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**Note to respondents:** Please speak to your healthcare professional if you have any questions about your HPN management.
This report presents the findings of qualitative and quantitative research with patients receiving total parenteral nutrition in the home setting (HPN). The research involved 20 face-to-face qualitative interviews and 69 quantitative interviews with respondents located in six Australian states and New Zealand. The fieldwork was conducted between November 2015 and May 2016.

**AIM OF THE RESEARCH**

The overall aim of the research was to explore HPN patient perceptions and experiences at various stages of the pathway from hospital to the home and with the Baxter Healthcare home PN service.

**KEY FINDINGS**

**Respondent profile:** Three quarters (74%) of quantitative respondents were HPN patients while the balance were carers (26%). The age of HPN patients ranged from under 10 years to over 70 years. The length of time on HPN ranged from less than six months to over 20 years.

**In-hospital training:** Most respondents (94%) received in-hospital training which ranged from less than a week to more than eight weeks. At the end of their training, most were very (45%) or somewhat confident (35%) in their ability to self manage HPN. Most were satisfied with their general HPN training (86%) and their infusion pump training (81%).

**Transition from hospital to home:** Perceptions about the ease of transition from the hospital to home varied, with over half of respondents (61%) saying it was very or somewhat easy, a fifth (19%) saying it was neither easy nor difficult and the balance (20%) saying it was difficult or very difficult. Most (75%) agreed their training helped them adjust quickly to managing PN at home and two-thirds (68%) agreed they received all the support they required in the first few weeks.

**PN solutions:** Most thought the timeliness of deliveries of PN solutions (91%), the condition of PN solutions when they arrive (93%) and the ease of use of PN bags (90%) were good or very good. Most were satisfied (45%) or very satisfied (54%) with PN solution products and service.

**Consumables:** Most respondents (78%) obtained some (26%) or all (52%) of their consumables from Baxter Healthcare. Most said ease of ordering consumables (92%), timeliness of delivery of consumables (93%), condition of consumables when they arrive (100%), stock availability (89%) and communications about back orders (70%) were good or very good. Most were satisfied (31%) or very satisfied (63%) with the products and service.

**Infusion pumps:** Most respondents (90%) used the BodyGuard 323 infusion pump provided by Baxter Healthcare while the balance used pumps provided by the hospital or other supplier. The majority of BodyGuard 323 users said ease of use (95%), ease of problem solving (79%), reliability (71%) and technical support (73%) were good or very good. Most respondents were satisfied (39%) or very satisfied (45%) with their infusion pump and Baxter’s technical service. A few were dissatisfied (8%) or very dissatisfied (2%).

**Overall satisfaction with Baxter:** The majority of respondents (98%) were satisfied (41%) or very satisfied (57%) with Baxter Healthcare overall. No respondent was dissatisfied. Baxter achieved a Net Promoter Score of 62.4%, a very good rating.

**Summary conclusions:** We concluded Baxter Healthcare was generally said to perform well with higher satisfaction reported by most respondents. A minority reported problems, particularly with infusion pumps.

We concluded there are opportunities for Baxter and Hospitals to improve training and support during transition to the home and opportunities for Baxter to refine and improve its home PN service. Suggestions are made in the body of the report.
INTRODUCTION AND BACKGROUND

BACKGROUND

Baxter International Inc. is a global, diversified healthcare company with a unique combination of expertise in medical devices, pharmaceuticals and biotechnology. It employs approximately 50,800 employees around the world.

BAXTER IN AUSTRALIA AND NEW ZEALAND

Baxter Healthcare has invested heavily in the Australia and New Zealand (ANZ) region for over 50 years.

In Australia, it has a manufacturing plant in Western Sydney; distribution and warehousing depots in NSW, QLD, VIC, SA, WA and TAS; and aseptic compounding facilities in NSW, QLD, VIC, WA and SA. In New Zealand it has warehouse, distribution centres and aseptic compounding pharmacies in both Auckland and Christchurch. All of Baxter’s facilities are TGA/Medsafe approved and audited.

BAXTER PHARMACY SERVICES

Baxter Pharmacy Services provides TGA/Medsafe regulated aseptic compounding services for patients in public and private hospital pharmacies and clinics throughout Australia and New Zealand. Products include chemotherapy, antibiotics, analgesics, intravenous additives and parenteral nutrition.

PARENTERAL NUTRITION

Baxter Healthcare has been involved in parenteral nutrition since the 1940s, when the company introduced liquid proteins in the form of amino acids. Since that time, it has continued to advance IV nutrition through ongoing improvements and innovation in PN solutions and packaging.

Parenteral nutrition (PN) is the feeding of a person intravenously, bypassing the usual process of eating and digestion. The person receives nutritional formulae that contain nutrients such as glucose, salts, amino acids, lipids, vitamins and dietary minerals.

HOME PARENTERAL NUTRITION

At the time of the research, Baxter Healthcare provided PN solutions to home PN patients located in most Australian states and territories and across New Zealand.

There has been significant growth in the number of patients self managing PN in the home setting, requiring Baxter Healthcare to continually expand and modify its home PN service.

THE NEED FOR MARKET RESEARCH

Baxter Healthcare is dedicated to continual improvement in the products and services it provides. To this end, it decided to commission market research to better understand HPN patient experiences with Baxter Healthcare HPN service and identify ways to improve it where necessary.

Baxter contacted HPN healthcare professionals in every Australian state and New Zealand to announce the research. It received positive support for the idea and was given a number of suggestions for topics to be covered, including in-hospital training, support during transition from hospital to home, coverage of non-metropolitan locations, coverage of paediatric patients, ease of use of PN solutions and infusion pumps and satisfaction with patient support generally.

VAWSER AND ASSOCIATES

Baxter Healthcare commissioned Vawser and Associates to undertake the research in mid 2015. Vawser and Associates is an independent consultancy in market and social research with particular expertise in healthcare. The organisation had previously conducted market research on parenteral nutrition for Baxter and had a good understanding of the area.

The exploratory qualitative research component was conducted in late 2015 and early 2016. The quantitative component was conducted in April and May of 2016. The final report was presented in June 2016.
AIM OF THE RESEARCH

The aim of the research was to explore HPN patient perceptions and experiences at various stages of the pathway from hospital to the home and with Baxter Healthcare home PN service.

Specific objectives included exploring experiences with HPN training, the transition from hospital to the home, and living with HPN at the time including the products, service and support provided by Baxter Healthcare.

METHODOLOGY

The research involved two stages:

► Stage 1: Exploratory qualitative research  Twenty face-to-face depth interviews were conducted across Australia and New Zealand designed to explore the research issues and as input to the design of a quantitative questionnaire.

► Stage 2: Quantitative research  Sixty-nine interviews were conducted across Australia and New Zealand using a ten to fifteen minute structured questionnaire. Sixty-five interviews involved respondents completing the questionnaire online and four respondents without email access were interviewed by telephone.

SAMPLING APPROACH

Respondents opted in to the research by responding to an invitation sent by Baxter Healthcare. A list of 76 potential respondents who provided their consent was then provided to Vawser and Associates.

Qualitative respondents were selected on the basis of location, to gain a geographical spread.

Table 1: Qualitative sample structure

<table>
<thead>
<tr>
<th>Location</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>6</td>
</tr>
<tr>
<td>Victoria</td>
<td>6</td>
</tr>
<tr>
<td>Queensland</td>
<td>2</td>
</tr>
<tr>
<td>Western Australia</td>
<td>2</td>
</tr>
<tr>
<td>New Zealand</td>
<td>4</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>20 interviews</strong></td>
</tr>
</tbody>
</table>

Quantitative respondents were sent an email invitation and three reminder emails over a three-week period. Those without email access were offered a telephone interview option.

Table 2: Quantitative sample structure

<table>
<thead>
<tr>
<th>Location</th>
<th>Number of interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>14</td>
</tr>
<tr>
<td>Victoria</td>
<td>9</td>
</tr>
<tr>
<td>Queensland</td>
<td>7</td>
</tr>
<tr>
<td>Western Australia</td>
<td>7</td>
</tr>
<tr>
<td>South Australia</td>
<td>3</td>
</tr>
<tr>
<td>Tasmania</td>
<td>6</td>
</tr>
<tr>
<td>New Zealand</td>
<td>23</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>69 interviews</strong></td>
</tr>
</tbody>
</table>

Data accuracy: The quantitative analysis was conducted at the 95% confidence level. The confidence intervals are estimated to be around ± 10.1%.

Non-response bias: Only 33% of total HPN patients serviced by Baxter (excluding South Australia) responded to the original invitation. It is possible the results in the quantitative research are influenced by non-response bias, an unknown.

Note: HPN patients in South Australia were to be excluded from the research on instruction to Baxter from local health providers. However, three South Australian HPN patients asked to participate and were allowed to do so.
RESPONDENT PROFILE: QUANTITATIVE

DEMOGRAPHICS (n=69)

RESPONDENT TYPE

- HPN Patient: 74%
- HPN Carer: 26%

GENDER

- Female: 77%
- Male: 23%

AGE OF HPN PATIENT

- Under 10 years: 16%
- 11 to 17 years: 3%
- 18 to 25 years: 4%
- 26 to 40 years: 16%
- 41 to 55 years: 20%
- 56 to 70 years: 32%
- 71 years plus: 9%

METRO / NON METRO

- Non-metro: 45%
- Metro: 55%

HOUSEHOLD SITUATION

- Live alone: 16%
- Home with parents/guardian: 9%
- Partner no children: 29%
- Partner and children: 38%
- Live alone with children: 3%
- Live with other singles: 1%
- Other: 4%

EMPLOYMENT STATUS

- FT employed: 3%
- PT employed: 17%
- Self employed: 7%
- Unemployed: 3%
- FT Student: 6%
- Home duties: 13%
- Retired: 22%
- Can't work medical reasons: 26%
- Other: 3%
**HPN PROFILE (n=69)**

**LENGTH OF TIME ON HPN**
- < 6 months: 6%
- 7-12 months: 14%
- 1-2 years: 20%
- 3-5 years: 25%
- 6-10 years: 16%
- 11-15 years: 4%
- 16-20 years: 7%
- 21 years plus: 7%

**DAYS PER WEEK ON HPN**
- 7 days: 64%
- 6 days: 10%
- 5 days: 13%
- 4 days: 6%
- 3 days: 4%
- 2 days: 3%

**TIME OF DAY HAVE HPN**
- During the night: 96%
- Both - Depends on circumstances: 4%
- During the day: 0%

**LENGTH OF HPN ADMINISTRATION**
- 15 hours plus: 16%
- 14 hours: 7%
- 13 hours: 9%
- 12 hours: 41%
- 11 hours: 13%
- 10 hours: 9%
- 9 hours: 1%
- 8 hours: 3%
- 5 or less hours: 1%

**INDICATION – PATIENTS AGED 10 YEARS PLUS**
- Motility disorder, pseudo-obstruction: 41%
- Other reason: 24%
- Surgical complications: 14%
- Crohn’s disease: 14%
- Cancer obstructing the GI tract: 3%
- Vascular disease, Ischaemia: 2%
- Coeliac disease: 2%
- Prefer not to say: 0%

**INDICATION – PATIENTS AGED UNDER 10 YEARS**
- Other reason: 27%
- Hirschsprung’s: 27%
- Necrotising enterocolitis (NEC): 18%
- Gastrochisis: 18%
- Volvulus: 9%
- Prefer not to say: 0%
The original HPN decision

There were a number of common characteristics associated with the original decision to go onto parenteral nutrition in the home setting:

- Long and complex medical histories
- Multiple medical conditions contributing to the situation
- Multiple surgical procedures over many years
- Long periods in hospital, often from weeks to many months
- A number of respondents were extremely sick at the time of the HPN decision.

Lack of alternative

A majority of respondents in the qualitative research emphasised the lack of available alternatives at the time of the original HPN decision. Potential alternatives had already been tried and failed, leaving total parenteral nutrition (TPN) as the only option. Moving to TPN in the home setting (HPN) was seen as the logical extension of the original TPN decision.

Various levels of involvement

The original TPN and HPN decisions were made by patients and/or carers.

A proportion of respondents said they were actively involved and felt fully informed during the original decision-making process. A proportion reported less involvement and understanding at the time and thought their situation could have been better explained, including the consequences, risks and implications of long-term HPN.

Given there was no alternative, most respondents in the qualitative research were thankful they were given the opportunity to go onto parenteral nutrition in the home setting.

“You just put your trust in the hospital and that’s why my daughter said she would do it [be a carer]. It could have been explained better, the consequences. We were just told I had to go on TPN if I wanted to live. It was the only option.”

“The lack of alternative made it easy. The way they explained it, they didn’t assume you didn’t know anything, they didn’t just pass it off and it was still my decision.”

“But I wasn’t really involved in the decision. I was aware of what was going on but there wasn’t a decision to be made. They simply told me that this was what I needed to do.”

“I understand the risks more now. I was a child at the time and my parents protected me. I now realise I was on my death bed but I didn’t have a clue. So the risks were generalised.”

“I was happy with the decision process simply because PN was like ‘life support.’ It was a case of home PN if I wanted to live.”
HPN TRAINING

Most respondents received in-hospital training (94%) prior to going home on HPN. A minority (4%) received training as an outpatient or in home by HITH nurses or a family member/carer.

LENGTH OF TRAINING

Reported length of HPN training varied across the quantitative sample:

► Half (50%) said their HPN training was a week or less.
► Over a quarter (29%) said their HPN training was 2 or 3 weeks.
► The balance (21%) said their HPN training was 4 weeks or more.

PERCEPTIONS OF TRAINING

Two-thirds or more of quantitative respondents thought the HPN training was good or very good for all training elements.

► Just under a fifth rated training in recognising and managing febrile episodes (18%) and problem solving lines and infusion pumps (19%) as poor or very poor.

Statistically, ratings for recognising and managing febrile episodes (3.7) and problem solving lines and infusion pumps (3.8) were lower than the other training elements.

SATISFACTION – GENERAL HPN TRAINING

Over three-quarters of quantitative respondents (86%) were satisfied or very satisfied with their general HPN training.

A minority (10%) said they were dissatisfied or very dissatisfied.
INFUSION PUMP TRAINING PROVIDER

Over two-thirds of respondents (69%) received infusion pump training from hospital staff while around a fifth (22%) were trained by both hospital and Baxter staff.

► More respondents in New Zealand (43%) received infusion pump training from both hospital and Baxter staff than in Australia (11%).

SATISFACTION – INFUSION PUMP TRAINING

Over three-quarters (81%) of respondents were satisfied or very satisfied with their infusion pump training. A minority (10%) were dissatisfied or very dissatisfied.

Satisfaction with infusion pump training was similar across training by hospital staff (85%), by Baxter alone (100%) and by both hospital and Baxter staff (80%). There were seven respondents who were dissatisfied or very dissatisfied with their infusion pump training. Four were trained by hospital staff, two by both hospital and Baxter staff and one by someone else (not specified).

CONFIDENCE AT THE END OF HPN TRAINING

Just under half of respondents (46%) were very confident and just over a third (35%) were somewhat confident in their ability to self manage PN at home at the end of their training.

Just under a fifth (19%) had limited confidence (16%) or were not confident at all (3%) at the end of their training.

CONCLUSIONS

Most respondents were satisfied with their HPN training and most were very or somewhat confident at the end of their training. However, training in recognising and managing febrile episodes and problem solving lines and infusion pumps was rated lower than other elements. We concluded hospitals and Baxter Healthcare should consider ways to improve these elements of HPN training.
EASE OF TRANSITION TO THE HOME SETTING

Just under a quarter of respondents (23%) said the transition from hospital to home was extremely easy and over a third (38%) said it was somewhat easy.

A fifth (19%) said the transition was neither easy nor difficult, while a similar number said the transition was somewhat difficult (14%) or extremely difficult (6%).

ISSUES IN THE FIRST THREE MONTHS

Three-quarters of respondents (74%) in both Australia and New Zealand experienced one or more of the issues listed in the questionnaire during the first three months.

► Over a third (36%) had problems with their infusion pump.
► A third (33%) were readmitted to hospital.
► A fifth (20%) had problems connecting or disconnecting.
► A few (13%) had one or more line infections.
► A few (12%) experienced a febrile episode.
► A few (10%) had supply problems with PN solutions or consumables.

Only a quarter (26%) of respondents didn’t experience any of the issues listed in the questionnaire.
CONCLUSIONS
While over half of respondents said the transition from hospital to home was extremely or somewhat easy, 20% said it was difficult or extremely difficult. Reported support received in the first few weeks at home varied in the extreme. We concluded a more standardised approach to patient support during the transition from hospital to home may be warranted and should be investigated by relevant hospitals and Baxter Healthcare.

TRANSITION FROM HOSPITAL TO HOME

TYPES OF SUPPORT IN FIRST FEW WEEKS
Reported support received in the first few weeks at home varied across respondents from daily contact and significant support to no contact or support.

Over two-thirds of respondents (72%) said they were given a phone number to ring the hospital if required, and over half (55%) said they were given training notes or manual. Over a third (36%) received telephone calls from hospital staff, 32% received home visits from district or community nurse, 30% were given support from a local hospital close by, 30% were given an email address to contact hospital staff if required and 25% received home visits from hospital staff.

EXTENT OF AGREEMENT WITH STATEMENTS
Three-quarters of respondents (75%) agreed their training helped them adjust quickly to managing PN at home and over two-thirds (68%) agreed they received all the support they required in the first few weeks. Just over half (58%) agreed they were extremely anxious when hooking up for the first time at home on my own and a quarter (26%) agreed they felt isolated and alone without access to immediate support from hospital staff in the first few days.

CONCLUSIONS
While over half of respondents said the transition from hospital to home was extremely or somewhat easy, 20% said it was difficult or extremely difficult. Reported support received in the first few weeks at home varied in the extreme. We concluded a more standardised approach to patient support during the transition from hospital to home may be warranted and should be investigated by relevant hospitals and Baxter Healthcare.
CONFIDENCE TO MANAGE HPN

A majority of respondents in the quantitative research (93%) were very confident in their ability to manage PN at home at the time of the research. A minority (7%) were somewhat confident.

ISSUES AND CHALLENGES

Respondents in the qualitative research mentioned a number of issues and challenges associated with living with PN in the home setting, including:

- Motivating oneself to hook up every night
- Energy depletion by the end of the day
- Coping with variable symptoms
- Living and managing PN on one’s own
- Line infections, complications with PN
- Managing eating in a social context
- Balancing/managing oral intake
- Frustration - Just can’t do some things
- Frustration - Can’t do what normal families do
- Coping with the demands of caring for a child
- Inability to commit to social activities
- A lack of understanding of PN by the community
- Infusion pump troubleshooting.

A core theme mentioned by qualitative respondents was the way HPN influenced every aspect of daily life and the need to consider HPN before planning or doing anything.

CONCLUSIONS

At the time of the research, most respondents were very confident in their ability to manage HPN. Issues and challenges associated with HPN were ongoing and significant. Respondents in the qualitative research were happy to be alive and remarkably positive about their situations and daily life.
ISSUES ASSOCIATED WITH PN SOLUTIONS

PN SOLUTIONS – LOGISTICS, EASE OF USE

A majority of respondents in the quantitative research thought the timeliness of deliveries (91%), the condition of PN solutions when they arrive (93%) and the ease of use of PN bags (90%) were good or very good. Only two respondents provided poor or very poor ratings.

RATING OF BAXTER CONTACT

Over half of respondents in the quantitative research (58%) had contacted Baxter to discuss PN solutions in the last 12 months. Proportions in Australia (57%) and New Zealand (61%) were similar. All respondents in New Zealand (100%) and most in Australia (88%) had a Baxter Healthcare phone number. A minority in Australia (12%) had to find the phone number in some way.

Of those respondents who contacted Baxter Healthcare, the vast majority gave a good or very good rating for all service attributes:

► Was courteous and polite (98%)
► Was knowledgeable and competent (96%)
► Provided a fast response (93%)
► Answered my calls quickly (91%)
► Understood my needs (90%)
► Followed up promptly where required (85%)

This applied equally to Australia and New Zealand.

OVERALL SATISFACTION – PN SOLUTIONS

A majority of the quantitative sample were satisfied (45%) or very satisfied (54%) with the product and service associated with their PN solutions. A single New Zealand respondent was very dissatisfied.

CONCLUSIONS

Most respondents were satisfied with the product and service associated with their PN solutions. Most respondents who contacted Baxter Healthcare to discuss their PN solutions had a positive experience.
INFUSION PUMPS – RATINGS

Most respondents in both Australia (91%) and New Zealand (89%) were using the BodyGuard 323 infusion pump provided by Baxter. A minority used a pump provided by the hospital (7%) or other supplier (3%).

Over two-thirds of the quantitative sample rated ease of use (95%), ease of problem solving (78%), reliability (72%) and technical support (71%) as good or very good. Between 5 and 10 respondents rated these elements as poor to very poor. These ratings involved all infusion pumps.

BODYGUARD 323 – RATINGS

There were 62 respondents using the BodyGuard 323 infusion pump provided by Baxter.

► Ease of use: The vast majority of users in Australia (93%) and all in New Zealand (100%) said ease of use of the BodyGuard 323 was good or very good.

► Reliability: Two-thirds or more of users in Australia (68%) and New Zealand (76%) said reliability of the BodyGuard 323 was good or very good. However, some users in each country (14% to 17%) thought reliability was poor or very poor.

► Ease of problem-solving: Around three-quarters of users in Australia (73%) and most in New Zealand (90%) said ease of problem-solving with the BodyGuard 323 was good or very good. A minority in each country (5% to 10%) said ease of problem-solving was poor or very poor.

► Technical support: Over two-thirds of users in Australia (71%) and New Zealand (76%) said the technical support provided for the BodyGuard 323 was good or very good. However, some users in each country (12% to 19%) thought technical support was poor or very poor.
ISSUES ASSOCIATED WITH INFUSION PUMPS

RATING OF BAXTER CONTACT

Over half of respondents using the BodyGuard 323 (55%) said they had contacted Baxter to get technical support for their infusion pump in the last 12 months. All respondents in New Zealand (100%) and most in Australia (83%) had a Baxter Healthcare phone number. Some users in Australia (17%) had to find the phone number in some way.

Of those users who contacted Baxter Healthcare for BodyGuard 323 technical support, the vast majority gave a good or very good rating for all service attributes:

- Was courteous and polite (94%)
- Was knowledgeable and competent (85%)
- Provided a fast response (88%)
- Answered calls quickly (94%)
- Understood my needs (85%)
- Followed up promptly where required (79%).

This applied equally to Australia and New Zealand.

OVERALL SATISFACTION – INFUSION PUMP

A majority of the quantitative sample said they were satisfied (43%) or very satisfied (42%) with their infusion pump and supplier service.

A majority (84%) of BodyGuard 323 users were satisfied (39%) or very satisfied (45%) with their infusion pump and supplier service. Four respondents in Australia were dissatisfied (9%) and two respondents in New Zealand were dissatisfied (4%) or very dissatisfied (4%) with their BodyGuard 323 infusion pump and supplier service.

CONCLUSIONS

Most respondents were satisfied with their infusion pump and associated service. Most who contacted Baxter Healthcare for BodyGuard technical support had a positive experience.

However, 6 of the 62 BodyGuard 323 users were dissatisfied with their pump and/or service, a concern for Baxter Healthcare.

“*It’s great, it’s portable, easy to use, no trouble unless someone switches it off and it’s not charged. That’s the only time we have a problem. I mean we do have problems with air in the line and things like that, which is what you expect.*”

“*It under infuses which means I have to calibrate the pump by over stating the capacity of the bag to ensure that all of the contents in the bag are used.*”
ISSUES ASSOCIATED WITH CONSUMABLES

SOURCE OF CONSUMABLES

Around half of respondents in both Australia (52%) and New Zealand (52%) ordered all of their consumables from Baxter Healthcare. A quarter (25%) ordered from both Baxter and the hospital while a fifth (20%) ordered only from the hospital or some other source (1%).

RATINGS – CONSUMABLES ISSUES

A majority of respondents in the quantitative research thought the condition of consumables on arrival (98%), ease of ordering (90%), timeliness of delivery (89%), stock availability (87%) and back-order communication (74%) was good or very good. These ratings included all sources of consumables.

RATINGS – BAXTER SERVICE

Of those respondents who ordered some or all of their consumables from Baxter Healthcare, the majority gave a good or very good rating for all service attributes:

► Is courteous and polite (97%)
► Is knowledgeable and competent (87%)
► Follows up promptly where required (89%)
► Answers calls quickly (97%)
► Understands my needs (93%)
► Follows up promptly where required (89%).

This applied equally to Australia and New Zealand.

OVERALL SATISFACTION – CONSUMABLES

A majority of respondents were satisfied (29%) or very satisfied (62%) with the service from their consumables supplier. Two respondents in Australia were dissatisfied (3%). Both ordered all of their consumables from hospitals.

CONCLUSIONS

Most respondents were satisfied with their consumables products and service, whether provided by a hospital or Baxter. Most who ordered from Baxter reported positive experiences.
OVERALL SATISFACTION WITH BAXTER

A majority of respondents in the quantitative research were satisfied (41%) or very satisfied (57%) with the products and service from Baxter Healthcare overall. Two respondents in Australia were neither satisfied nor dissatisfied.

NET PROMOTER SCORE

When asked how likely are you to recommend Baxter Healthcare to another patient on home parenteral nutrition, the majority of the quantitative sample provided higher likelihood scores (mean score of 8.9 out of 10).

This equated to a Net Promoter Score of +62.4% which is generally considered to be a very good NPS rating.

CONCLUSIONS

At a summary level, we concluded most respondents in the quantitative research were satisfied with the products and service they receive from Baxter Healthcare overall. We also concluded there were a few individuals who reported less positive experiences (a minority of the total sample).

“As far as I am concerned, I can only extoll the virtues of Baxter. I do not have a single criticism of them. It has been a good experience from the TPN side.”

“Everyone has their ups and downs occasionally and they solve the hiccups very well.”

“In all honesty, there is nothing that could be improved. I am totally satisfied with everything.”

“Very happy with them. It’s been a smooth transition coming from hospital back home and no muck-ups so far with anything.”

“Very satisfied. The service is great, the quality of the gear is A1, they are quick to solve problems. I really can’t ask for any more.”

“They always come across as professional, whoever you deal with.”
SUGGESTIONS AND IMPROVEMENTS

A wide range of suggestions and improvements were mentioned by individuals in both the qualitative and quantitative research components.

The most mentioned issues in the quantitative research were various problems with the BodyGuard 323 infusion pump (12 respondents).

The other most mentioned issues were:

- The need to update Baxter contact numbers
- Better communication about product complaints and back orders
- Improve reliability of PN deliveries
- Provision of a consumables product list with product codes
- Introduction of an online or email ordering system
- An ability to deal with Baxter direct for PN deliveries (an issue for those required to communicate via hospitals)
- The need for regular infusion pump servicing.

Note: A full list of improvements and suggestions was provided to Baxter Healthcare.

“None really, other than perhaps a nice-to-have which would be to have a set delivery time.”

“It would make life easier if we could sign an authorisation that if not home on a Friday, TPN can be left in a safe, covered area at our house.

“I put in a complaint about it but I have never heard anything from them.”

“They didn’t give us an after hours number, so I just ring the technical number and eventually get it done.”

“They should be checking pumps regularly because if a person’s pump is not working they won’t get the TPN and fluids and will end up in hospital, dehydrated.”

“When an item is on back order, Baxter needs to advise that is the case so then I don’t have to ring to ask why the item was not sent.”

“Send out a text message with the TOLL tracking number when the TPN is dispatched from Baxter.”
THE ORIGINAL TPN/HPN DECISION

“They were operating every three months and if I continued I would die. I had to sign waivers because they had to take all of the bowel out or I would die. It was go on or die or PN or die. So it was a no-brainer. There were not a whole lot of options available especially with 3 young children and this gave me some control over my situation.”

“I recognised that for me PN was an opportunity to continue to live. Without it I would not survive.”

“It was no big deal really in terms of consultation and decision making as it was really just an extension of being at home on jejunal EN - just another way of getting nutrition since nothing else was working anymore.”

“The benefits were obvious, but the risks? It was more like the odd comment thrown in over the weeks and months. It was more like osmosis, more gradual, becoming aware.”

IN-HOSPITAL TRAINING

“Very comprehensive, went into a lot of detail. I just can’t fault them at all.”

“Excellent training. They don’t let you go home without knowing what to do. We took it at our own pace. They didn’t care how long it took. On the 1st hook up at home they came out and watched. It helped me comfortable with the idea of what we had to do. The training was really exceptional.”

“Between the PN nurse and Baxter, they made it an easy process.”

“Baxter were excellent. They came into the ward with the pump and trained us what to do. XXX also trained the teacher aid at the local primary school. And we could always contact XXX if we had any problems.”

“Instruction in the hospital was pretty basic really and there was not a good manual. Other than that, it worked well enough. No problem there.”

“It would have been helpful if I had some training on problem solving [infusion pumps]. You know - the sorts of things that happen and what you do if they occur in the middle of the night and you have no-one to phone.”

“We were taught the basics but the odd alarm would come up and we were not sure what to do. It caused a bit of stress. I was with Biomed originally, so that was Biomed.”

“I remember developing an infection at home and wondering what was going on. They really should provide patients with information as to what they should look out for.”

“There was nothing wrong with it per se. It was adequate but just not good enough to get rid of the fear factor. I am not being critical, it was just lacking in consideration of the people who have to take responsibility and in the beginning, can be quite scared.”

“We had meetings about going home but I didn’t know what questions to ask about TPN.”

TRANSITION FROM HOSPITAL TO HOME

“Easy. I came home with everything I needed. I remember how impressed we both were at the time. They called us every two days and if I needed I could call them.”

“The hardest thing about going home was questioning myself. Can I do this?”

“So the hardest part was probably not having that back-up person right there. Even though I had someone to call, it was different to them actually being here.”

“Extra difficult. Even though I was extremely confident I was really nervous with it all. I was anxious I was going to make a mistake, the fear of infection, the fear I would cause an infection.”

“Extremely stressed. I wasn’t sure which part of the bag to spike and the first time, I didn’t spike it in the correct place. I had no idea what to do.”
LIVING IN A REMOTE LOCATION

“Isolated from the people with the support. Remote, nobody understood; the family, the local doctors, the little country hospital.”

“I went to my daughter’s place in XXX [non metro location] because she was doing it all. It was very hard. I relied on her the whole time. And because we went to XXX no one came and visited.”

“When we came back the nurses at the local hospital would do anything for him. But they didn’t follow the PN protocols we were taught. They should have been told - this is the process you will follow for this patient. So there was a lot of anxiety for us. How are they going to do it tonight? And the older nurses did it differently again. The risks and processes were drummed into us only to find the local nurses not doing what we have to do. So that was one of the more challenging things.”

“Everything is dealt with in Sydney and I don’t have a high degree of confidence that if something went wrong they could respond quickly. It is really stressful.”

CARING FOR AN HPN CHILD

“A sense of feeling overwhelmed with XXX’s schedule of care and all that had to be organised to ensure that her needs were met: ordering of consumables, scheduling of medical appointments, being at home to sign for receipt of PN solutions, administering medications when needed.”

“But there is a lot of psychological stuff here as well. Coping as a parent and trying to work. It really messes with your mind.”

“The quality of life of the whole family is affected. We can’t look after him without support. He is over it, we are all over it too but it’s not going to go away. Like family events, we can’t be spontaneous about anything. There are so many things you have to remember. So quality of life sucks.”

LIVING WITH HPN

“Just coping with the symptoms, nausea, pain, vomiting. I can’t get out often.”

“I’m alive’ and I’m thankful for that. But my health is a daily challenge. I often feel unwell.”

“If I visit somewhere over night you have got to take all the equipment so the car is full. And if it’s a weekend you almost need a truck. And even then you can’t go out at night.”

“Look, I think I’m one of the lucky ones, the support around me, we think positive, lots of friends and family to support. We just laugh our way through life, take one day at a time.”

“We manage to do everything we need to. She functions extremely well. There are those days where she just has to sleep but she fights her health. She doesn’t let it get on top of her.”

“Now that we are married we don’t get the disability pension, we lost the rent assistance and I don’t have a healthcare card. We had to borrow money from the family. They have really helped us out.”

“We have a happy little life. We have our routines, listen to music while on the pump, use the back pack and do the shopping.”

“I am doing everything I want to do. There are things we would like to do, sure. But we have our routine and we go to the club once a fortnight.”

“I have achieved everything I wanted to. The kids have grown up, I’ve seen the first grandchild and the other one married. I really didn’t think I would see any of that.”

“You have your good and bad days and this year has been good. So long as you can avoid infections. The bugs love this heat and you have to watch the dehydration. But the past year has been great. We had our first holiday in 10 years, went to XXX by train. I’m just thankful that I am still here and we have done more than I had ever imagined in the past year.”