

PN-DU consumer survey – findings and conclusions, August 2012

Purpose of survey and methodology

Parenteral Nutrition - Down Under (PN-DU) is an Australian/New Zealand consumer support group for adults on Home Parenteral Nutrition (HPN) and parents/carers of children on HPN.

In June 2012, PN-DU conducted a survey of its members. The survey asked for HPN consumers' opinions on the levels of compliance by Australian and New Zealand HPN centres with the published Australasian Society of Parenteral and Enteral Nutrition (AuSPEN) Clinical Practice Guidelines for HPN Patients in Australia and New Zealand (Nutrition 2008:24;998-1004) (the guidelines).

The survey included some introductory questions followed by questions relating to 10 different aspects of HPN. These correlated to the 10 topics covered in the guidelines.

The survey was seen as a pilot study of current PN-DU members, with a hope that AuSPEN might be willing to work with PN-DU to develop a more comprehensive questionnaire suitable for distribution amongst the entire HPN consumer population in Australia and New Zealand. This would inform the development of the next version of the guidelines and complement any parallel survey work being undertaken by AuSPEN and/or other professional societies with clinicians involved in HPN.

As far as possible, the wording of the survey questions was drawn from the terminology in the guidelines. This meant the survey was not always written in plain English, but PN-DU did not want to reframe technical terms into lay language without active involvement by the authors of the guidelines. This would be a valuable improvement to the survey if AuSPEN were to consider a wider roll out of the survey amongst all HPN consumers in Australasia.

Participation in the survey was entirely voluntary, anonymous and confidential. Some specific comments made by respondents have been withheld from this summary of the survey findings, as they could potentially identify individual respondents.

Introduction

A total of 15 consumers or carers started the survey with 13 completing all questions. Throughout the analysis that follows, we clarify how many respondents completed each series of questions.

Just over half the people who started the survey (8) were adults dependent on HPN, with the remaining 7 being parents or carers of a child on HPN.

For the purpose of this analysis, we refer to adult and child HPN patients as "HPN patients" unless we specify different trends between the adult and paediatric groups. In the case of the children on HPN, their parents or carers completed the survey, but the survey findings relate to the patient, hence the findings are reported from the perspective of the patients.

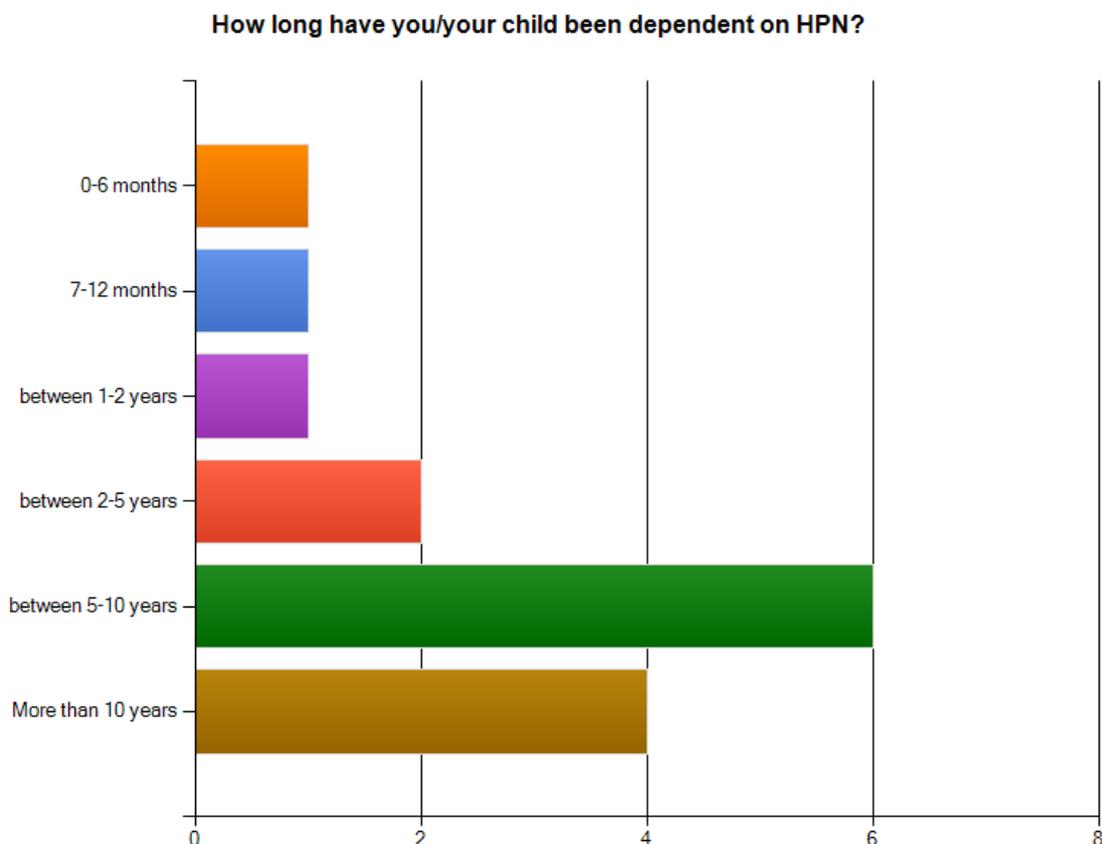
About the group that completed the survey

Many have been on HPN for a long time (refer to figure 1). Ten (67%) patients have been dependent on HPN for over five years, with four (26%) of these on HPN for more than 10 years. This is significant as 10 of the

respondents were established on HPN therapy before the guidelines were published. In a larger survey, it would be useful to disaggregate responses from patients who started HPN from 2008 onwards, as compared with those who started HPN therapy earlier.

All patients live in Australia or New Zealand. To protect patient privacy, locations and treating hospitals have been withheld from the report of survey findings.

Fig 1: length of time on HPN



Starting on HPN

This section of the survey reveals that treating hospitals, in the main, provided care at the standards outlined in the AuSPEN HPN guidelines (noting that 10 of the patients started on HPN before the guidelines were published). Of the 14 patients that responded to this set of questions it was reported that before commencing HPN: 11 (79%) received a diagnosis of intestinal failure, 12 (86%) were reviewed by a team with expertise in intestinal failure, and 11 (79%) reported that attempts were made to establish enteral nutrition.

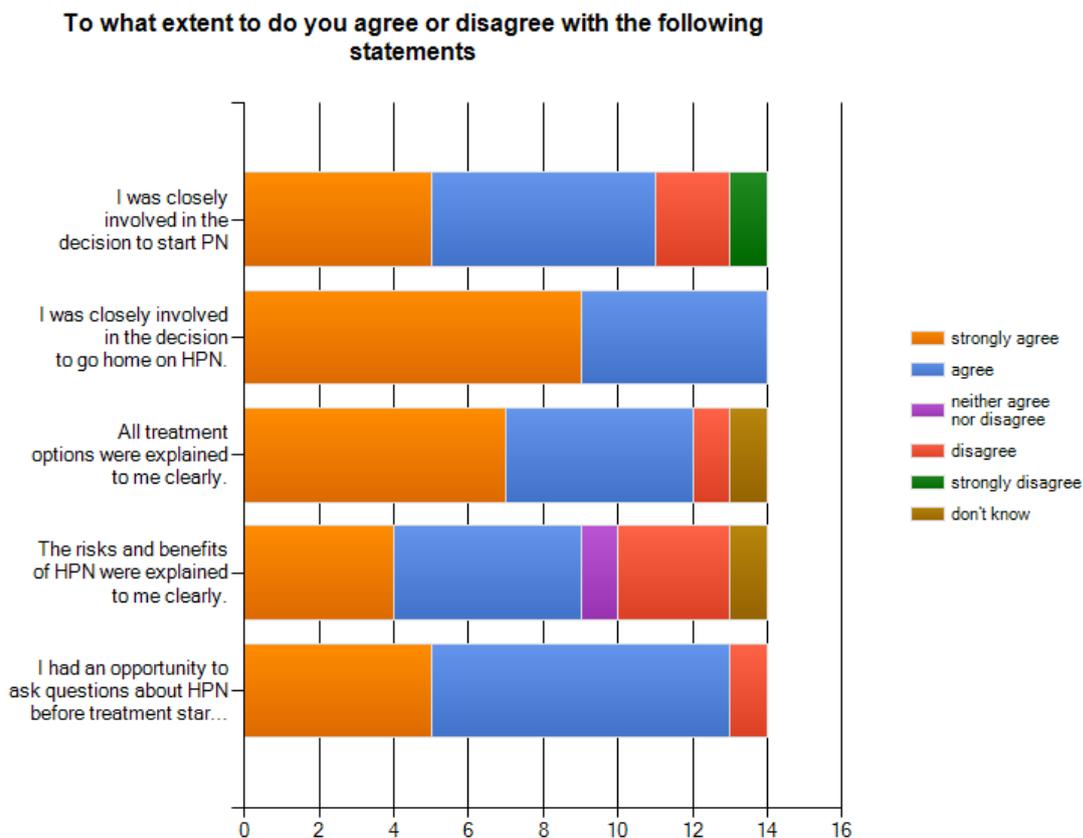
Notably, **all** patients (100%) reported they were closely involved in the decision to go home on HPN (see fig 2, below). The majority of patients also reported that: they were involved in the decision to start PN; had available treatment options explained to them; had the risks and benefits of HPN clearly explained to them; and had the opportunity to ask questions about HPN before treatment started.

Whilst overall this section of the survey highlights quite high compliance with the AuSPEN guidelines, it is nonetheless concerning that any patient would report: not having had the risks and benefits of HPN explained to them (3 out of 14 respondents, or 21%); not having all treatment options explained nor the

opportunity to ask questions (1 out of 14, or 7%); not being closely involved in the decision to start PN (3 of 14, or 21%).

If this survey were to be rolled out amongst the wider Australasian HPN consumer population, it would be interesting to probe these responses further. For example, it is possible that some adult patients may have been too unwell to be involved in initial decision making about starting PN. (Of the three patients that were not closely involved in the decision to start PN, two were adults).

Fig 2. Patient involvement in starting and going home on PN



Preparing to go home

As with the section “Starting HPN”, this section should be read in the context of 10 patients having been trained and sent home on HPN prior to the publication of the guidelines.

a) Training

A positive finding is that all respondents to this series of questions (14 or 100%) reported having received training in managing HPN. Thirteen (93%) received training whilst inpatients, and one received training in community and outpatient settings. An expanded survey might probe the community-based training method further eg to determine what level of home nursing support was available until the patient achieved full competency in nursing a central line and preparing and administering HPN.

While it is positive that all respondents received training, the findings about the **content** of the training are concerning. Only half of all respondents were issued written information to take home and refer to. Given the high risk nature of nursing a central line and managing HPN, we would have expected patients to report

that their training covered all of the content areas covered in the AuSPEN guidelines. Responses are reproduced in full, below, at figure 3. Notably, less than half of the 14 respondents received training regarding the following high risk or life threatening situations: line blockages (5, or 36%); febrile episodes (6, or 43%); prominent veins (1, or 7%); and catheter fracture (4, or 29%). Of the eleven patients with external catheters (ie tunnelled or non-tunnelled central lines, as opposed to an implanted port), seven (64%) did not receive training in managing catheter fracture, and three (27%) of these were carers of paediatric patients – arguably, more at risk of snapping their central lines and, with less blood volume, making a rapid response even more critical.

These findings are concerning as they place patients in potential situations of high risk and leave HPN centres exposed in terms of having met their duty of care to HPN patients before discharge.

Fig. 3 – Training provided to patients

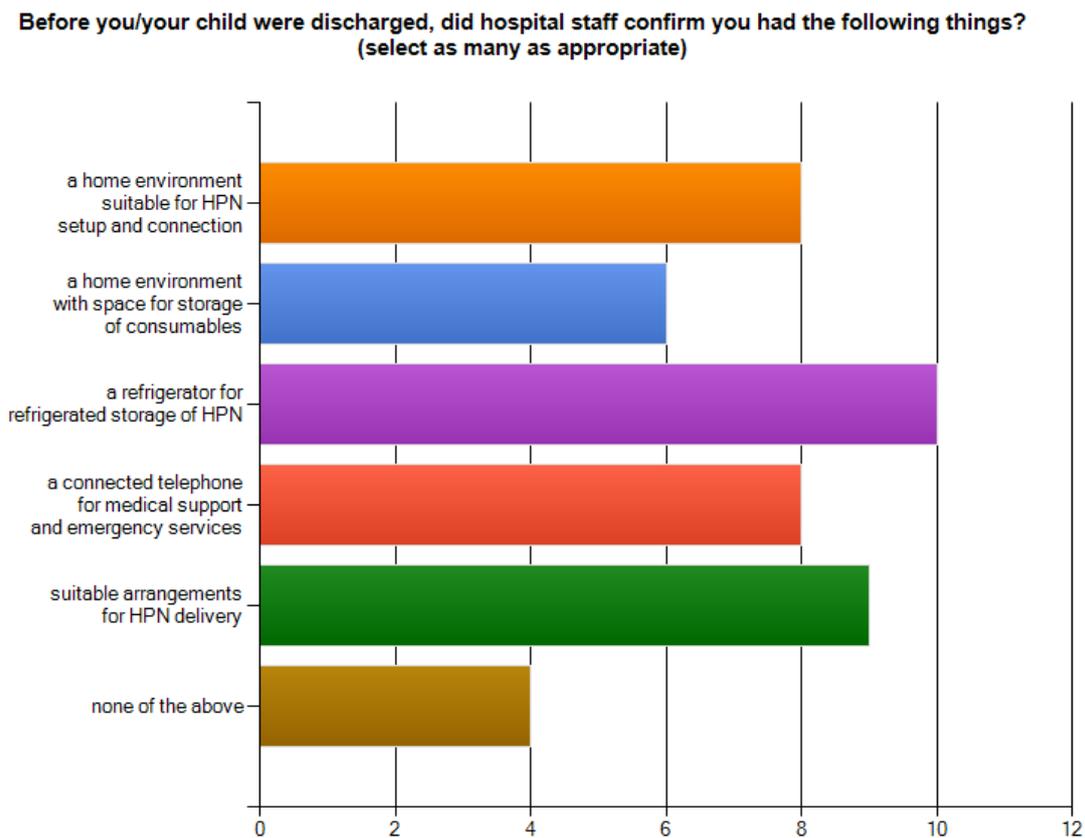
What did your training cover? (select as many responses as appropriate)	Response count	Percentage
I had to meet a checklist of criteria to demonstrate that I was competent to self-manage HPN.	9	64.3%
I was required to show an understanding of, and demonstrate, aseptic technique according to hospital guidelines.	12	85.7%
I was required to demonstrate safe delivery of HPN according to my hospital's nursing protocols for the administration of PN and nursing of a central venous access device guidelines	10	71.4%
I was given information about managing HPN to take home and refer to when I needed it.	7	50%
I was taught how to recognise and respond appropriately to line blockages	5	35.7%
I was taught how to recognise and respond appropriately to line breakages	4	28.6%
I was taught how to recognise and respond appropriately to febrile episodes	6	42.9%
I was taught how to recognise and respond appropriately to prominent veins	1	7.1%
I/my child was on a stable HPN regimen before I went home.	9	64.3%
none of the above	1	7.1%
answered question	14	

b) The home environment

The survey findings are similarly variable in respect of preparing a suitable home environment. As seen in figure 4, below, HPN centres were inconsistent in assessing whether patients had a suitable home set up, with four (29%) out of 14 respondents reporting that their HPN centre did not confirm any aspect of their home set up prior to discharge.

These aspects of home set up are fundamental to the safe management of HPN (eg a refrigerator, space for consumables, telephone connection). Again, failure to confirm these basic safety arrangements leaves patients at risk and leaves HPN centres exposed in terms of their duty of care to patients.

Fig 4. – home arrangements for the safe management of HPN



Ongoing care and monitoring

Written information

The first question in this series related to provision of written information, such as a care plan, medical summary, admission letter or referral to consumer support groups. Such information is important for patient reference and advocacy, but is also potentially lifesaving in terms of fast-tracking triage and hospital admission, particularly if patients are presenting to unfamiliar hospitals.

It is alarming, then, that five (36%) of 14 respondents reported they had not received any type of written information – two adult patients and three children. Just under half (43%) had received information to assist in expedited hospital triage and admission. Nine (64%) of the respondents had a written summary of their medical condition from their treating doctor. Only four (29%) patients had been made aware of patient

support groups. Written information is essential for ensuring prompt treatment in the event of emergency hospital presentations, where parents of sick children may be too distraught, or adult patients too unwell, to provide critical information to clinicians.

Multidisciplinary care

A positive finding is that nearly three quarters of respondents (10, or 71%) reported their care is provided by a multidisciplinary team, and in a centre with expertise in the delivery of HPN.

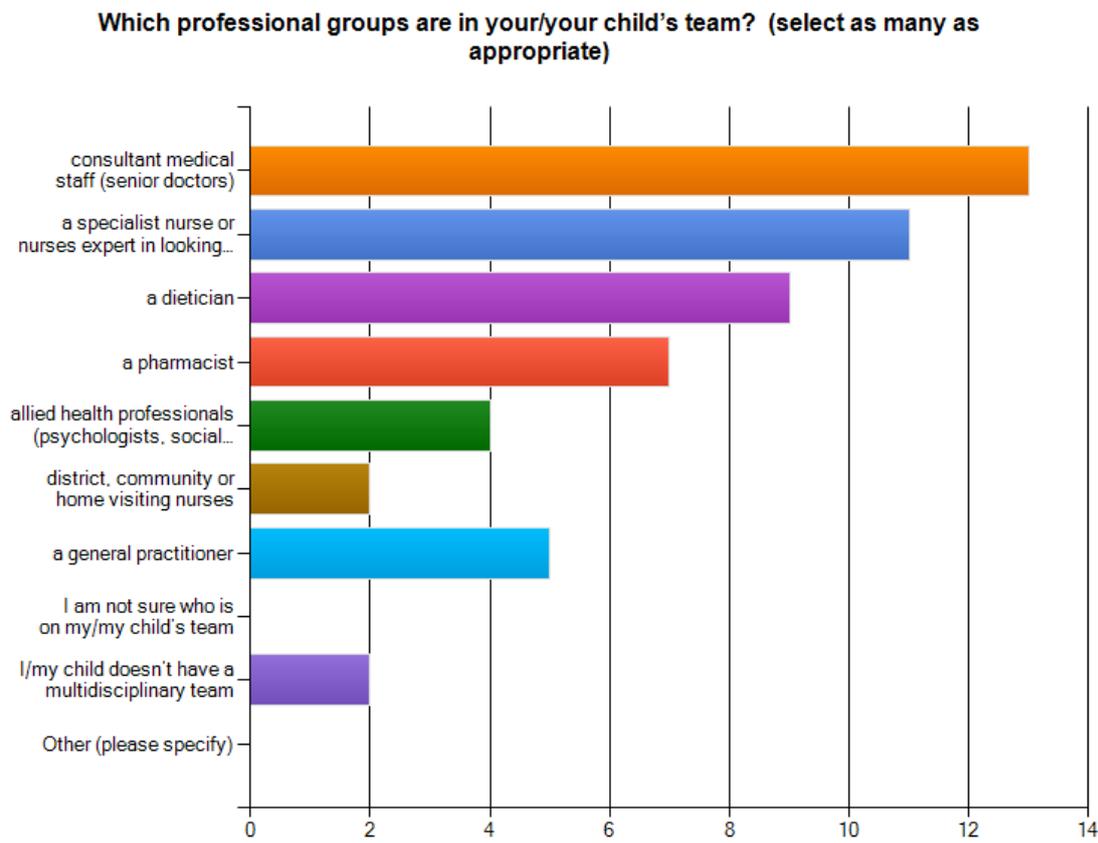
For all other questions in this series, about half of the respondents reported positively that: they have a senior doctor on their multidisciplinary team who is known to them (7, or 50%); a senior doctor provides coordination of HPN within the multidisciplinary team (8, or 57%); they had documented contact information for all hospital personnel with a significant role in their care (8, or 57%); were provided updated contact information when positions changed (7, or 50%); and knew all members of their team and were confident to contact them (8, or 57%).

The remaining respondents fell into one of two categories: either they responded with an equivocal “neither agree nor disagree” to the ensuing questions; or, in two cases (14%) they reported not having a multidisciplinary team at all, with subsequent answers reflecting this. This suggests some HPN centres could be doing better in providing multidisciplinary care and/or communicating the multidisciplinary nature of their patients’ care and making contact information available.

Figure 5, below, provides an overview of which disciplines were reported to be involved in each patient’s care. As might be expected, almost all respondents (13, or 93%) reported a senior doctor to be involved, and most (11, or 79%) reported involvement of a nurse specialist in HPN and central venous access devices. Two respondents (14%) reported they do not have a multidisciplinary team. The variable involvement of other health disciplines is of concern, given the centrality in particular of dieticians and pharmacists in safe HPN management.

Given the complex nature of HPN management across health care disciplines, it would be valuable to tease out these questions in any larger-scale survey to gain a better understanding of how patients perceive their care. It is possible that multidisciplinary coordination is occurring “behind the scenes” but not being communicated to patients.

Fig 5 – health professions reported to be involved in HPN multidisciplinary team



Central venous access

Types of devices

Thirteen patients responded to this series of questions. Ten (77%) had tunneled central venous catheters, 2 (15%) had an implanted port and 1 (8%) had a non-tunneled central line.

Choice, insertion and care of central venous access device

The experience of clinician-patient communication seems to be more positive in this area than in the areas of ongoing care and communication, reported above.

For more than half of the 13 respondents to this series, a positive experience was reported in terms of: being involved in selecting the type of central venous access device (8, 62%); having the type of device and the insertion site clearly explained by a skilled practitioner (9, or 69% with well over half responding “strongly agree”); having the technique for catheter insertion clearly explained (8, or 62%); and the need for weekly dressing changes being clearly explained (11, or 85%).

The only question which did not follow this predominantly positive pattern was that relating to whether the choice of skin antiseptic was explained to patients, where 6 (46%) responded positively. Given patients can have allergic and irritable reactions to some antiseptics, this is an area where it would be important for HPN centres to improve in patient communication.

Of course, the fact that **any** patients reported not being involved in decisions about the type of central venous access device, and not receiving clear explanations about the insertion process, remains a cause for concern.

HPN formulation and delivery

Formulation and logistics

Thirteen people responded to this section. Over half responded positively to three questions about HPN delivery and formulation: having their prescription regularly reviewed and modified as needed (9, or 69%); delivery in stout, temperature controlled containers at regular, predictable times and with drivers instructed about proper storage (8, or 62%); and easily being able to obtain additional items in the event of contamination or defective items (8, or 62%).

Three (23%) patients reported negatively (as opposed to neutrally) to the second and third questions relating to delivery and obtaining consumables. This is concerning given how fundamental these logistical aspects are to the safe management of HPN.

Freedom of movement

All 13 respondents reported they have time off HPN every day to enable freedom of movement and quality of life.

HPN pump and consumables

Pump

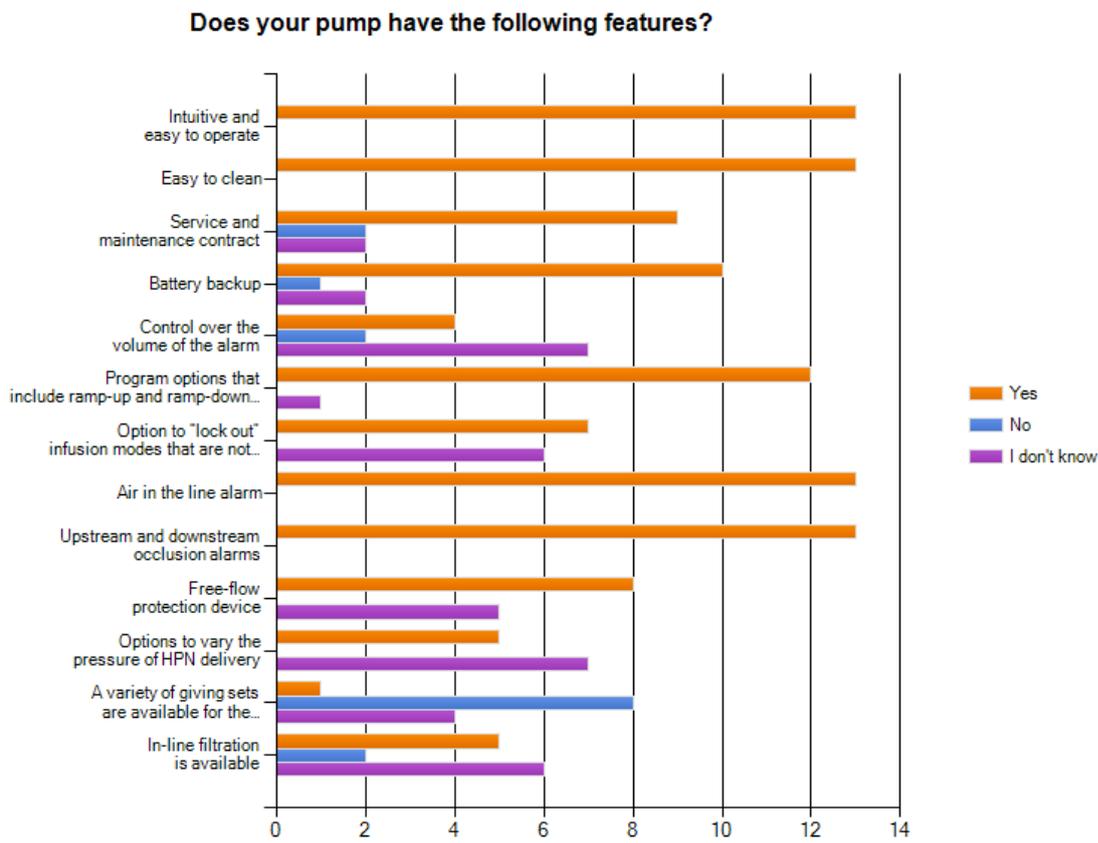
Twelve (92%) out of 13 respondents reported having an ambulatory pump. The one patient (8%) without an ambulatory pump was a child, which is concerning given children are unlikely to have either the physical strength or maturity to move safely with an IV pole. The survey followed up with a series of questions about the pump's features, drawn directly from the AuSPEN guidelines. All patients indicated their pump: was intuitive and easy to operate; easy to clean; had air in the line alarms and upstream and downstream occlusion alarms. However, a number of questions resulted in significant "don't know" responses, as seen in figure 6, below.

This suggests that a broader consumer survey (and possibly the guidelines themselves), would benefit from a plain English explanation of pump features. It may also suggest that patients are not receiving adequate training or information about their pumps. This is borne out by the follow up question about information and support.

Although ten patients (77%) had written instructions for their pumps, less than half (6, or 46%) had been required to demonstrate competence in using the pump before discharge, and less than half (6, or 46%) had been provided with further information and training when they were provided with a different sort of pump. Of most concern, only three (23%) patients reported they had contact details for a 24/7 pump troubleshooting service and zero (0%) patients reported they have been able to access an after-hours pump troubleshooting service.

This is alarming and a wider survey could probe this issue further to ascertain whether consumers have needed, tried and/or failed to obtain after hours support for their pumps in the event of malfunction.

Fig 6. HPN pump features



Managing complications with central venous catheters

This question raises some alarming issues about the level of information HPN patients have been provided prior to discharge. The question duplicates some of the information gathered in the section “Preparing to Go Home” but asks for more detail. This reflects the structure of the AuSPEN guidelines, but could be rationalised in a wider survey. PN-DU elected to reflect the structure of the guidelines rather than attempt to consolidate two sections of the guidelines into one set of questions for patients.

Reassuringly, 12 out of 13 (92%) respondents had been made aware of the signs and symptoms of central line associated bloodstream infections and the need to present to hospital urgently if an infection is suspected. However, less than half of patients reported having been given information about the remaining high risk and potentially life threatening complications highlighted in the AuSPEN guidelines. Four (31%) patients were informed of the signs and symptoms of thrombosis, while one (8%) patient reported not having been informed of any of these risks.

Of the eleven patients with tunnelled or non-tunnelled central venous catheters, five (45%) were not informed of the risk of catheter fracture, six (55%) were not advised of techniques for clamping in the event of fracture, and **none (0%)** were provided emergency management kits to deal with catheter fracture (eg sterile gauze, clamps and dressings).

Interactions between HPN and other medications

Thirteen patients responded to these questions. Nine (69%) were aware that some medicines may interact with HPN and lose their effectiveness. Eight (62%) reported that their pharmacist checked medications added to their HPN for compatibility and stability.

However, only one (8%) patient reported that their pharmacist checks other medications for compatibility with HPN before dispensing them and only four (31%) patients had been informed that oral medications could interact with HPN.

Responses to these questions perhaps reflect the fact that only half of respondents reported that a pharmacist was a member of their multidisciplinary team, and suggests an area for further focus in HPN centres.

HPN monitoring

Thirteen patients responded to this quite detailed series of questions.

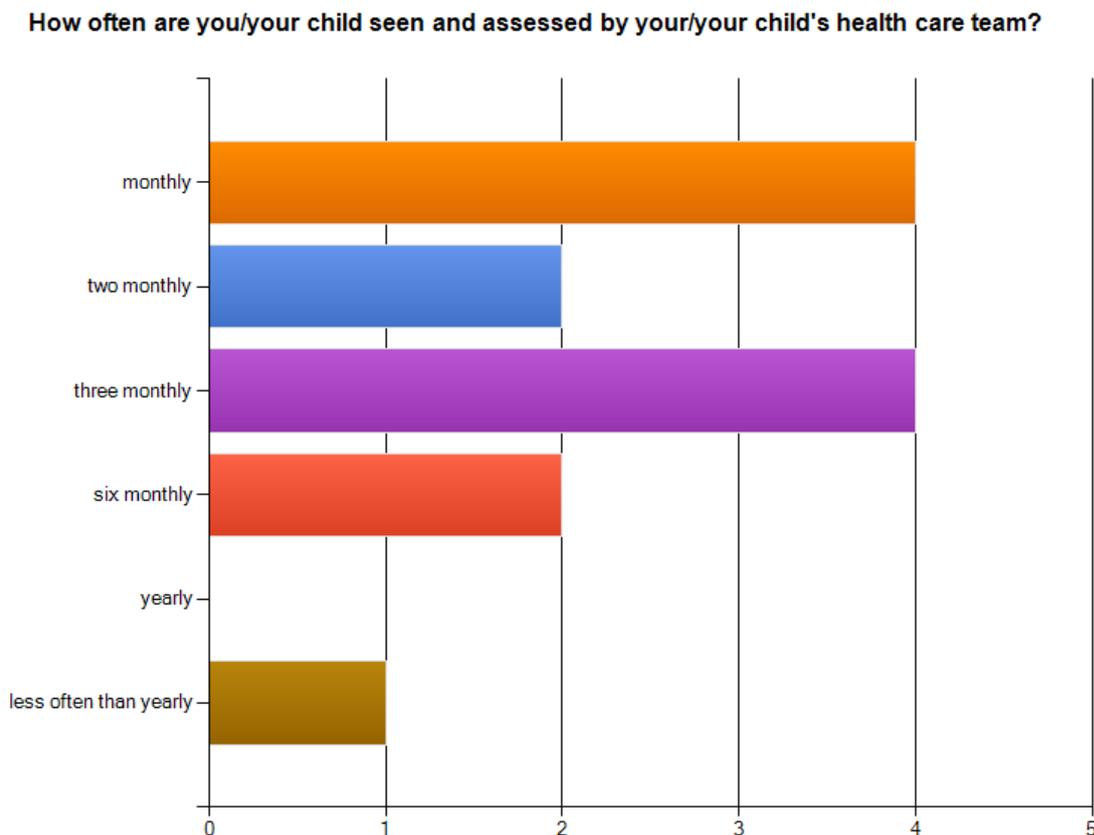
Baseline assessment

Six (46%) patients reported having had a baseline nutritional assessment at the start of HPN treatment, three (23%) did not, whilst four (31%) responded “don’t know.”

Frequency of monitoring

The overwhelming majority of patients reported regular, frequent monitoring, as seen in figure 7, below. However, the fact that one respondent reported being seen less than yearly is of concern.

Figure 7 – Frequency of monitoring



Involvement of professional disciplines

The participation by health professionals in monitoring appointments was less positive. Only three (23%) respondents indicated they have a multidisciplinary team always in attendance at their appointments, five (38%) indicated their team attends sometimes, and a further five (38%) indicated their team did not attend monitoring appointments at all.

The following health professionals were reported to attend monitoring appointments regularly: doctor (10, or 77%); nurse (7, or 54%); dietician (5, or 38%); and pharmacist (1, or 8%); with a further respondent (8%) indicating they saw the first three professions but at different times as opposed to a team based appointment.

Record keeping at monitoring appointments

This question asked whether written records were made at each appointment, including assessment, outcomes and adjustments to therapy. Nine (69%) patients reported that written records are always kept at their appointments; one (8%) sometimes; two (15%) not at all; with one (8%) respondent unsure.

Issues discussed at regular appointments

Issues discussed at patients' regular monitoring appointments were reported to include: regular medicines (9, or 69%); status of the patient's central venous catheter and adequacy of care (10, or 77%); general wellbeing (9, or 69%); and results of tests and changes to care (9, or 69%).

Frequency and type of tests

As the AuSPEN guidelines are quite specific regarding required tests, and the frequency with which each test should be conducted, the findings here are reported by exception. That is, for each test, we report how many patients were **not** being tested at the required frequency, and how many patients were unsure if they were being tested at all. Thirteen patients completed these questions.

The survey questions included the wording from the guidelines with additional prompts such as an explanation of how the tests would be written up on a pathology form, given this is what most patients would take away with them from an appointment.

Fig 8 – frequency of monitoring required for all HPN patients

Test	Number of patients not being monitored at the recommended interval	Number of patients unsure of the frequency with which testing occurs, if at all
Weight	1 (never)	0
Oral or enteral intake	4 (never)	0
Biochemistry	2	0
Haematology screen	3	2
Lipid screen (frequency not specified in the guidelines)	1	4
Trace elements	1	1
Iron status	1	2

The second question asked about tests which are required for some, but not all, patients on HPN, depending on their condition and co-morbidities. It is possible that patient reporting about these tests may be less reliable as not all patients would necessarily know if the tests are applicable.

Fig 9 – frequency of monitoring for some HPN patients

Test	Number of patients not being monitored	Number of patients unsure if this test is conducted	Number of for whom the test is not applicable
Glycaemic monitoring	4	1	6
Height (only for children)	0	1	7
Annual bone health check using DEXA machine	7 (3 infrequently; 4 never)	2	0
Quality of life survey	6	3	0
Body composition measurement	4	3	0
Inflammatory markers	4	4	1
INR	4	4	0
Problem solving checklists for other conditions or complications	2	4	2

Funding arrangements

A positive finding of the survey is that 100% of respondents reported they were clearly informed of funding arrangements prior to discharge for: provision of HPN solution; consumables; and pump and equipment.

Conclusion and recommendations

The survey, although not statistically valid in terms of the total Australian and New Zealand HPN patient group, nonetheless serves as a useful pilot snapshot and highlights areas where a wider survey could provide more valuable comprehensive insights into HPN practices and areas needing improvement.

Overall, the survey suggests that HPN centres do best at involving patients in decisions about starting and going home on HPN, and selecting and placing a central venous access device.

There seems to be a need for more concerted efforts in relation to:

- ensuring patients receive comprehensive training before discharge, particularly in relation to the timely and appropriate management of emergency situations and life-threatening complications associated with HPN and/or a central venous access device
- confirming patients have suitable home environments
- providing written information, particularly to facilitate rapid triage and treatment in the event of emergency hospital admissions
- providing multidisciplinary care and/or assuring patients that a team of multidisciplinary health care professionals is coordinating their care “behind the scenes”
- ensuring regular testing is occurring as per the guidelines, and/or clarifying with patients that these tests are occurring, why they are needed and how often they are being done
- information around pump operation and after hours support
- communication between pharmacists and patients about HPN and drug interactions.

PN-DU would welcome the opportunity to discuss the survey findings further with AuSPEN, with a view to:

1. work together to adapt the survey for wider use across Australasia
2. provide consumer input into the next iteration of the guidelines
3. explore strategies to address some of the issues of concern which emerged out of this survey.

Options might include:

- a. development of checklists to empower patients to advocate for the best possible care eg what to expect before discharge, what sort of monitoring should occur and with what frequency.
- b. Parallel checklists or written information templates may be useful for specific disciplines within HPN centres eg topics for nursing staff to cover during training, patient information booklets on HPN management, care of lines, expedited triage information templates, electronic spreadsheets that can be downloaded and used for monitoring regular testing of HPN patients, suggested makeup of emergency kits that patients could be issued prior to discharge.