them comply with their treatment safely?

5k) Do patients, their families/carers, feel confident and safe in the place where they are receiving their treatment?

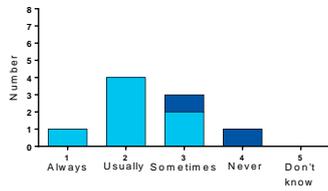
The experience of patients and their families/carers was found to be variable, and some concerns were raised that problems with nutrition and hydration remained under-recognised and undertreated. It was felt that patients and their families/carers were not sufficiently involved in decisions about treatment options and care setting, and the timescale for the treatments. It was felt that patients and their families/carers frequently did not receive the right training and support to enable them to become fully involved or more involved with issues related to their treatment. Indeed, the majority felt that the treatment was only 'sometimes' tailored to their own needs or to the needs of their patient groups.

As a consequence the respondents to the questionnaire (**Figure 2**) generally indicated that they 'usually' and 'sometimes' experienced problems with:

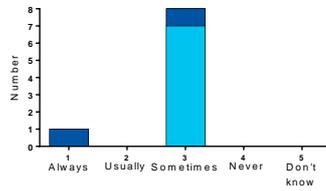
- Continuity of care, e.g. from hospital to home
- Problems with follow-up
- Access to information and receipt of support from healthcare professionals out of normal working hours and at weekends.

In addition, the healthcare professionals were often considered to have inadequate training, competence and confidence in delivering nutrition and hydration services. Most respondents felt that patients and their families/carers only 'usually' or 'sometimes' received the right training to comply with their treatment safely, and that they only 'usually' or 'sometimes' felt confident and safe in the place where they received treatment. The responses from the two governmental organisations were scattered within those of the voluntary organisations, with no consistent differences in the pattern of the responses.

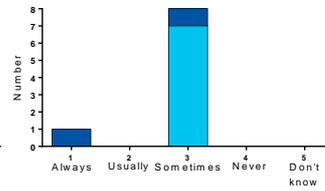
5a) Are nutrition and hydration issues under-recognised and undertreated?



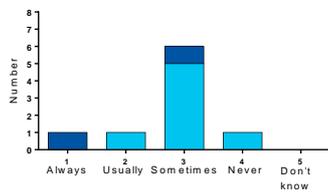
5b) Are patients, their families/ carers, sufficiently involved in making decisions about their nutritional treatment?



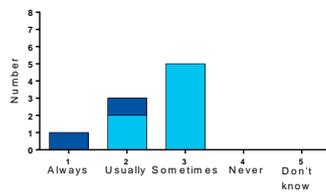
5c) Are patients, their families/carers, aware that they have a right to expect to be involved in making decisions and choices regarding treatment options, where that treatment is delivered and over what timescale?



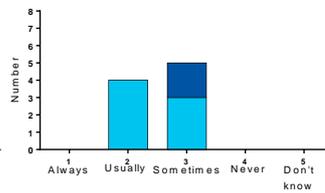
5d) Do patients, their families/ carers receive the right training, information and support to enable them to become fully involved in making decisions about their nutritional treatment?



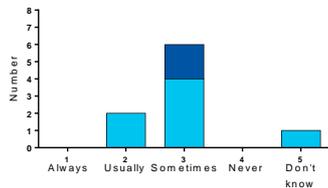
5e) Do patients receive nutritional treatment and care that is tailored to their own needs?



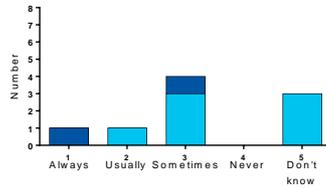
5f) Do patients experience problems with continuity of care during their journey from one setting to another, e.g. hospital to home?



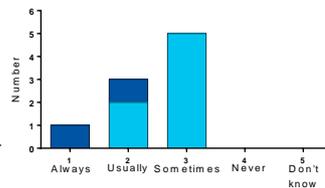
5g) Do patients experience follow-up problems with those services catering for their needs?



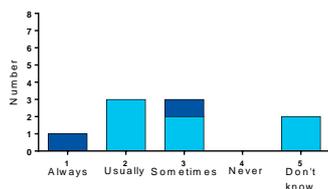
5h) Can patients managing more complex treatments at home (such as parenteral nutrition, enteral feeding) access information and support from healthcare professional out of usual working hours and at weekends?



5i) Do the healthcare professionals dealing with patients and families/carers have the right training, competence and confidence in delivering nutrition and hydration services?



5j) Do patients, their families/ carers receive the right training, information and support to help them to comply with their treatment safely?



5k) Do patients, their families/ carers, feel confident and safe in the place where they are receiving their treatment?

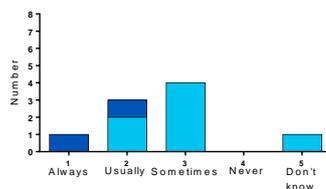


Figure 2 Responses to questions 5a–5k from individuals involved with non-governmental (lighter blue) and governmental organisations (darker blue)

2.1 Roundtable discussion

Question 5a)

Are nutrition and hydration issues under-recognised and under-treated?

“Definitely!”

At the meeting it was suggested that healthcare professionals still tend to be reactive in treating the detrimental effects of malnutrition and dehydration, rather than proactive in preventing these conditions. The **UCLH** dietitian agreed that these issues need to be identified much earlier in healthcare systems, including hospitals, in order to prevent unnecessary infections, prolonged length of hospital stay and mortality.

Box 10 summarises the prevalence of malnutrition in care facilities according to the Nutrition Screening Week Survey^{34,35}. **Box 11** highlights that an understanding of the importance of hydration does not always translate into appropriate action in practice, and that despite knowledge of the risk factors in vulnerable groups such as older people^{36,37} dehydration remains an important problem³⁸, with economic implications associated with utilisation of hospital resources, according to the NHS Institute of Innovation and Improvement³⁹ and the NHS Information Centre⁴⁰.

Box 10 Prevalence of malnutrition among patients admitted to hospitals, care homes and mental health units^{34,35}

‘Malnutrition’ was found to affect:

- More than 1 in 4 adults on admission to hospitals.
- More than 1 in 3 adults admitted to care homes in the previous six months.
- Up to 1 in 5 adults on admission to mental health units in the UK.

Most of those affected were in the high risk category.

Russell CA, Elia M. Nutrition Screening Surveys in UK Hospitals, 2007-2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.

Russell CA, Elia M. Nutrition Screening Survey in the UK and Republic of Ireland in 2010. A report by BAPEN: BAPEN, 2011.

Box 11 Risk factors for dehydration in the elderly and utilisation of hospital resources

Although nurses may understand the importance of hydration, the reports from the CQC, Health Service Ombudsman and the Patients Association demonstrate that this does not always translate into clinical practice³⁸. (based on *Campbell N (2011) Dehydration: why is it still a problem? Nursing Times: 107.2212-15*)

Risk Factors in Older People^{36,37}:

- Reduced sense of thirst
- Female gender
- Onset of dementia
- Fear of incontinence linked to oral fluid intake
- Medications, in particular diuretics.

Source: Wakefield et al (2009) Mentis (2006)

Resource use^{39,40}:

NHS Institute for Innovation and Improvement (2010) and NHS Information Centre (2011)

Question 5b)

Are patients and their families/carers, sufficiently involved in making decisions about their nutritional treatment?

Some concerns were raised during the discussion about the limited involvement of patients and their families/carers in decision-making. The following quotation and case study (**Box 12**) help to illustrate these concerns, as well as the grave consequences of malnutrition if it is not detected and treated appropriately.

“Patients are not involved in decisions about their care including those about nutrition.”

“Definitely not as good as it should be” said **MENCAP**.

Although healthcare professionals are experts in their own personal circumstances and bodies, they do not appear to have the same respect for those with a learning disability. This can make it hard for patients with learning disability to express their own

preferences or to make choices. In such cases, extra time must be allocated to consultations and advocates, such as family members, friends or trained health advocates, must be allowed to participate in the discussions.

Box 12 Case Study (Death by Indifference)

Martin had a severe learning disability and no speech. This case study summarises the 26 days he spent in hospital following a stroke when he went without food. The hospital failed to use a feeding tube at the critical time to prevent his condition from deteriorating dangerously. This left him too weak to undergo surgery to have a feeding tube inserted into his stomach.

Martin had a stroke and was sent to hospital, where he contracted pneumonia. He had trouble swallowing after his stroke and so was visited by a speech and language specialist. But Martin's swallow reflex did not return. He could not take food or water orally and so he was put on a drip. He did not tolerate the drip well and he sometimes pulled it out. During the second week of his hospital stay Martin was still unable to eat, and the drip was not providing him with adequate nutrition. He was visited and tested several times by the speech and language team, which recorded in its notes that he should remain 'nil by mouth' and that 'alternative feeding methods should be considered'. However, no action was taken. This situation continued into a third week, but by this time, his veins had collapsed, which meant that the doctors couldn't even get the limited amount of glucose from his drip into his body. So, they decided it was appropriate to insert a feeding tube into his stomach using a surgical procedure. However, by the time they had made this decision, Martin had been without nutrition for 21 days and his condition deteriorated so much that he was in no state to undergo an operation. Five days later, Martin died.

The hospital admitted that it did not act on information that Martin was at 'high risk' on the 'Malnutrition Universal Screening Tool' (MUST) scale, and that it did not follow its own enteral feeding policy, which states that alternative feeding methods should be considered after seven days.

The hospital carried out an internal investigation. This found that there had been a multidisciplinary communication failure, which resulted in the doctor being 'under the impression' that the nurses had been feeding Martin via a naso-gastric tube when this was not the case. There had been a complete breakdown of communication, resulting in Martin being without food for 26 days before he died.

Based on *Death by Indifference – MENCAP (2007)*

PINNT noted that when the patient is a child, the family unit is usually given ample time to talk through the problems and to receive the necessary support. This process is facilitated by having an appropriate patient/healthcare professional staff ratio. Difficulties commonly start to occur when teenagers have grown up to the point when they are suddenly expected to cope on their own with the practical, emotional and psychological problems of their condition. This transition period often throws up some of

the most difficult problems, which may not be handled well, either by the healthcare professionals or the families.

Question 5c)

Are patients, their families/carers, aware that they have a right to expect to be involved in making decisions and choices regarding treatment options, where that treatment is delivered and over what timescale?

As recipients of services, patients and patient groups recognise that they have a responsibility to themselves and to the support group they represent to become informed, and to pass on the necessary information, including that associated with 'training'. In this way both they and others can benefit from the knowledge and experience they have gained. The quotation below highlights the importance of this attitude in relation to the transition from paediatric to adult services:

"In the 'Let's run a 'go and see' campaign' adult teams go and learn from paediatric teams about how they engage patients and families in decision-making."

The NICE quality standard on nutrition support in adults (**Box 13**) also helps to emphasise the importance of these issues.

Question 5d)

Do patients, their families/carers receive the right training, information and support to enable them to become fully involved in making decisions about their nutritional treatment?

While examples of high quality care were acknowledged to exist (e.g. a self-management programme involving patients with cancer at NHS Glasgow and Clyde), the participants felt there was room for improvement.

"Being given an information booklet is not enough", said **BLT**. Appointments in hospital are stressful and many cannot take in all the spoken and written information provided, particularly if they have had to wait, undergo tests and receive bad news. It is important that someone takes the time to go through the written information at a pace that matches the individual patient, according to their physical and emotional circumstances at the time. Even more importantly, the patient needs to know when and where to obtain further support and information to reinforce the messages and establish confidence that the treatment will deliver the agreed results.

Box 13 The NICE Quality Standard for Nutrition Support in Adults

The NICE quality standard for Nutrition Support in Adults, issued in November 2012, requires that all care services take responsibility for the identification of people at risk of malnutrition and provide nutritional support to everyone who needs it. An integrated approach to the provision of services is fundamental to the delivery of high quality care to adults who need nutritional support. It is particularly important that nutrition support services are multidisciplinary and overseen and led by senior level staff from across settings, for example through nutrition steering groups or committees.

The quality standard should be read in the context of national and local guidelines on training and competencies. Implementation of this quality standard is dependent on all care professionals involved in providing nutritional support to adults being appropriately trained and competent to deliver the actions and interventions described in the quality standard. The quality standard is accompanied by an explanatory document for patients.

NICE (2012) Quality standard for nutrition support in adults, available at:
<http://publications.nice.org.uk/quality-standard-for-nutrition-support-in-adults-qs24>

QS24 Nutrition support in adults: information for patients available at:
<http://guidance.nice.org.uk/QS24/PublicInfo/pdf/English>

There appears to be some variation in both the presentation and type of information received by patients receiving artificial nutritional support, as indicated by **Box 14**.

Box 14 Variation in the presentation and type of information received by patients

In PINNT's experience the type of information and the way it is presented varies from hospital to hospital. Some provide good written resources and allow sufficient time for each patient to consider the information and to ask specific questions. However, many of the enterally fed patients PINNT comes into contact with receive little or no information about the placement of a feeding tube, which makes them feel 'removed' from the decision-making process. On the other hand, many PINNT members report that they receive an abundance of information upon discharge from hospital, and when a homecare company provides part of their care package they receive even more written information.

Patients may not understand all the written information they are given about home artificial nutrition. Discharge from hospital represents a time for patients to focus on their understanding and needs, but when asked if they have 'everything they need and understand it all?' many automatically reply 'yes'. When they realise they need specific information, they turn to the written material only to find it confusing and unclear, which means that they are unable to obtain the answer to their query (at least not in a way they can understand). For this reason many patients come to PINNT seeking guidance on how to interpret the written materials they have received.

PINNT

Question 5e)

Do patients receive nutritional treatment and care that is tailored to their own individual needs?

Participants felt that there was at least some room for improvement in the provision of personalised care.

"Providing generic information from a booklet is totally inadequate. It is often only tailored for the most extreme cases. But it is also variable dependent on the person giving the advice."

The information provided to patients with liver problems, which may concern lifestyle and dietary habits, is too generic, or unclear, said **BLT**. Liver problems can have extremely serious consequences, including death, or the need for transplantation. However, these outcomes and the management pathways are often not explained well to patients. Those

with liver problems need customised information and ongoing support, which they do not always receive.

Question 5f)

Do patients experience problems with continuity of care during their journey from one setting to another e.g. hospital to home?

During the roundtable discussion, continuity of care was identified as a key problem for many of the patient groups.

‘Continuity of care is only useful if that care is good!’

Continuity of care was identified as a major problem for all patient groups represented, not only when moving between one setting and another, but also when moving from paediatric to adult care. Both of these may involve different services, but these are not always coordinated.

MENCAP noted that people with a learning disability are often not given enough information to help them manage transitions. Patients feel that not enough time is given by health and care teams to ‘hand over’ information on aspects of their lifestyle that really matters to them. The arrangements needed to ensure a high quality experience require some improvement, and the aspirations expressed in the government report³ ‘Nothing about me without me’ are still not a reality.

BLT’s commented that while information may be handed over, there may also be inadequate follow-up:

‘It feels like a ‘tick box’ exercise and that once the paperwork is completed, that’s that!’

PINNT’s experience is that transition between settings can be a challenge, leaving both families and the individual concerned anxious and feeling isolated. Healthcare professionals need to recognise that patients and their carers are far more ‘expert’ about the impact of their condition and their treatment on their daily lives than the professionals.

‘Patients experience these issues 24/7/365, whereas healthcare professionals don’t.’

This means that in order for healthcare workers to execute their professional responsibilities they need to recognise that the transition from one care setting to another or from one service to another provides an ideal time for listening and sharing

knowledge. The type of problem that may arise during the transition from children to adults is illustrated by a case study below (**Box 15**).

Box 15 Case Study (Transition from children to adults)

“Overnight my healthcare changed. One day my family were involved in every aspect of my care; they were present for all my appointments, they had a say in what the next steps would be and they were instrumental in helping me to achieve the goals and objectives set out.

Next thing, I was officially an adult and everything was different. I was expected to attend all appointments on my own, to take on board everything that they recommended and make decisions on my own. I was scared and nervous of every decision that I made and felt totally out of my depth.

If I had been given a more structured handover from child and adolescent services to adult services this would have been easier to manage and would have allowed me time to build my confidence in making decisions.”

***HEN (Home Enteral Nutrition) patient, 33 years old, male
PINNT***

Question 5g)

Do patients experience follow-up problems with those services catering for their needs?

Only a limited roundtable discussion took place on follow-up problems, but some of these issues are captured in other parts of the report.

“Sometimes it feels that healthcare professionals paint the worst picture focusing on the negatives of a condition – maybe even fear-mongering. What patients need, especially the most vulnerable, is positive empowerment.” MENCAP

Question 5h)

Can patients managing more complex treatments at home (such as parenteral nutrition, enteral feeding) access information and support from healthcare professionals out of usual working hours and at weekends?

The roundtable discussion identified the need for specialist advice on the management of complex and acute problems, but the experience of patient groups suggests that the quality of that the advice, even when it is about accessing that advice, was variable. It was recognised that the NICE quality standard on nutrition support in adults made a specific recommendation that specialist ‘out of hours’ advice should be available for

problems associated with home enteral tube feeding and home parenteral nutrition²³. Below is a summary of the sentiments raised during the discussion, and a case study that illustrates the concerns of one patient on home parenteral nutrition (**Box 16**).

“Patients with complex problems need access to specialist advice 24 hours.”

“Having your care team’s mobile number can be a lifeline but you don’t want to use it unless it’s absolutely necessary.”

Some patients and their families are managing highly complex therapies at home and issues can arise at weekends and out of hours when staff may not be available.

PINNT stated that although patients *may* have access to healthcare advice, they may also have uncertainties and concerns about the quality of the advice and information. The advice may vary according to the expertise and knowledge of the staff member they talk to. Many usually have access to dedicated staff with knowledge of their complex needs. However, as a consequence of poor advice patients may defer seeking help or advice until the next morning or next working day, which could be detrimental to their well-being or safety.

Some patients and their families are given information at the start of their treatment and at intervals thereafter, but because of their underlying condition they may not comprehend the importance of that information. Many feel that the information provided is too generic and does not answer all their questions. Furthermore, although some patients are able to speak up they often do not do so because they feel it is inappropriate. It is only when they have an unusual experience at home that they refer to the information provided, if they can locate it. If they are unsure about what to do, all too often they do nothing so as not to ‘worry the doctor or nurse’ with what might be a non-urgent problem. They wait, with the potential risk that their condition and situation get worse. Additionally, some patients and families are given contact numbers and information for ‘out of hours’ service that simply do not work. When they try to obtain advice from health professionals they may encounter difficulties, as the case study in **Box 16** illustrating a patient seeking advice about how to manage a blocked central venous catheter used to administer intravenous nutrition.

Attending a local Accident and Emergency department for complex treatments such as parenteral nutrition can also pose problems, as the staff often have little or no experience of these therapies and are ill-equipped to deal with them. Additionally, the voice of the ‘expert patient’ and their family/carer is often ignored or dismissed, leaving them feeling disempowered and belittled. Healthcare professionals may provide advice and support outside NHS premises and they may do so using a mobile phone on a one-to-one basis. Some of them are uncertain whether such ‘out of hours’ services are regulated and whether they have ramifications when complications develop. There should be

clarity on all these issues, especially since they may not be as straightforward as they first appear. Some out of hours cover for home enteral and parenteral nutrition is provided by home care companies but they were not represented at the meeting.

Box 16 Case Study (A problem with a central venous catheter)

“As an HPN patient who is at home and is self-caring, I noticed that over time my central line was not flushing as smoothly as normal. Typically the central line blocks on a Friday night.

I contacted my usual hospital and come Saturday morning I had still not heard back from them. I knew I was unable to manage another night without fluids and so I called the hospital back. As I had had no response from the on-call number I rang the ward and was told the doctors were busy but they would call back. Hours passed and nothing. I rang again and was told the same.

Then I decided to ring PINNT as I felt presented with a dilemma of waiting or going to the local accident and emergency department. I felt that at my local hospital they do not understand about my CVC [Central Venous Catheter], so I was worried.

After my call with PINNT, I rang the hospital back and after insisting that I hold on the phone and wait for the doctor, I finally received the right advice and support.”

HPN patient, 48 years old, female

PINNT

Question 5i)

Do the healthcare professionals dealing with patients and families/carers receive the right training, competence and confidence in delivering nutrition and hydration services?

While good training in delivering high quality nutrition and hydration care was acknowledged, it was felt that there was also room for improvement. There were indications that the issue may be difficult to assess and address, since it became apparent that some patients are somewhat ‘afraid’ to ask questions. This may be due to inherent difficulties for certain patients in asking questions, but it may also be due to the attitude of healthcare workers that can make patients reluctant to ask questions. In either case the healthcare worker should be aware that such problems could develop, with detrimental effects on patient care, and that appropriate steps can be taken to prevent them.

“This is so variable, dependent on staff numbers and their level of training and experience.”

In PINNT's experience, the answer across the system is sadly not a resounding 'yes'. There are pockets of very high quality services and pockets of very poor quality services. Patients 'expert' in their condition and therapy often wait until they can access the right level of support, if at all possible. There needs to be more training at a local level in order to establish more uniform high quality care. However, if staff do not have regular opportunities to put this knowledge into practice then the benefits of the training may be lost. PINNT recognises that this is a difficult issue to solve. It also recognises that the training should be 'fit for purpose'.

Young people accessing services for long standing health problems such as Type 1 diabetes may also be afraid to ask for extra help and support, especially if they think that they are considered by healthcare professionals to be both knowledgeable and satisfied with their treatment. The healthcare professionals must recognise that such patients need to be given time to discuss issues of potential concern, and to 'never assume' a level of comfort or expertise without checking.

Question 5j)

Do patients, their families/carers receive the right training, information and support to help them comply with their treatment safely?

Meeting attendees agreed that the training provided to patients and their families/carers to help them comply with treatment was very variable and that this issue was addressed within the context of other topics.

Question 5k)

Do patients, their families/carers, feel confident and safe in the place where they are receiving their treatment?

PINNT noted that the majority of patients and their families/carers feel confident and safe in the place they receive treatment, but unfortunately just one 'poor' incident between a patient (or their family/carer) and a healthcare professional can cause a loss of trust between them, possibly hampering communication. Such a situation may arise because one or both parties misunderstand each other or because the goals and expectations of treatment have not been adequately explained.

Key points emerging from the questionnaire and discussion about the patient experience are summarised in **Box 17**.

Box 17 Key points (The patient experience)

1. Healthcare systems and professionals must be more proactive in addressing nutrition and hydration issues. They should not only react to problems when they arise, but also take measures to prevent problems from arising.
2. Where systems are in place to screen patients for particular problems such as malnutrition then it is vital not only to treat the patients, but also to monitor and follow them up.
3. Each patient, along with their family/carer, must be treated individually because one size does not fit all.
4. Always check, and never assume that a patient is comfortable with the information and advice provided.
5. Patients and their families/carers must also play a proactive role by informing themselves and asking questions of health professionals about issues that they are not clear about, preferably in circumstances where a good working partnership exists between the parties involved.
6. The transition period between one care setting and another must be planned and managed well by both sides as it can set the 'tone' for the rest of that patient's experience of adult services.
7. Provision of out of hours service must not be a 'tick box' exercise. It must work for both parties.
8. All patients on complex therapies must be 'trained' and supported to recognise when an urgent situation exists, and that training must be reinforced regularly.

3. Inequalities

3.1 Results of survey (Question 6)

Question 6)

Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to:

a) Location (geography)?

b) Lack of attention to ethnic, religious or cultural differences?

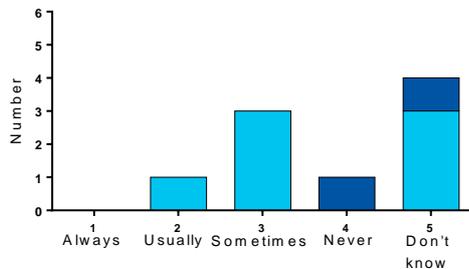
c) Communication or language difficulties?

d) Disabilities such as mobility or flexibility issues affecting treatment options?

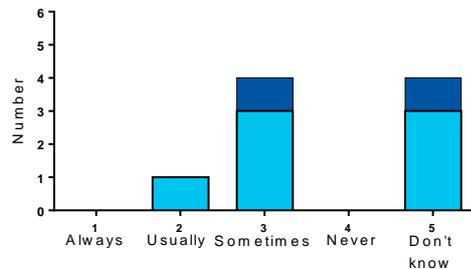
Most individuals indicated that patients and their families/carers experience differences (inequalities) in the quality of the nutrition and hydration care they receive from the services. In response to question 6 (Q6; **Figure 3**) the answer was mostly 'usually' or 'sometimes', although in a substantial proportion it was 'don't know'. These inequalities were related to location and lack of attention to ethnic, religious and cultural differences, as well as communication or language difficulties and disabilities. The individual responses summarised in **Figure 3** are based on the answers provided to question 6 (Q6).

Q 6. Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to:

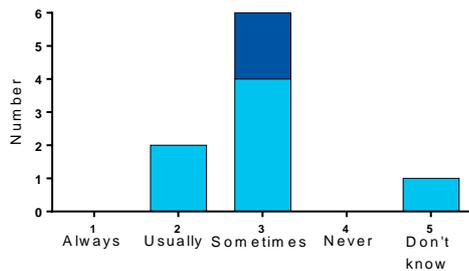
a) Location (geography)



b) Lack of attention to ethnic, religious or cultural differences



c) Communications or language difficulties



d) Disabilities such as mobility or flexibility issues affecting treatment options

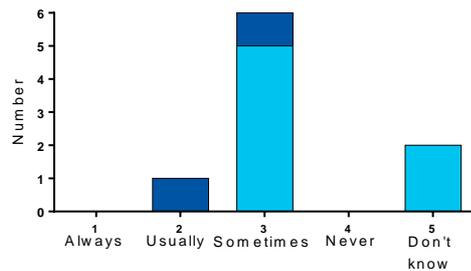


Figure 4 Responses to questions 6a–d from individuals involved with non-governmental (lighter blue) and governmental organisations (darker blue)

3.1 Roundtable discussion

Question 6)

Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive?

The roundtable discussion at the meeting confirmed the results of the questionnaire in showing wide variation in dealing with nutrition and hydration problems, These variations or inequalities affected all four domains mentioned in question 6 (Q6; **Figure 3**), namely location, cultural and religious diversity, communication and language, and mobility and flexibility. Each domain is considered separately below, after an initial and brief consideration of the importance of attitudes and methods of communication.

“How they tell you is crucial.”

Studies have clearly demonstrated that there is huge variability in the overall ‘quality’ of the patient and family experience of care services. The **PA** raised some concerns about this issue (**Box 18**).

Box 18 (Postcode lottery)

Based on the information received through the Patients Association helpline wide variations in the way the NHS services are being provided across the country have been identified. Inequality continues to distort healthcare in this country. How can it be that 11% of cancer deaths could have been avoided if survival rates were the same for poorer people as they are for richer people? This persistent and damaging disparity between rich and poor is truly alarming. Similarly, due to inconsistent decision-making processes the access to treatments is also quite varied based on geographical location. We need to get rid of this dangerous postcode lottery for good.

Patients Association

The problem is also evident from the Dignity and Nutrition Inspections by the Care Quality Commission, which showed that although many hospitals met the basic national standards when they were inspected, many only partially met the standards and others did not meet the standards (**Box 19**).

Box 19 (Variable standards of care according to CQC's Dignity and Nutrition Inspections (DANIs) of hospitals)

The Report on 100 hospitals inspected on Outcome 1 (Respecting and Involving People in Services) and Outcome 5 (Meeting Nutritional Needs) indicated that:

- 45 hospitals met both standards and were fully compliant
- 35 hospitals met both standards but needed to improve in one or both
- 20 hospitals did not meet one or both standards.

For Outcome 5 significant inconsistencies were found between two wards in the same hospital, with one being fully compliant and the other non-compliant or giving cause for serious concern.

Based on CQC's DANIs: Inspection Programme: National Overview, October 2011

http://www.cqc.org.uk/sites/default/files/media/documents/20111007_dignity_and_nutrition_inspection_report_final_update.pdf

This variability may be due to differences in resources, training and experience of staff, as well as to the attitude of the staff on duty. The variation may also be due to practical problems resulting in long delays before a person is seen by a healthcare worker. This is more likely to happen during exceptionally busy periods, or at weekends when staff/patient ratios are often reduced.

Since 'attitude costs nothing', healthcare professionals on the one hand and patients and families/carers themselves on the other, should respect each other and endeavour to 'put themselves in each other's shoes' and appreciate the stresses they are under.

Timely information can also help prevent the development of adverse relationships between patients and professionals. Updated information, even if it provides no solution, is preferable to no information at all.

MENCAP stated that unfortunately the quality of care experienced by people with a learning disability was still an absolute 'lottery'. With the devolvement of commissioning at a local level and the current reorganisation of the NHS, it was felt that the situation will not improve and it was feared it will get worse. Without centrally established and

enforced standards of care involving patient perspectives, the work of voluntary organisations can become very difficult. What hope has an organisation dealing with vulnerable people of making its voice heard across the hundreds of local commissioning groups and other fragmented services?

The importance of the role of learning disability nurses in helping achieve good practice has been emphasised by the Michael Report⁴¹ and a report by the Royal College of Nursing⁴². However, the number of learning disability nurses halved between 2002 and 2012 (**Box 20**).

Box 20 (Learning disability nurses are valued but their numbers are decreasing)

Approximately 1.4 million people in Britain are living with a learning disability (MENCAP). Despite the fact that these people are “58 times more likely to die before the age of 50 than the general population” (Michael Report, 2008)⁴¹, between 2002 and 2012 the number of learning disability nurses in the UK was cut dramatically. Although it is difficult to ascertain exact numbers, the Nursing and Midwifery Council estimated that there was a 34% decrease in the number of community learning disability nurses, and 51% in other disability nurses. People with a learning disability often have multiple, layered, physical and mental health needs. With the added complications of issues relating to communication, behavioural challenges, autism spectrum disorders, mental illness and early onset dementia, this group experiences particular vulnerabilities when accessing and receiving healthcare” (Royal College of Nursing, 2011)⁴². The work of learning disability nurses ensures that their clients still receive an effective and high standard of healthcare that includes:

- Undertaking comprehensive assessments of health and social care needs.
- Enabling equality of access and outcomes within health and social care services.
- Providing advice, education and support to people with learning disabilities and their carers throughout their care journeys.
- Providing education and development opportunities for other practitioners on the needs of people with learning disabilities.
- Acting to safeguard and protect the rights of people with learning disabilities when they are vulnerable and in need of additional support (Royal College of Nursing, 2011)

www.mencap.org.uk/all-about-learning-disability/information-professionals/more-about-learning-disability

Michael Report (2008) Healthcare for All: Report of the independent inquiry into access to healthcare for people with learning disabilities. London. HMSO.

Royal College of Nursing (2011) Learning from the past – setting out the future: Developing learning disability nursing in the United Kingdom. An RCN position statement on the role of the learning disability nurse. London. RCN.

Nutrition nurses are also highly valued and many of them belong to the National Nurses Nutrition Group (NNNG) (**Box 21**), which aims to promote education in nutrition and related subjects for members of the nursing profession for the public benefit, and especially for the benefit of patients in the hospital and community.

Box 21 National Nurses Nutrition Group (NNNG)

Around half of the National Nurses Nutrition Group's 300 members are specialist nutrition nurses. These nurses are located widely across the British Isles and a few of them outside the British Isles.

Question 6a)

Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to geography/location of services?

Access to healthcare can be a problem, especially for patients requiring specialist services provided at only a few centres, which can be a long way from the patients home. Indeed, with the centralisation of specialised services into 'centres of excellence', the impact on patients and their families/carers can be considerable, as can be gleaned from the following summary of the roundtable discussion that took place.

BLT stated that some patients who live in Wales have to travel to Birmingham for their appointments and treatment, and patients living in Cornwall are required to travel to London to see their specialist team. These are just two examples of the long distances patients need to travel for treatment. Many have long and awkward journeys to make, which may not be easy, especially for those who are not at all well. In addition, the journey has to be worthwhile as the personal and financial cost can be considerable.

For **PINNT** patients, many of whom do not live close to their referred centre, travel for routine and emergency appointments can be extraordinarily difficult. Early morning appointments, delayed appointments and unexpected appointments pose challenges both in relation to timing and financial expense. In addition, a change in residence may require a change in the type of hospital providing care, which can also cause problems (**Box 22**).

Box 22 Case Study (Changing hospitals)

“I have recently changed hospitals due to moving and find myself well cared for but without a dedicated nutrition nurse. I do feel that this leaves me feeling vulnerable; the ward nurses are good but they are not as expert as my previous nutrition nurse. I find myself waiting for communication due to the busy ward when a simple call back could easily solve an issue and prevent things getting more complicated.”

HPN patient, 48 years old, female
PINNT

Question 6b)

Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to religious/cultural diversity?

With regard to cultural and religious diversity, **UCLH** stated that their trust places a good emphasis on special diets. Such diets are included in the standard menus available on all wards. However, some patients and their families bring in their own food, reflecting the vast array of cultures seen within the London population in particular.

The meeting noted however that not all hospitals allow patients and families to bring in their own food. Since no formal data are currently available on this issue, it would be useful to conduct a survey on this topic.

BLT observed that many district and more rural-based hospitals do not see such diversity and therefore their catering systems do not have the capacity to routinely deal with special requests catering for different cultures.

Question 6c)

Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to communications and language?

The roundtable discussion about communication and language difficulties was initiated by **MENCAP**, which supports patients with greatly variable capacities to communicate appropriately.

“Nutrition information and support is critical at all stages of all diseases and must be communicated well.”

MENCAP stated that for individuals with profound and multiple learning disabilities who have a limited capacity to communicate, there is a need to engage with them using materials with appropriate images, which should be available in hospitals, and to communicate with them using accessible language that ensures patient understanding and engagement in choices. Some hospitals are well set up to use this approach, but others are not. A 'Hospital Passport' can help (**Box 23**), but this depends how well it is completed.

MENCAP also noted that people with a learning disability can sometimes feel under pressure to 'comply' or agree with the person asking the questions (social desirability of complying), particularly if that person is in a position of authority. It is important that healthcare staff are aware of this and are adequately trained to ensure that the answers given by patients accurately reflect or take into account their true feelings and choices.

PINNT added that although it seems obvious, it takes time to help those less able to communicate effectively. For example, when a person admitted to hospital after a stroke is asked about his preference for food, he may reply with no understanding of the answer he has given.

BLT agreed that for anyone in a vulnerable position, there is a tendency to comply and take the 'route of least resistance'. They don't want to be a 'problem' or a 'burden' or to ask too many unnecessary questions, or to be put in a position that encourages us to state that they understand when in fact they don't.

Sometimes, **PINNT** noted, it is useful to consider using tactics such as dressing comfortably for appointments at hospital, as this can give the patient a feeling of equality with the staff and put them at ease during the appointment, helping open lines of communication.

Question 6c)

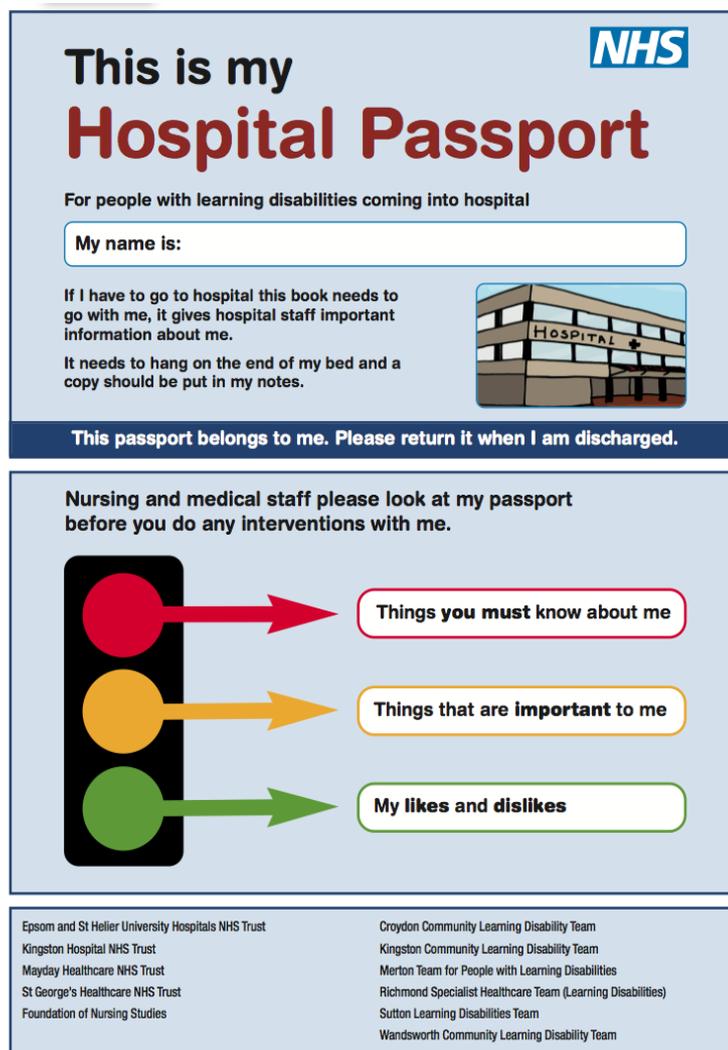
Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to mobility and flexibility

The roundtable discussion on mobility and flexibility ranged widely, from the attitudes of healthcare workers towards patients with disabilities to availability of toilets in public places. Healthcare assistants were urged not to assume that the weight of patients in wheelchairs is irrelevant to their care.

MENCAP stated that it knows of incidences where wheelchair users have not been weighed because healthcare assistants assume that it does not matter whether they are under- or over-weight. In fact it matters very much, both for the individual, since it is relevant to their well-being, and also for those caring for them. Most wheelchair users do not spend the whole of their lives in wheelchairs: they move around by themselves or with the help of others. The ease with which this is done can depend on their body weight and its composition.

Box 23 Hospital Passports

The advantages of hospital passports are that they communicate some key information about an individual and provide a quick reference point for hospital staff. The traffic light system is particularly useful as it clearly indicates the most important information, which may include allergies, whether someone is a risk of choking and other relevant medical history. The key disadvantages are that there is no standard health passport, so that their quality and content varies. Also, hospital staff are not always aware of the passports, which means that they do not make use of them as a resource.



An example of a front cover of a Hospital Passport
[www.easyhealth.org.uk/listing/hospital-passports-\(leaflets\)](http://www.easyhealth.org.uk/listing/hospital-passports-(leaflets))

MENCAP is part of a consortium which leads an ongoing campaign, known as ‘Changing Places’, to ensure the availability of fully accessible toilets (**Box 24**) in all large public places and especially in places where the demand for such facilities is greatest, including venues where people have meetings and appointments to discuss health, housing and social care.

With regard to the need for easily accessible toilets, **BLT** added that in order to avoid the need to use a toilet, patients may stop drinking water and other drinks so they are not ‘caught out’ which may lead to the development of dehydration.

Box 24 The ‘Changing Places’ programme

‘Changing Places’ toilets are specially equipped, safe, and clean, with enough space for disabled persons and their carers. Without such facilities thousands of people around the UK would have to change on cramped and potentially dirty floors, or would be forced to only go out for short periods of time, if at all. There are currently 529 Changing Places toilets in the UK. The 500th opened at the O2 in Greenwich, London, in May 2013. Within the next three years ‘Changing Places’ hopes to double that figure and campaigns are currently ongoing around the country to introduce these toilets to shopping centres, hospital, service stations, and transport hubs.

<http://www.changing-places.org/Default.aspx>

Some of the key points emerging from the questionnaires and the roundtable discussion on inequalities and nutritional care are summarised in **Box 25**.

Box 25 Key points (Inequalities in nutritional care)

- Service provision and the experience of patients and their families are variable across the NHS.
- The most vulnerable patients often experience the greatest inequalities.
- Communication is a key issue in the care of vulnerable people, and so it is necessary for healthcare workers to allow sufficient time to exchange information and to be creative in the method of communication when required.
- Hospital Passports may help to capture core information for healthcare professionals but they need to be complete and accurate.
- Healthcare organisations in less urban areas often have less experience of the attitudes of diverse populations.
- The weight status of patients in wheelchairs should not be dismissed as being irrelevant to care.

4. Surveys and reports (Question 7)

Question 7)

What surveys, reports or publications relevant to nutrition and hydration has your organisation produced within the last 5 years and are currently available?

We plan to list these in our Report.

Details of some of the surveys and reports on nutrition and hydration produced by the organisations involved in the roundtable discussion are indicated in Appendix 2 (web links provided).

5. Other issues

Two other topics were discussed during the meeting which did not feature in the questionnaire. The first was whether health trusts and patients share the same priorities,

and second was whether patient involvement in nutritional self-screening was feasible and practical.

5.1 Do health trusts and patients share the same priorities?

a) Workshop

At the meeting a short workshop about priorities in healthcare was coordinated by Ailsa Brotherton. Although she represented the Malnutrition Task Force at this roundtable discussion, she has also been working with a group of trusts aiming to establish common priorities in healthcare. She indicated that the nutritional priorities proposed by a group of trusts fell into four categories: screening, individual care plans, implementing care and ongoing monitoring (e.g. fluid intake, which has been found to be assessed by nurses with an accuracy of only 50%). Attendees at the meeting were divided into four groups and then asked to discuss the following question:

Do these four priorities/categories 'chime' with what patients want? And if not –

1. What do you want us to do first for your patients/groups?
2. How do you want us to do this?
3. How should we evaluate what we do?

Four key issues were identified from the first session:

1. Identify nutritional issues much sooner
2. Recognise complexity
3. Establish high quality information and communicate it
4. Undergo a culture change to embrace listening and allocating more time to it.

b) Group discussions

Participants were then asked to identify the one priority that would make a real difference to the patient experience. Specifically, they were asked to address the following question:

What single change in daily practice would 'chime' with patient/family priorities?

A range of responses were provided:

1. To be treated as an individual not just another patient.
2. Improvement in hospital food.
3. Practical initial point of contact.
4. Privacy when answering personal questions and ensuring that appropriate data are gathered at first practical initial point of contact.

5. Encouragement of patients to reach their goals as individuals, not the goals of national targets and standards.
6. Establish hospital passports with top line information, e.g. disabilities, allergies and personal preferences, such as dislike of certain types of food.
7. Improve accessibility of information from GP to Accident and Emergency services; reduce unnecessary duplication of information and activities; check patient understanding:
 - Ensure the GP writes things down so that they can be checked by the patient afterwards.
 - Encourage patients to write down the questions that need to be asked of the doctor.
8. Ongoing care post discharge.
9. Seek clarity on collective responsibilities with more effective interaction between patient and professional. This activity can be supported by the creation of a simple flyer with common questions and answers. It can be designed for use by all by describing what the organisation does and can offer, and how patients can help themselves and the system.

It is clear that many different priorities exist and to address them all would require considerable resources. At the meeting there was an awareness of national recommendations for patient representation at all levels within healthcare organisations²⁹, which would help implement the most important priorities.

Box 26 Key points (Priorities in nutritional support vary)

- A wide range of different priorities for changes in nutritional support services were identified, which means that a single change is unlikely to satisfy all patients and their families/carers.
- Multiple changes at multiple levels are required to bring about the 'achievable' care requested by patients and their carers/representatives.
- It is recommended that there should be patient representation at all levels in healthcare organisations, from boards to wards, in line with other national recommendations

5.2 Patient involvement: Is self-screening feasible and practical?

Marinos Elia introduced the topic of self-screening by discussing the importance of nutritional screening. He raised the possibility that patients could become involved in the process by measuring their own height and weight, which are key components of several screening tools including the Malnutrition Universal Screening Tool (MUST). Interest in this area has been increased by work in which the subject stands on an instrument that measures weight, height and calculates BMI automatically, so that screening can be undertaken quickly and reliably⁴³.

Two questions were asked at the meeting:

- 1) Can this system be accurate or reliable?
- 2) Would it be acceptable to patients and their families and individuals and would they be happy to use it?

BLT said 'yes' to giving patients ownership and access to a reliable automatic system, which avoids errors associated with establishing and relaying correct information. Technology limits room for error.

PINNT expressed some concern by asking the following question: 'How far will self-screening go?' It may not be suitable for everyone and must therefore not be applied to everyone or replace the interaction that occurs between patient and healthcare workers. The term 'self-screening' has strong clinical connotations associated with activities normally undertaken by healthcare workers. It would be helpful to consider using a different term that gives the impression that patients are helping create their own private profile of data that is relevant to their care. In this way they can have a greater sense of ownership and involvement in their own care.

It was generally agreed that self-screening would not be suitable for everyone; for example, for those patients with confusion, dementia and physical problems that prevents them from standing on a weighing scale/stadiometer. As in other areas of patient care, healthcare workers need to provide a rationale for the tests or procedures undertaken and to discuss the results with the patients and/or carers/family members. The discussion at the meeting did not focus on self-screening at home where the equipment may not be accurate and reliable, or on patients already receiving nutritional support.

The key points emerging from the discussion on self-screening are listed in **Box 27**.

Box 27 Key points (Self screening)

- Self-screening using appropriate equipment is feasible and potentially valuable as a practical procedure for obtaining accurate and reliable information.
- It is necessary to explain to the patient the reasons for undertaking self-screening and to discuss the results with them and/or their carers.
- Self-screening is not suitable for all types of patients.
- Consideration should be given to replacing the term 'self-screening' with another term that conveys greater ownership by the patient based on building a personal profile and greater involvement of the patient in their own care.

6. Closing the gap

A discussion took place about closing the gap between the professional agenda and that associated with patient experience and needs. It involved a consideration of the priorities for healthcare professionals emerging from patients'/carers' perspective, dominated by their own experiences and needs. The following list summarises the main points that emerged from this discussion.

- Attitude is cost free.
- Your open, positive, friendly approach can help overcome my worries or difficult situations.
- Please treat me as a person not as a problem, or just as a diagnosis or a service user.
- Manage my expectations by sharing information regarding timing, tests and outcomes – and share information about any delays or changes in management.
- Allow extra time for initial consultations so that matters can be explained well.
- Make key information about each patient/person accessible to the whole team.
- Staffing levels need to be adequate.
- Effective communication is essential.
- Use plain language.
- Check my understanding.

Box 28 Key points (Closing the gap)

- To reduce discrepancies in attitudes between healthcare workers and patients/carers, healthcare workers should think about developing a more open and friendly approach by taking time to explain the problems and treatment in a simple way using plain language and checking the patients'/carers' understanding.
- The following phrases which emerged during the discussion capture the sentiments: 'attitude is cost free'; 'treat me as a person and not just a problem or a diagnosis or a client/user' and 'manage my expectations'.

7. Limitations and relevance of this report

If the path towards patient-centred care is to progress in a constructive way to satisfy the public, it is necessary to develop a pathway of care that has a sound infrastructure with a broad evidence base. This should take into account a wide range of perspectives, from clinical to public health perspectives, as well as from individual to societal perspectives. Since this report focuses only on the clinical perspectives of patients and families/carers and the nutritional care they receive, it is necessary to contextualise the findings into a broader framework of thinking. For example, it is necessary to balance and integrate the clinical needs of patients and carers with public health needs, which may have different priorities.

A relatively small number of organisations were involved in this project (n=11), which may not be representative of all patient or carer organisations. Although the findings, conclusions and recommendations in this report are based on information that was reported rather than practised, the information provided nevertheless reflects a reality to patients/carers, which is important to clinical practice. Indeed the patient experience and the patient point of view (PREMs or Patient Reported Experience Measures; and PROMs or Patient Reported Outcome Measures) are increasingly being used to formulate key performance indicators to assess the quality of clinical and social care. At the very least, the report indicates that there are some concerns about current nutritional care which have been voiced by a range of individual organisations from a patient/carer perspective.

It is clear from the survey and discussions that there is room for improvement that would help in the quest towards achieving routine patient-centred nutritional care. Larger studies with more organisations would allow more robust results to be established using both clinical and statistical evaluations.

It is noteworthy that several messages on nutritional support coming from patients, carers and their advocates are consistent with those made generally in other areas of health and social care. Therefore, many of the recommendations made in this report about nutritional care probably have wide implications to healthcare as a whole. Some of the roundtable discussion involved aspects of social care, but an in-depth evaluation of social care issues was not undertaken during the roundtable discussion. These issues are important enough to deserve separate consideration in their own right, however the interface between social care and healthcare is by no means clear.

Finally, in order to bring about the multiple aspirational changes alluded to in this report a culture change is required, analogous to that recommended in the Francis Report. Some of the changes can be achieved readily in routine care through better understanding and respect of patient needs. Other changes may require considerable extra time, effort and human resources, which can be in high demand in clinical practice. These areas need to be explored carefully so that a pragmatic solution can be achieved.

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Further reading and web links

1. NHS Patient Experience Framework: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/215159/dh_132788.pdf
2. Shared decision making in the NHS:
 - (i) *The NHS Right Care Shared Decision Making project*: www.rightcare.nhs.uk/index.php/shared-decision-making/
 - (ii) *The Health Foundation's MAGIC* www.health.org.uk/areas-of-work/programmes/shared-decision-making/
 - (iii) *Co-Creating Health programmes*: www.health.org.uk/areas-of-work/programmes/co-creating-health/
3. Improving the experience of care for people using NHS services: summary of NICE guidelines: <http://www.ncbi.nlm.nih.gov/pubmed/?term=flynn+improving+the+experience+of+care+for+people+using+nhs+services>
4. Quality standards on nutrition: <http://guidance.nice.org.uk/QS24>

Acknowledgements

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Appendix 1: Survey Questionnaire

Nutrition and Hydration Survey – Priorities, Services, Patient Experiences	
About your charity, patient or population group	
Your name:	
Your position:	
Your email & phone numbers:	
Charity/group name:	
Charity/group address:	
Charity/group website:	
Are you a membership organisation? Yes / No	Do you have a Helpline? Yes / No
Do you have an online forum? Yes / No	Do you conduct surveys? Yes / No

Note: please make *one choice only* when you answer the questions below and select your answer by highlighting your answer in yellow like this – **Very high**. Thank you!

Nutrition and Hydration Services – priorities and trends over time	
Question 1	<p>How high a priority are nutrition services and malnutrition and dehydration issues:</p> <p>a. In your own organisation?</p> <p>Very high High Neutral Low Very Low Don't know</p> <p>b. In government and policy circles?</p> <p>Very high High Neutral Low Very Low Don't know</p> <p>c. Among the public?</p> <p>Very high High Neutral Low Very Low Don't know</p>
Question 2	<p>In the last 5 years have delivery and experience of nutrition and hydration services improved or not?</p> <p>Improved a lot Improved The same Worse A lot worse Don't know</p>
Question 3	Are nutrition and hydration services regulated and inspected appropriately?

	Very well	Well	Poorly	Very poorly	Don't know
Question 4	<p>In the last 5 years has there been a change in the priority given to nutrition services and the issues of malnutrition and hydration:</p> <p>a. In your our own organisation</p> <p>Greater priority No change Lower priority Don't know</p> <p>b. In government and policy circles</p> <p>Greater priority No change Lower priority Don't know</p> <p>c. Among the public</p> <p>Greater priority No change Lower priority Don't know</p>				
The Experience of your Patient or Population Group of Nutrition and Hydration					
Question 5	<p>a. Are nutrition and hydration issues under-recognised and under-treated?</p> <p>Always Usually Sometimes Never Don't know</p> <p>b. Are patients and their families/carers, sufficiently involved in making decisions about their nutritional treatment?</p> <p>Always Usually Sometimes Never Don't know</p> <p>c. Are patients, their families/carers, aware that they have a right to expect to be involved in making decisions and choices regarding treatment options, where that treatment is delivered and over what timescale?</p> <p>Always Usually Sometimes Never Don't know</p> <p>d. Do patients, their families/carers receive the right training, information and support to enable them to become fully involved in making decisions about their nutritional treatment?</p> <p>Always Usually Sometimes Never Don't know</p> <p>e. Do patients receive nutritional treatment and care that is tailored to their own individual needs?</p> <p>Always Usually Sometimes Never Don't know</p>				

	<p>f. Do patients experience problems with continuity of care during their journey from one setting to another, e.g. hospital to home?</p> <p>Always Usually Sometimes Never Don't know</p> <p>g. Do patients experience follow-up problems with those services catering for their needs?</p> <p>Always Usually Sometimes Never Don't know</p> <p>h. Can patients managing more complex treatments at home (such as parenteral nutrition, enteral feeding) access information and support from healthcare professionals out of usual working hours and at weekends?</p> <p>Always Usually Sometimes Never Don't know</p> <p>i. Do the healthcare professionals dealing with patients and families/carers have the right training, competence and confidence in delivering nutrition and hydration services?</p> <p>Always Usually Sometimes Never Don't know</p> <p>j. Do patients, their families/carers receive the right training, information and support to help them comply with their treatment safely?</p> <p>Always Usually Sometimes Never Don't know</p> <p>k. Do patients, their families/carers, feel confident and safe in the place where they are receiving their treatment?</p> <p>Always Usually Sometimes Never Don't know</p>
<p>Question 6</p>	<p>Do your patients, their families/carers experience differences (inequalities) in the nutrition and hydration services they receive due to:</p> <p>a. Location (geography)?</p> <p>Always Usually Sometimes Never Don't know</p> <p>b. Lack of attention to ethnic, religious or cultural differences?</p> <p>Always Usually Sometimes Never Don't know</p> <p>c. Communication or language difficulties?</p>

	<p>Always Usually Sometimes Never Don't know</p> <p>d. Disabilities such as mobility or flexibility issues affecting treatment options?</p> <p>Always Usually Sometimes Never Don't know</p>
Your organisation's publications, reports and information about nutrition and hydration	
Question 7	<p>What surveys, reports or publications relevant to nutrition and hydration has your organisation produced within the last 5 years and are currently available? We plan to list these in our Report.</p> <p>1.</p> <p>2.</p> <p>3.</p> <p>None available</p> <p>What reports or publications relevant to nutrition and hydration are your organisation planning to produce in the next 2 years?</p> <p>1.</p> <p>2.</p> <p>3.</p> <p>None</p>
<p>Comments: Please add here any further relevant comments and issues that you wish to be considered for discussion at our meeting on 14 March 2013.</p>	
<p>Many thanks for taking the time to complete our Survey. Please return your completed Survey by email to rhonda@minervacomms.net by 27 February 2013 in preparation for our meeting on 14 March 2013.</p>	

Appendix 2: Organisations Involved

British Association for Parenteral and Enteral Nutrition



BAPEN is a charitable association that raises awareness of malnutrition and works to advance the nutritional care of patients and those at risk from malnutrition in the wider community. BAPEN brings together the strengths of its Core Groups to raise awareness and understanding of malnutrition in all settings and provides education, advice and resources to advance the nutritional care of patients and those at risk from malnutrition in the wider community. BAPEN's Core Groups include:

- Dietitians – The Parenteral and Enteral Nutrition Group of the British Dietetic Association (PEN Group)
- Doctors and Scientists
- BAPEN Medical (mostly doctors)
- The British Society of Paediatric Gastroenterology, Hepatology and Nutrition (BSPGHAN)
- Nurses – National Nurses Nutrition Group (NNG)
- Patients – Patients on Intravenous and Nasogastric Nutrition Therapy (PINNT)
- Pharmacists – British Pharmaceutical Nutrition Group (BPNG)

Its committees include:

- Malnutrition Action Group
- Clinical Guidance and Education
- Programmes
- Quality Group
- Special Interests Group

BAPEN works with all stakeholders, including patients and professionals, healthcare commissioners and providers at local, regional and national levels, and industry to deliver the nutritional agenda.

BAPEN members are passionate about ensuring that good nutritional care is delivered in all health and social care settings and have established the 'BAPEN 4 Tenets of Good Nutritional Care'.

Recent surveys and reports on Nutrition and hydration include:

1. Brotherton A, Simmonds N, Stroud M. Malnutrition matters: meeting quality standards in nutritional care. Redditch: BAPEN, 2012.
2. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Northern Ireland, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
3. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Wales, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
4. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in Scotland, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
5. Russell CA, Elia M. Nutrition Screening Surveys in Hospitals in England, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.
6. Russell CA, Elia M. Nutrition Screening Surveys in UK Hospitals, 2007–2011: A report based on the amalgamated data from the four Nutrition Screening Week surveys undertaken by BAPEN in 2007, 2008, 2010 and 2011: BAPEN, 2014.

www.bapen.org.uk

Patients on Intravenous and Nasogastric Nutrition Therapy



Imagine being unable to nourish your body from normal food and drink...

Instead you have to rely on liquid nutrients being pumped or infused into your body through a tube. This may be enteral or parenteral. This is your lifeline. Hopefully you won't be in hospital but will be in the comfort of your own surroundings.

We welcome and work with healthcare professionals, industry (in relation to products and services) and the general public and of course, PINNT members, both adults and children.

Our aims are to:

- Promote greater understanding of the therapies amongst patients, potential patients and the medical profession
- Provide contact between patients
- Work towards improving homecare services and range of equipment
- Have a united voice to campaign for a better, flexible and safer service

Over the years we have not only brought together patients from around the world, but also doctors, nurses, pharmacists, dietitians and other healthcare professionals, and industry, as well as other charities working in the field of artificial nutrition worldwide.

<http://www.pinnt.co.uk/>

<http://pinnt.com/Home-Artificial-Week/Archive.aspx>

Alzheimer's Society



Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website and more than 2000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive

Alzheimer's Society report – Counting the Cost (2009) examines the variation in the quality of dementia care provided on general hospital wards. It found that the lack of help with eating and drinking was the biggest area of dissatisfaction among carers of people with dementia. Carers complain that the person with dementia might not eat or drink in hospital as there is nobody to prompt them. One carer reported that hospital staff complained that the person with dementia left all their food, despite the carer explaining that the person with dementia needed support to eat.

www.alzheimers.org.uk/site/scripts/download_info.php?downloadID=356

Belong



Belong is a charitable organisation that provides high quality, specialist care for older people in the North West, and are recognised market leaders in dementia care. Belong villages provide a continuum of services that offer a 'home for life' including:

- Households providing 24-hour nursing care
- Apartments where people continue to live independently
- A village centre with a range of facilities open to the public
- Belong at Home domiciliary care

<http://www.belong.org.uk/>

British Liver Trust



The British Liver Trust is Britain's only national charity for adults with all forms of liver disease, existing to improve the lives of people affected by all liver conditions. Our key roles are in education and awareness, support and research. We aim to improve knowledge of the liver within the general public and the medical profession; to provide support through our information line, website, publications and the facilitation of support groups nationwide; and to co-ordinate funding/provide support for research.

Our 'Diet and liver disease' publication can be downloaded via our website www.britishlivertrust.org.uk or a hard copy can be sent by request via telephone 01425 481230 and email info@britishlivertrust.org.uk

The Crohn's in Childhood Research Association



The Crohn's in Childhood Research Association (CICRA) is dedicated to creating a wider understanding of Crohn's Disease and ulcerative colitis, particularly as it affects children and young adults. It raises funds to support approved medical and scientific research aimed at finding more effective treatments and an eventual cure. In addition to research,

CICRA offers support to children, young people and their families affected by Crohn's or colitis by organising three meetings each year, one in London and two in different regions of the UK. These days offer parents, children and young people an informal day of meeting others and learning more about their condition including 'meet the expert' sessions.

<http://www.cicra.org>

CORE (the Digestive Disorders Foundation)



Core (the Digestive Disorders Foundation) is a national charity working to fight all diseases of the gut, liver and pancreas. We support research that increases our understanding of disease leading to cures and improved outcomes, we provide evidence-based information to patients enabling them to take control of their condition, and we work to raise awareness of digestive conditions.

Core regularly funds research projects that cover the areas of nutrition:
www.corecharity.org.uk/archive/research-projects/nutrition-diet.

We are also part of the 'Love Your Gut' group, a collaboration with the IBS Network and Yakult which promotes good gut health linked to diet and nutrition. There are more details at www.loveyourgut.com.

Dementia UK



Dementia UK is a national charity, committed to improving quality of life for all people affected by dementia.

We promote and develop Admiral Nursing, through partnerships with host organisations.

Dementia UK also runs a national helpline and email service [Admiral Nursing DIRECT](#), which is for family and professional carers, people with dementia and those worried about their memory. Call 0845 257 9406 or email direct@dementiauk.org.

Malnutrition Task Force



The Malnutrition Task Force is an independent group of experts across health, social care and local government united to address the problem of preventable malnutrition in older people. The Task Force was established in June 2012 to influence behaviours across the NHS, residential care and in the community, developing mechanisms and collating examples of how to identify, prevent and minimise the risk of malnutrition.

We have drawn together principles of best practice and developed a framework to help those working in health and care settings make the changes needed to counter malnutrition. A series of guides have been developed for hospitals, for care homes, for food and beverage providers and for local communities. All of these can be downloaded from our website.

www.malnutritiontaskforce.org.uk

MENCAP



MENCAP support 1.4 million people with a learning disability in the UK and their families and carers. They fight to change laws and for improved services and access to education, employment and leisure facilities, supporting thousands of people with a learning disability to live their lives the way they want to. MENCAP is one of the largest providers of services, information and advice for people with a learning disability across England, Northern Ireland and Wales.

www.mencap.org.uk

Death by indifference (2007)⁴⁴

www.mencap.org.uk/sites/default/files/documents/2008-03/DBIreport.pdf

Death by indifference (2012) Progress Report⁴⁵

www.mencap.org.uk/sites/default/files/documents/Death%20by%20Indifference%20-%2074%20Deaths%20and%20counting.pdf

The Patients Association



The Patients Association is a healthcare charity which for 50 years has advocated for better access to accurate and independent information for patients and the public; equal access to high quality healthcare for patients; and the right for patients to be involved in all aspects of decision-making regarding their healthcare.

By listening to patients, we are able to campaign to improve services. We will work with all healthcare providers to improve services. Very often patients think they are alone with the problem or complaint they have. When patients talk to us we are able to track problems arising in more than one place and realise there is a nationwide issue that needs change.

www.patients-association.com

www.thecarecampaign.co.uk

University Hospitals London Hospitals NHS Foundation Trust

University College London Hospitals 
NHS Foundation Trust

UCLH is one of the largest NHS trusts in the United Kingdom and provides first-class acute and specialist services in six hospitals. The Dietetics Department at UCLH is involved in

providing effective, evidence-based nutritional assessment, dietary advice and support to patients, their carers and all staff involved in patient care. The department offers an in- and out-patient service to all six hospitals. The team consists of over of over 30 registered dietitians and two assistant practitioners providing expertise in a wide range of specialties.

<http://www.uclh.org/Pages/home.aspx>

Wrightington, Wigan and Leigh NHS Foundation Trust

Wrightington, Wigan and Leigh 
NHS Foundation Trust

Wrightington, Wigan and Leigh NHS Foundation Trust is a major acute trust serving the people of Wigan and Leigh in North West England. The trust employs over 4000 staff and has approximately 750 beds across three hospital sites and a state-of-the-art outpatients centre.

The Royal Albert Edward Infirmary in Wigan is a redeveloped modern District General Hospital providing a base for emergency and acute healthcare. Leigh Infirmary is our elective diagnostic and rehabilitation site. Wrightington Hospital is a specialist centre for orthopaedic surgery.

The trust is consistently delivering harm free care to >95% of patients as measured by the NHS Safety Thermometer and the work to improve nutrition and hydration is believed to be a contributory factor.

<http://www.wwl.nhs.uk/>

Meeting Attendees – London 25th April 2013

BAPEN/MAG	Marinos Elia (co-chair)
BAPEN	Ailsa Brotherton
British Liver Trust	Sandy Forsyth
MENCAP	Clare Lucas
Patients Association	Michael Watson
UCLH	Kassie Montanheiro
PINNT	Carolyn Wheatley (co-chair)
PINNT	Steve Brown

Charities and Patient Groups – Survey Participants

Admiral Nurses	Julia Botsford
Alzheimer's Society	Laura Cook
Belong Wigan	Rebecca Woodcock
British Liver Trust	Sandy Forsyth
CICRA	Margaret Lee
CORE	Jon Smalldon
Malnutrition Taskforce	Margit Physant
MENCAP	Clare Lucas
Patients Association	Michael Watson
PINNT	Steve Brown
WWL NHS Foundation Trust	Andrew Foster

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