

Home Enteral Nutrition (HEN) Project

Development  
of a  
Best Practice Model  
for  
Service Delivery of HEN

Phase I  
Research Report

July 1999



## **Funding**

This project was funded by the Victorian Government Department of Human Services, Acute Health Division, as part of the HEN Pilot Program.

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# Acknowledgments

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Thankyou to all the professionals who gave their valuable time to participate in this project.

Participation from the HEN clients interviewed is gratefully acknowledged. Their thoughtful insights and suggestions are greatly appreciated.

The Project Officer would particularly like to thank the following people for their generous support and guidance:

- Dr Beverly Wood
- Dr Sharryn-Lydell Smith  
Psychologist, Centre for Applied Gerontology  
Bundoora Extended Care Centre



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# Glossary of Terms

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AIDS	Acquired Immunodeficiency Syndrome
A&RMC	Austin and Repatriation Medical Centre
AuSPEN	Australian Society for Parenteral and Enteral Nutrition
BHCG	Bendigo Health Care Group
DAA	Dietitians Association of Australia
DHS	Department of Human Services (Victorian Government)
GIT	Gastrointestinal Tract
GP	General Practitioner
HACC	Home And Community Care
HEN	Home Enteral Nutrition
HITH	Hospital In The Home
HIV	Human Immuno-deficiency Virus
PAC	Post Acute Care
PEG	Percutaneous Endoscopic Gastrostomy
PHACS	Primary Health And Community Support
RDNS	Royal District Nursing Service
SHCN	Southern Health Care Network
SIG	Special Interest Group

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# Executive Summary

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## Introduction

The management of Home Enteral Nutrition in Victoria has recently received considerable attention with the formation of the Ministerial Working Party on HEN in 1996. Research undertaken by the Ministerial Working Party revealed an apparent disparity between health care facilities in their management of HEN clients. Coinciding with this insight was the development of the 'Clinical Practice Guidelines for Home Enteral Nutrition in Australia' (Appendix 1). It was proposed by the Ministerial Working Party on HEN that the introduction and adoption of these clinical practice guidelines would assist in consistency of best practice in HEN therapy throughout Australia. As such it was recommended that the provision of HEN in Victoria should be based on this framework (DHS July 1997; Appendix 2).

The question of how to best implement the AuSPEN Clinical Practice Guidelines in this era of finite health care resources was the impetus behind this project. The intent of the project was to identify the most efficient and cost effective manner in which to manage this growing client group. As such the overall aim of the project was to develop a service delivery model, and corresponding recommendations, for the implementation of best practice guidelines for HEN in Victoria.

This document outlines the research conducted in the first phase of the project. In this phase the objectives were to:

1. Profile existing HEN service systems in metropolitan and rural Victoria.
2. Identify gaps in service systems from a customer and service provider perspective.
3. Determine characteristics of service systems integral to implementation of best practice clinical guidelines.

This information was attained through a series of interviews with dietetic managers from HEN funded hospitals, a questionnaire to dietitians state-wide, and interviews with HEN clients managed by the organisations conducting the project.

## Key Findings

The results of our research supported the initial finding of the Ministerial Working Party; delivery of HEN services is managed in a variety of different ways across Victoria. At the time of our research there was no standardised infrastructure in Victoria to support a generic system for provision of HEN services. A number of gaps were consistently highlighted as factors limiting optimal provision of HEN services:

- A. Limited domiciliary services for the management of HEN.
- B. Varying access to multi-disciplinary expertise for the management of HEN, particularly with regard to the management of tubing and stomal issues.
- C. Multiplicity of contacts for clients with regard to HEN.
- D. Inequitable access to supply of HEN products.
- E. Lack of 24-hour support service for HEN.
- F. Lack of definition of roles and responsibilities of professionals involved in the management of HEN.

**A. Limited domiciliary services for the management of HEN.**

At the time of our research it appeared that few areas had the capacity to provide a domiciliary service for the purpose of managing their HEN client group. This apparent gap in service structures can present a number of logistical barriers to meeting standards of care for HEN. In the initial phase of establishing HEN, clients may be discharged prior to receiving adequate education regarding management of their HEN. This situation seems to be becoming increasingly common with the pressure to decrease hospital length of stay. The capacity to conduct a home visit in this situation is necessary if the client is to be adequately skilled such that they can manage independently.

A view put forward by both HEN clients and dietitians proposed that the ability to conduct a home visit in the initial phase was something that would benefit all HEN clients. It was suggested that more effective client education could be achieved in the home environment. It was also suggested that more accurate assessments can be made in the home, enabling development of care plans that better meet the needs of the individual.

Similarly the lack of domiciliary services for management of HEN presents issues for reviewing HEN clients. Many clients, particularly non-ambulatory clients, have great difficulty in attending the hospital for review of their HEN. Consequently those clients living in an area not serviced by a domiciliary team can only be reviewed by telephone.

**B. Varying access to multi-disciplinary expertise for the management of HEN, particularly with regard to the management of tubing and stomal issues.**

It is recommended that HEN clients are best managed by a multi-disciplinary team, however in practice this did not always seem to be occurring. Very few organisations had a specific team established to manage HEN, either through provision of an outpatient clinic, or as a domiciliary service. Management was commonly reported to be left to a single professional, often the dietitian. Alternatively a variety of professionals might be involved, however this was often managed in an uncoordinated manner. This lack of centralised coordination can result in poor communication and a disjointed and inefficient plan of care for the HEN client.

An aspect of care that has raised particular difficulties for many organisations managing HEN clients was with regard to the management of stoma and tubing issues. There was an apparent gap in many existing service structures in terms of access to professionals with expertise in these areas. This can result in untimely or poor management of tubing or stoma sites. These aspects of care require access to professionals with specific training or extensive practical experience in this area of enteral nutrition therapy.

**C. Multiplicity of contacts for clients with regard to HEN.**

An issue raised by many of the HEN clients interviewed was the multiplicity of contacts associated with the management of their HEN. A single point of contact to either manage or coordinate management was perceived as a better alternative. Similarly it would seem from a professional's perspective that centralised coordination has the potential to facilitate a more streamlined service for HEN.

#### **D. Inequitable access to supply of HEN products**

An issue raised by clients and professionals alike was equity of access to HEN supplies for clients. Access difficulties can occur for non-ambulatory clients, for clients with no means of transport and for clients who live in geographically isolated areas. Access restricted to business hours was also a limitation of many supply systems.

Home delivery of HEN supplies offers a solution to overcome this issue, however it was not a service generically integrated into supply structures at the time of our research.

#### **E. Lack of 24-hour support service for HEN.**

An area of concern raised by a number of HEN clients interviewed was the lack of a specific 24-hour contact for HEN. The main concern for clients is the scenario of their enteral tube falling out. At the time of our research it seemed that hospital emergency departments were the only points of contact in this situation. However there is a feeling of dissatisfaction or lack of confidence, amongst HEN clients interviewed, in the ability of these services to adequately manage issues associated with HEN. This suggests that new options or modification of existing systems might need to be explored for managing such situations.

#### **F. Lack of definition of roles and responsibilities of professionals involved in the management of HEN.**

Our research revealed an apparent lack of clearly defined roles and responsibilities of the various professionals that might be involved in the management of HEN. Variability in the profile of service providers in different areas was considered to contribute to this situation. It was proposed during our research that clearly defined professional responsibilities would facilitate more streamlined and cost effective care.

It was apparent from our research that concomitant to the need for clarification of professional roles and responsibilities is the perceived need for allocation of adequate resources for service provision. Ensuring client access to appropriate service providers is integral to attaining and maintaining best practice standards for HEN.

In addition to the perceived gaps in existing service systems described, the need for a number of auxiliary resources for supporting best practice was raised. Commitment to ongoing review and development of state-wide policies and procedures was seen to be important for standardisation and streamlining of HEN services. Support in the development and maintenance of professional expertise was also highlighted as a key requirement for best practice.

The findings and suggestions from this research have been used to define the elements intrinsic to best practice in service delivery for HEN in Victoria, as described in the document entitled: 'Development of a Best Practice Model for the Service Delivery of HEN. Phase II, Best Practice Model and Recommendations'.



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# 1. Introduction

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## 1.1 Background

Enteral nutrition is a feeding modality used to support individuals who are unable to manage adequate nutrition via the oral route as a result of impaired ingestion, digestion or absorption of nutrients. Enteral nutrition is commonly used in clients with neurological disorders, gastrointestinal disorders, cancer, cystic fibrosis and HIV/AIDS. It involves delivery of a nutritionally complete formula directly into the intestinal tract via a feeding tube. In the shorter term enteral nutrition is usually delivered via a naso-gastric or naso-jejunal tube. For longer-term nutritional therapy a gastrostomy or jejunostomy feeding tube is usually inserted.

Home enteral nutrition (HEN), as the name implies, is the use of enteral nutrition therapy in the home setting. HEN support allows enterally fed hospital clients, who are otherwise medically stable, to be discharged to the community. There are many benefits to the provision of enteral nutrition in the home. It enables improved quality of life and increased independence for the client by return to their home environment. The cost benefits to the health care system can be significant. Timely introduction of HEN can result in reduced length of hospital stay, the transfer of care to the community enabling more efficient and effective use of hospital beds. In addition, the increased acceptance and use of enteral nutrition in the home setting has obviated much of the former need for long term care in health care institutions.

The use of HEN is increasing both nationally and internationally. In line with the national and international trends, the number of HEN clients managed throughout Victoria continues to increase each year (Elia, 1995; DHS July 1997; Winter et al. 1999). As a result the management of HEN in Victoria has recently received considerable attention. In 1996 a Ministerial Working Party was formed to review the provision of HEN in Victoria. Coinciding with this, the Australian Society for Parenteral and Enteral Nutrition (AuSPEN) released the first set of 'Clinical Practice Guidelines for HEN in Australia' (Appendix 1).

In October 1997, subsequent to recommendations made by the Ministerial Working Party on HEN (Appendix 2), the Department of Human Services (DHS) introduced the HEN Pilot Program. This program is the first state-wide initiative to assist in the provision of HEN.

The HEN Pilot Program entitles recipients of HEN, managed under the public health care system, to subsidised HEN supplies (formula and equipment). DHS has delegated this funding for HEN supplies to public Health Care Networks and Major Rural Regional Hospitals throughout Victoria. Under the current funding model for the HEN program, these Networks or Regions receive an annual block grant, based on historical patterns of HEN provision. Funds are distributed as appropriate to health care facilities, within these Networks / Regions, that manage eligible HEN clients (adult and paediatric). From here it is up to the health care facility to determine the most appropriate vehicle of supply for their HEN client population.

The funding has been granted contingent on agreement from health care organisations to meet a number of conditions. One such contingency is to collect a minimum data set of information. A lack of data on the extent of HEN usage in both Victoria and Australia was noted by the Ministerial Working Party. As a result of this finding the Working Party commissioned the

development of a minimum data set for HEN. Subsequently a database was developed to collect information on HEN clients incorporating the agreed minimum data set.

Another contingency for acceptance of HEN funding is that HEN providers must implement and adhere to best practice guidelines, as described by the AuSPEN Clinical Practice Guidelines for HEN (Appendix 1). This incorporates:

- Adoption of a multi-disciplinary team approach or a case management approach for HEN clients
- Regular review of HEN clients, at least within the first three months of discharge and every six months thereafter (at a minimum) with clinical reviews to be undertaken by a dietitian and a medical specialist (Appendix 2)

The question of how to best implement the AuSPEN practice guidelines in this era of finite health care resources was the impetus behind this project. At the time of release of these recommendations there was an apparent gap in the literature with regard to the structure of HEN service delivery systems in Australia. The report from the Ministerial Working Party was the first state-wide review undertaken with regard to HEN in Victoria (DHS July 1997). In this review it was noted that the delivery of HEN services appeared to be managed in a variety of different ways across Victoria. Anecdotal evidence suggests that the HEN service systems in Victoria have been initiated, designed and implemented on an individual basis by the various health care facilities that manage HEN clients. In light of these findings, the intent of this project was to identify the most efficient and cost effective manner in which to manage this growing client group.

## **1.2 Aims and Objectives**

The overall aim of the project was to develop a service delivery model, and corresponding recommendations, for the implementation of best practice guidelines for HEN in Victoria. This document outlines the research conducted in the first phase of the project. In this phase the objectives were to:

1. Profile existing HEN service systems in metropolitan and rural Victoria
2. Identify gaps in service systems from a customer and service provider perspective.
3. Determine characteristics of service systems integral to implementation of best practice clinical guidelines.

With this research being funded through the Victorian Government Department of Human Services' HEN Pilot Program, the project has focused on the provision of HEN in the public health care system in Victoria. As such HEN managed through privately funded health care facilities has not been examined in this project. Similarly the management of enteral nutrition in nursing homes was not considered in this project, as provision of enteral supplies is funded through a Commonwealth Government grant.

The methodology and results of research conducted in the first phase of the project are presented and discussed in the following report.

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## 2. Study 1 - Method

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As the budget holders for the HEN Pilot Program and key stakeholders in the management of HEN, dietitians were targeted for a professional perspective on HEN service systems. It is clearly recognised that other health professions such as nursing, medical, stomal therapy and speech pathology are also involved in the management of HEN. However, owing to time constraints, consultation with such a large number of people was beyond the scope of this phase of this project.

In study 1, two methods of data collection were undertaken:

- Part A – Dietitian interviews.
- Part B – Dietitian survey.

### 2.1 Part A

This part of the study was undertaken to obtain a profile of some established HEN service systems in Victoria and to obtain a preliminary picture of issues or gaps in established service systems.

#### 2.1.1 Participants

Managers, or their delegates, from HEN funded public health care facilities in metropolitan Melbourne and rural Victoria were invited to participate in an interview. The health care facilities were selected on the basis of allocation of HEN budget as per the 1998/1999 DHS funding round for the HEN Pilot Program. In rural regions, the health care facilities responsible for management of the Regional budget were invited to participate.

A total of 33 dietitians across Victoria were interviewed. See Appendix 3 for details.

#### 2.1.2 Materials

The purpose of the interview was to describe the following aspects of HEN provision originating from the respective health care facilities:

- Initiation and education of the HEN client.
- Provision of HEN supplies.
- Review and monitoring of clients.
- Management of tubing and stomal care.
- Administration of the HEN program.
- Other funded or ambulatory care programs and their association with HEN.
- Issues or gaps associated with present service systems.

A semi-structured approach to the interview was taken to ensure consistent coverage of all the above listed topics, while allowing for exploration of new issues.

### **2.1.3 Procedure**

An introductory letter was written to all Dietetic Managers from health care facilities allocated a HEN budget. A follow-up telephone call was made to arrange an interview time with those who agreed to participate.

The majority of subsequent interviews were conducted face to face. In a few cases interviews were conducted over the telephone. Interviews were approximately one hour in length. The interview was recorded by hand on an interview schedule pro-forma.

## **2.2 Part B**

This part of Study 1 was conducted to expand upon the data collected in Part A. The aim was to explore in more detail issues or gaps that might exist within current HEN service systems, and to identify areas of need, such as additions to service structures and development of training programs or resources.

### **2.2.2 Materials**

A questionnaire was developed specifically for the purpose of this survey. It was designed to obtain the following information:

#### **Demographics**

- A profile of dietitians in terms of experience with management of HEN.

#### **HEN Service Systems**

- Perceived gaps in current service systems:
  - establishment of HEN
  - supply of HEN products
  - review of HEN clients
  - administration of HEN program
- Views on the benefits of domiciliary services for HEN.

#### **Management of HEN**

- Views as to whether dietetic management of HEN should be a generalist or specialist role.
- Perceptions about dietitian's role or ability in screening/identifying issues with stoma sites and tubing.
- Views on adequacy of resource allocation for service provision.
- Perceptions as to the level of access to support regarding management of HEN.
- Role of various professionals in the management of HEN as perceived by dietitians.

#### **Dietetic Skill Base**

- Dietitians self-assessment of their level of knowledge/expertise in managing various aspects of HEN.

## Training / Resource Development

- Dietitian's assessment regarding the need for development of training/professional updates and resources for dietitians with regard to HEN.

### 2.2.1 Participants

Participants in this study consisted of dietitians currently residing in Victoria. The membership listing of the Dietitians Association of Australia (DAA), Victorian Branch was used as the sampling frame. This enabled us to reach dietitians across the full spectrum of geographical locations and areas of employment within Victoria.

It was decided to sample the full data set (excluding addresses outside of Victoria) in order to provide all members with the opportunity to comment on the topic, not just those who are presently involved in HEN. A response rate of 56% was obtained (493 questionnaires mailed out).

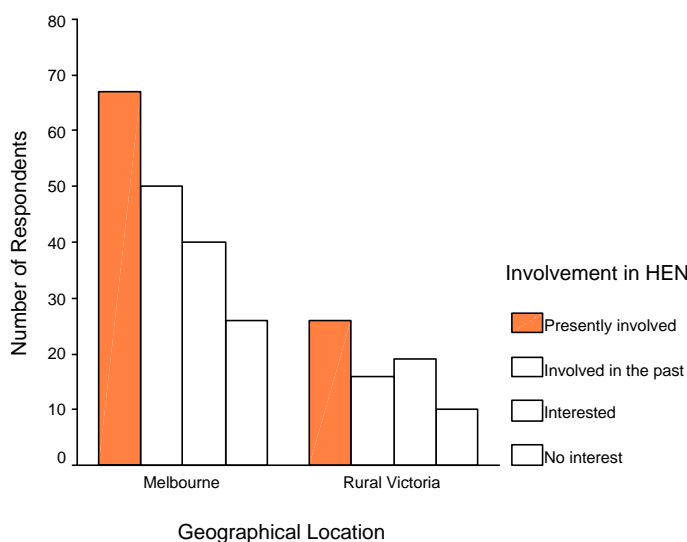
A total of 277 dietitians participated in this study. Five responses were deemed invalid through missing information. Dietitians from a wide range of employment areas responded to the questionnaire, however the majority of respondents were employed at public hospitals (n=106), with smaller numbers being from community settings (n=55) and private hospitals (n=23). In terms of geographical location, 72% (n=196) of respondents were from metropolitan Melbourne area and 28% (n=76) were from rural areas of Victoria.

Responses were received from dietitians with varying years of experience ranging from 0 (students) to 50 years experience, with the mean years of experience being 12.0 years (SD = 9.5). In addition to general dietetic experience, data was also obtained on respondent's experience with the management of HEN. At the outset of the questionnaire, respondents were asked to categorise themselves in terms of their level of involvement or interest in HEN according to the following categories:

1. Presently involved in the management (clinical and/or administration) of HEN clients.
2. Not presently involved in the management of HEN clients, but have been in the past.
3. Never managed a HEN client, but is an area of interest.
4. No interest in HEN.

This information was then used to direct respondents to relevant starting points in the questionnaire.

Figure 1 below displays geographical distribution of respondent's according to how they rated their level of involvement in HEN.



### Figure 1 Experience with HEN by geographical location

As can be seen in Figure 1, the majority of responses were received from dietitians presently working in HEN. The percentage distribution of experience in HEN was similar between metropolitan and rural areas.

### **2.2.3 Procedure**

The questionnaire was mailed out to the sample selected from the data set (total of 493) in November 1998. Dietitians were asked to complete the questionnaire and return in self stamped and addressed envelopes provided.

Descriptive statistics were generated from the returned data using SPSS computer software.

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## 3. Study 1 - Results

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The results of Parts A and B have commonalities in the content of the data obtained. As such the results of the two Parts in Study 1 have been amalgamated in order to present a more complete and comprehensive picture of our findings.

The results have been presented in a manner that follows the sequence of events that a HEN client might experience throughout their episode of HEN. Following that, data is presented relating to support processes and structures associated with the delivery of HEN.

### 3.1 Establishment of HEN

'Establishment of HEN', as used in this context, is referring to the process of preparing a client receiving enteral nutrition for the transition from hospital to home. Generically this involves:

- Establishment of a feeding regimen.
- Education of the client and/or carer in the self-management of enteral nutrition.
- Discharge planning for enteral feeding in the home environment.

As observed in the dietitian interviews, a range of systems and professionals were utilised in the process of establishing a client on HEN. These appeared to vary from organisation to organisation depending on the level and type of services available. While in most cases structures and processes were in place for managing HEN, there appeared to be a number of issues within these frameworks that impacted on the ease with which a client was established on HEN. The dietitian questionnaire indicated that 69 % (n=65) of respondents who were working in the area of HEN had issues with the process of establishing a client on HEN.

What follows is a description of how organisations differed in their reported management of HEN, in this initial phase, and a summary of the issues in service systems, raised by dietitians.

#### 3.1.1 Location

Our interviews with dietitians indicated that it was common practice for HEN clients to have their enteral feeding tube inserted in the hospital setting. In most instances, clients commenced on enteral nutrition, with the view to continuation at home, were initially educated on the ward during their hospital admission. On occasion some clients were reported to be educated, entirely or in part, in their home.

##### **Hospital**

In our interviews a situation impacting on the adequacy of education for HEN clients in the hospital setting was highlighted. With increased pressure on the public hospital system to reduce length of stay, HEN clients were perceived to be discharged more rapidly than what they might previously have been. It was observed that in this situation there was insufficient time to provide the appropriate level of training to enable these clients to manage independently at home. This issue was also raised in the dietitian questionnaire as can be seen by some of their comments quoted below.

*“Length of hospital stay often limits the training of HEN patients.”*

*“There are problems with early discharge. This occurs due to doctors lack of understanding about HEN.”*

*“Often the ideal discharge date from the medical stability point of view is earlier than the ideal discharge date from the ‘independent with HEN’ point of view. If dietitians could visit patients at home to assist with becoming independent with HEN, this would reduce the reliance on services such as Post Acute Care, Royal District Nursing Service, or private nursing agencies which, while able to help, are not specifically expert in HEN.”*

The suggestion was put forward that home visits would be required to ensure the HEN client was adequately skilled should early discharge occur.

## **Home**

Other comments received from respondents to the questionnaire suggested that some dietetic practitioners viewed assessment and education of the HEN client in the home environment as the most appropriate way to introduce HEN:

*“It is extremely valuable to view the client in their home environment as a lot of issues/concerns are not picked up in the hospital environment, eg feeding technique, cleaning/hygiene, equipment set-up.”*

*“Assisting patients when they are first discharged home is important. People often benefit from help in setting things up at home.”*

*“A home assessment enables improved problem solving and integration of feeding into the clients living environment.”*

*“The home setting allows for a more relaxed atmosphere, perhaps allowing for better dissemination of information and improved demonstration abilities on the part of the dietitian/demonstrator.”*

The comments quoted above indicate the ability to conduct an initial home visit was thought enable more accurate assessments. The retention of information on the part of the HEN client or carer was also thought to improve outside of the hospital environment.

The ability for a home visit to be conducted seemed to be dependent on a number of factors. A few hospitals reported using other government funded programs such as Post Acute Care (PAC) or Hospital In The Home (HITH) to educate the HEN client at home and continue the discharge planning. Unfortunately not all hospitals had programs such as these available and often HEN clients were ineligible for management under these programs, as per the eligibility criteria of the respective programs. A few hospitals indicated that they were able to conduct home visits if necessary, however many noted that Nutrition and Dietetic Departments did not have the staffing capacity to provide such a service.

The other option available to some hospitals, where an initial home visit was deemed essential, was to utilise a community dietitian who was funded under the Home And Community Care

(HACC) program. Access to this service was once again an issue for many organisations as there were only a limited number of HACC dietitians in metropolitan and rural Victoria at the time of our research.

Community based nurses such as the Royal District Nursing Services (RDNS) were often involved with HEN clients when they were initially discharged home. However this service was not necessarily organised for all HEN clients.

See Appendix 4 for a description of other DHS funded programs used for the management of HEN.

### 3.1.2 Service Providers

Through our interviews with dietitians, it became apparent that a range of health professionals could potentially be involved in the process of establishing a client on HEN. The reported range and combination of professionals involved in this phase varied from organisation to organisation.

#### Dietitians

##### Hospital versus Community

As most HEN clients have their enteral nutrition tube inserted in the hospital setting, hospital dietitians, as opposed to community dietitians, were predominantly involved in the initial education of clients. Involvement from community dietitians in this initial phase varied. In the situation where a client was discharged from hospital without adequate education, a community-based dietitian might become involved. However, as discussed previously the availability of community dietitians was perceived to be a limitation.

##### 'Specialist' versus 'Generalist' Role

Our interviews revealed that hospital Nutrition and Dietetic Departments also varied in their management of HEN clients. Some hospitals had allocated a 'HEN dietitian'. This 'HEN dietitian' was either responsible for educating all HEN clients in hospital or they might take over their management around the point of discharge. In the majority of hospitals, the establishment of HEN was undertaken by the dietitian associated with the medical / surgical unit, under which the HEN client was admitted.

It was the view of one hospital that the management of HEN should remain an area that is managed by all dietitians:

*"We avoid creating a 'specialist' position as it is an interesting area of practice and we aim to maintain 'generalist' expertise."*

The question as to whether HEN should be managed by a 'specialist' dietitian, or whether it is an area that all dietitians should be able to manage, was explored further in the dietetic profession in our survey. In the questionnaire, respondents were asked to rate their attitude to various statements, pertaining to this issue, on a scale of agree to disagree. Responses to two such statements are shown below in Figure 2 and Figure 3.

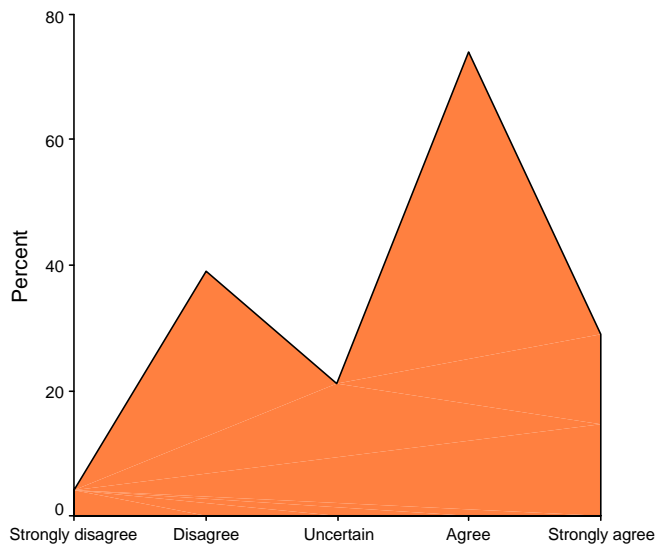


Figure 2 “HEN is best managed by a dietitian with a high level of expertise”

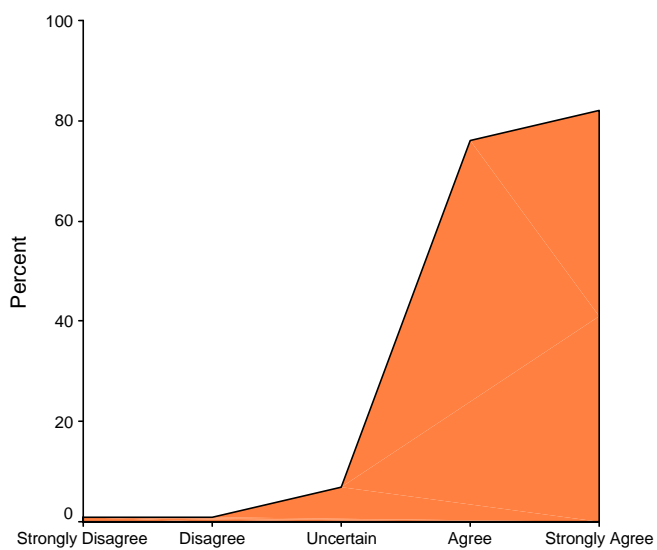


Figure 3 “With additional support or training, HEN is an area that all dietitians would be able to manage.”

The results presented in Figure 2 suggest that the majority of respondents agreed (61% n=103) with the view that HEN would be best managed by a ‘specialist’ dietitian. However, as shown in Figure 3, it would appear that most respondents (95%, n=158) felt that, with additional support or training, HEN would actually be an area that all dietitians would be able to manage.

## **Coordination**

Throughout the dietitian interviews, some comment was received with regard to the advantages of having the nutritional management of HEN delegated to a single dietitian:

*“We have found having just one person following up HEN clients and coordinating the program has been much easier than everyone in the department being involved.”*

Those departments who had a single dietitian assigned to manage HEN, either entirely or just prior to discharge, reported that this system had enabled HEN to be managed in a more efficient and coordinated manner than when everyone in the department had some involvement.

## **Other Health Professionals**

The service profiles indicated a number of health professionals, in addition to dietitians, were involved in the process of establishing and educating HEN clients.

### **Nurses**

Nurses (ward nurses, endoscopy nurses, discharge liaison nurses) were reported to have involvement in this phase, with the majority of HEN clients.

### **Stomal Therapists**

Input from stomal therapists appears to be less frequent, as not all hospitals have the services of a stomal therapist for HEN. In these situations it seems that education regarding stomal care is taken on mainly by nursing staff, or less frequently by the dietitian.

### **Medical Professionals**

Medical professionals (unit registrars, gastroenterologists, and surgeons) were reported to be involved in the initial phase of HEN, mainly with regard to insertion of feeding tubes. They were generally perceived to have less involvement in the education and discharge planning associated with establishing a client on HEN.

### **Speech Pathologists**

Speech pathologists were generally only involved when HEN was initiated as a consequence of dysphagia.

### **Social Workers**

Social workers were perceived by dietitians to have less of a role in HEN since the introduction of HEN funding. However a few dietitians interviewed noted that social workers might still be involved in cases with more complex psychosocial issues.

### **Enteral Company Representatives**

At one hospital interviewed, enteral company representatives were involved in education of HEN clients that would be using a pump provided by the company. Otherwise no involvement from these commercial sources was noted in the initial establishment phase of HEN.

### 3.1.3 Roles and Responsibilities of Service Providers

Given the range of service providers that were identified as having involvement in the establishment of HEN, we were interested to see if these professionals were perceived to have clearly defined roles and responsibilities. In the questionnaire, dietitians that had experience with the management of HEN (n=167), were asked to nominate professionals they felt should ideally be responsible for managing various aspects of HEN. The results pertaining to aspects of care associated with the establishment phase of HEN are presented below. Note that respondents were able to nominate multiple professionals for each aspect of care.

#### Nutritional Assessment and Requirements

Figure 4 and Figure 5 display the professionals nominated by dietitians as having roles in the nutritional assessment of a client and the determination of nutritional requirements, respectively.

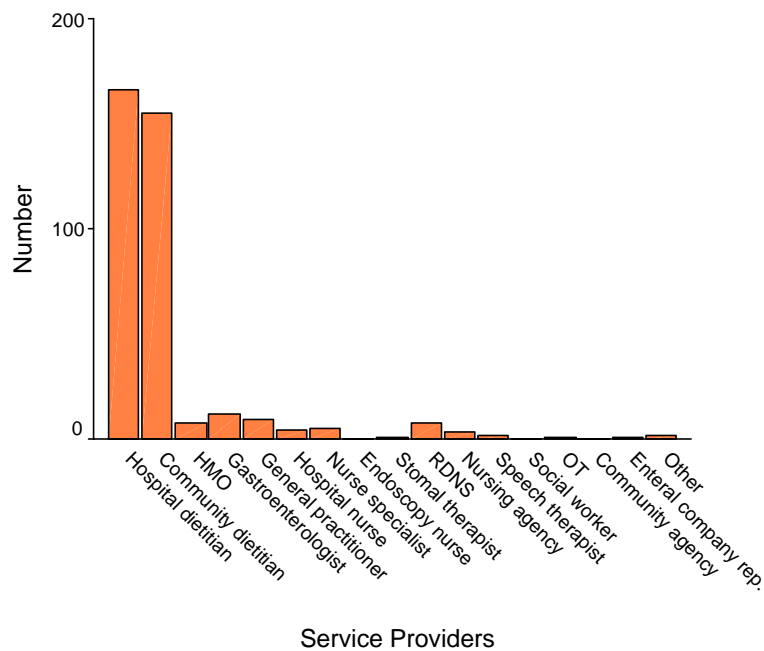


Figure 4 Roles and Responsibilities – Nutritional Assessment

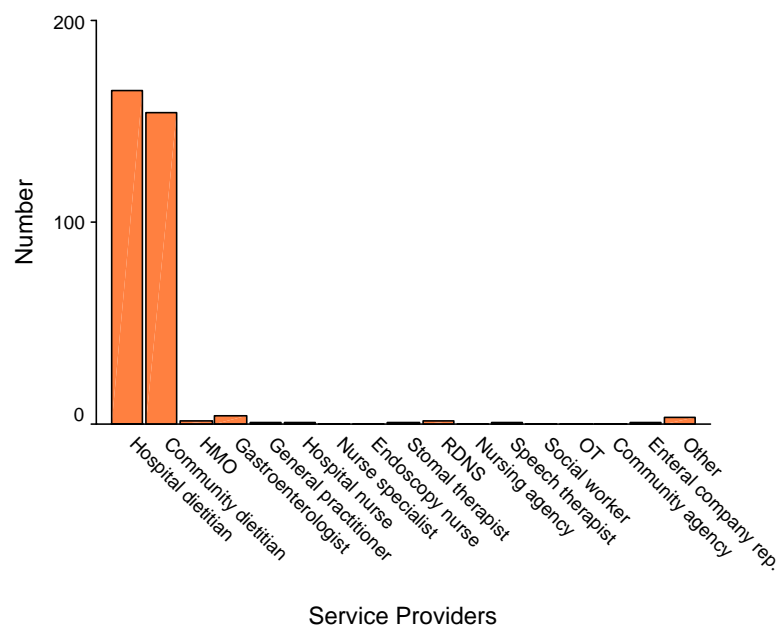


Figure 5 Roles and Responsibilities – Nutritional Requirements

With regard to nutritional assessment and determination of nutritional requirements there was a clear consensus that this was the role of dietitians, hospital or community based.

**Education of Formula Administration**

Education of the HEN client in administration of their enteral feeding regimen was perceived by dietitians to be the responsibility of the professionals depicted in Figure 6.

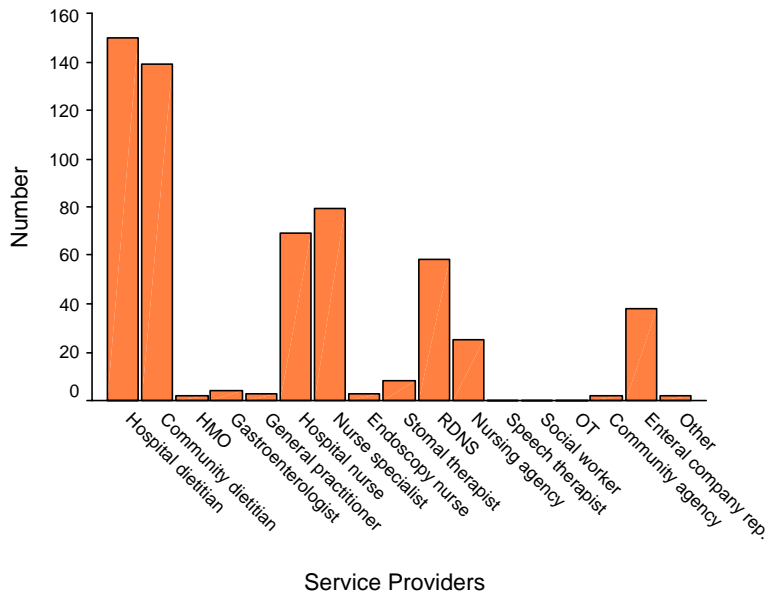
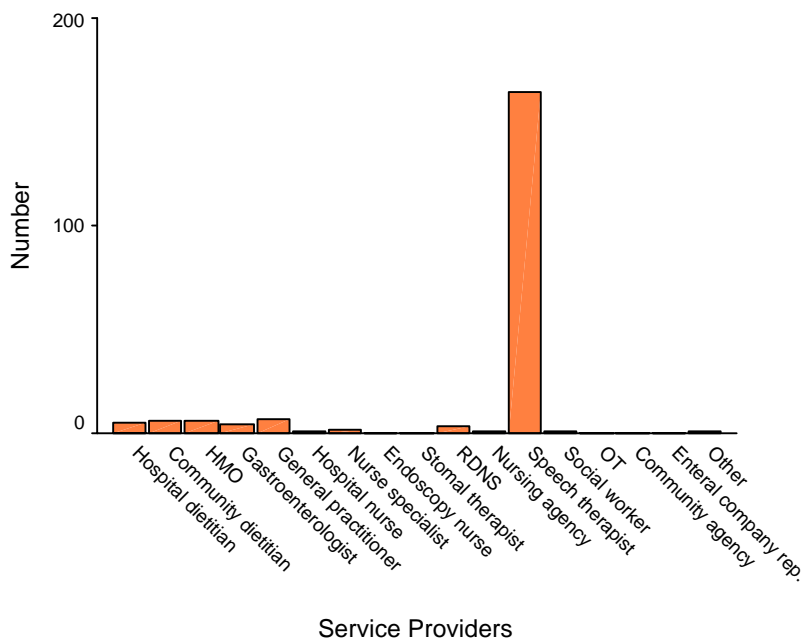


Figure 6 Roles and Responsibilities – Education of Formula Administration

As can be seen in Figure 6, education of formula administration was thought to be predominantly the role of dietitians, followed by the nursing profession (hospital based or community based). Enteral company representatives were also seen to have a role in this aspect of management.

**Assessment of Swallow**

Figure 7 displays the professionals perceived as being responsible for the assessment of a HEN client’s swallowing status.



### Figure 7 Roles and Responsibilities – Assessment of Swallow

Assessment of clients with dysphagia was clearly perceived by dietitians to be the role of the speech pathologist.

### Discharge Planning

The perceived roles and responsibilities of service providers with regard to discharge planning are illustrated in Figure 8.

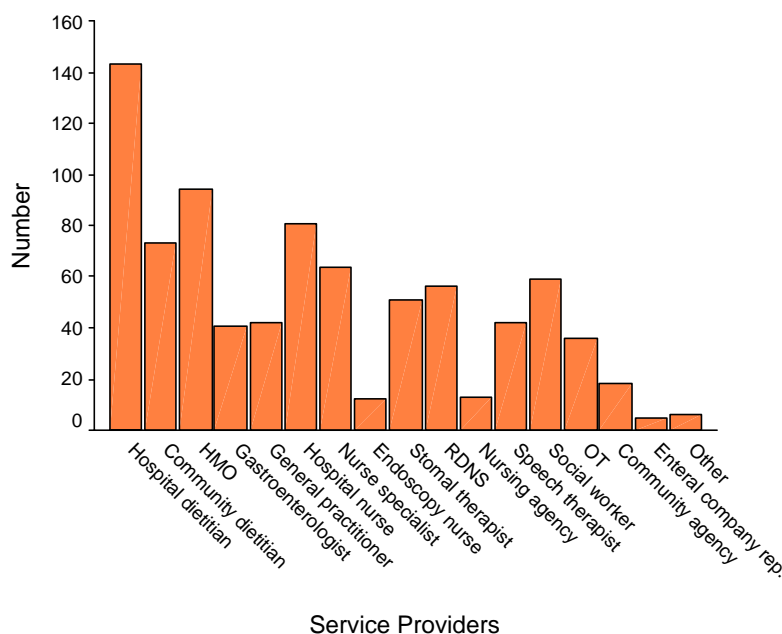


Figure 8 Roles and Responsibilities – Discharge Planning

In comparison to other aspects of care discussed previously, the responsibility of discharge planning is not clearly seen to be the sole responsibility of any particular professional discipline. Hospital dietitians rated highly with a rather even distribution of responses to medical, nursing and other health professionals.

### Care of Enteral Tubing and Stoma Sites

Roles and responsibilities regarding stoma care and management of enteral tubing are discussed in the Section 3.2.5.

### 3.1.4 Issues

From the dietitian questionnaire a number of other issues were raised with respect to establishing a client on HEN. These included:

- Difficulties with transfer of care to other hospitals.
- Workload and funding issues.
- Client eligibility for the HEN Pilot Program.

#### Transfer of Care

The need to transfer the care of a HEN client typically occurs when a client lives geographically distant from this initiating health care facility. For example this might typically occur if a rural client has their HEN initiated while attending a metropolitan hospital. In this situation the usual process would be to transfer the care of the client's HEN to a hospital local to the client's place of residence. This process appears to have caused some issues for dietetic practitioners. Below are some examples of comments received that highlight of these issues.

*“Transfer to rural areas is time consuming and does not always run smoothly.”*

*“Coordination and communication can be difficult in transfer to a rural or more inaccessible location.”*

*“Poor communication through discharge summaries to rural dietitians.”*

*“Not all Melbourne hospitals provide adequate transfer information.”*

In transferring HEN, the time taken to coordinate the transfer was been highlighted as problematic. In our interviews, actually locating a dietitian to manage care, or one with experience with HEN, was a difficulty raised, particularly if the HEN client lived in a more isolated area of the state. The lack of a ‘dietitian directory’ was seen as a problem. Inadequate hand over and/or poor communication were noted as issues for the receiving practitioner.

A number of comments were received regarding supply of formula and equipment when transferring HEN clients, particularly when transferring a client from a metropolitan hospital to rural areas:

*“On transfer to rural areas, metropolitan hospitals do not always supply an adequate quantity of feeds and our service cannot guarantee seeing a new client immediately on transfer. It would help to have a standard discharge supply, eg 1 month.”*

*“Clients are sometimes ‘hand-balled’ to rural areas with insufficient feed. It takes time to order special products we don’t have in stock.”*

## **Workload / Funding**

With the increasing number of HEN clients, a number of comments were received regarding human resources for the management of this client group:

*“The work involved in education and organisation for home on the part of the dietitian is an issue. This is time well spent but often hard to find.”*

*“Establishing a client on HEN is a time consuming process, especially if it is a small dietetics department.”*

The management of HEN clients can be time consuming, as noted in both our interviews and in the questionnaire. The allocation of time required for establishing a client on HEN was seen to place significant strain on many departments' resources.

## **Client Eligibility**

Some confusion and perceived inequities in the eligibility of nutritionally supported clients for the DHS funding were raised through our interviews and survey. These are highlighted below.

### **State Borders**

*“Patients living on VIC/NSW border areas (ie Echuca/Moama, Albury/Wodonga, Cobram/Barooga) not eligible once in NSW but often managed by Victorian hospital.”*

Eligibility of clients who live just outside of the Victorian borders has been questioned. There was confusion as to whether HEN clients who reside in NSW, but are managed by a Victorian Hospital, are eligible for funding.

### **Other Government Programs**

There was some confusion in terms of eligibility of clients who are funded under brokerage programs such as 'Linkages'. The query was made regarding which program should cover the cost of the formula and equipment for HEN clients in this situation.

### **Oral Supplements**

*“Many of our patients are able to meet their nutritional requirements by consuming nutritional supplements orally (occasionally up to 80% of requirements). These people have been forgotten by the HEN funding because they do not have an enteral tube. Need some sort of financial support as the present system is inequitable.”*

A situation of perceived inequity in the funding system involved clients who are able to consume nutritional supplements orally. Inequity was mainly seen for those clients who depend on nutritional supplements to maintain their nutritional status. However, because they were able to manage orally, they did not have an enteric feeding tube in situ, and as such were ineligible for funding under the Program's eligibility criteria.

## Private Patients

*“I believe patients admitted to private hospitals and discharged home with gastrostomies are not eligible for feed subsidies. I believe this is inequitable and discriminatory as many elderly people have private health insurance but are not affluent. Can anything be done?”*

*“Private hospital patients should be covered by the government.”*

There was also some concern over the ineligibility of clients who have private health insurance. Often these clients might be pensioners who have maintained their private health insurance. These clients subsequently had their HEN initiated in a private hospital. At the time of our research private health insurance did not cover formula and equipment for HEN. As such these clients were left to pay the bill for their supplies. This was seen to place significant financial strain on many of these HEN clients, the cost of formula and equipment being substantially higher than the average weekly cost for food.

## 3.2 Ongoing Management of HEN

As with the process of establishing a client on HEN, the systems and personnel involved in the review and ongoing management of HEN clients were found to vary between organisations. Similarly there appeared to be a number of gaps or issues with aspects of systems that impacted on the ease with which HEN clients were managed. The dietitian questionnaire indicated that approximately 70% (n=65) of respondents, who were involved in the management of HEN at the time of our survey, had issues with the system structures in place for reviewing HEN clients.

What follows is a description of some of the structures and processes used by various organisations to manage their established HEN clients and an outline of some the issues raised by dietitians.

### 3.2.1 Location

From the service profiles obtained with dietitians, it was found that HEN clients were reviewed in many ways. Most commonly HEN clients were seen by the dietitian, as an outpatient, either in a specific dietetic clinic, or at a time arranged on an individual basis with the client.

Alternatively clients were reviewed by the dietitian in conjunction with another outpatient appointment, such as with the client's primary unit review. In only a few organisations was a specific multi-disciplinary HEN outpatient clinic established. Other options for review included review during an in-patient stay or during attendance at a day clinic such as day rehabilitation. If a HACC dietitian was available in the area, the review of the client might be handed over so as a home visit could be undertaken, particularly if the client was non-ambulatory. In a few instances (as with the process of establishing a client on HEN) dietitians in acute centres might conduct home visits if required. The telephone was utilised in most organisations to review their HEN clients. It was used as an interim contact with the client between hospital or home visits, or was used exclusively as the medium for review.

In nearly all organisations, no single method of review was used in isolation. Owing to the diversity of the HEN client group, a variety of follow-up systems invariably needed to be used in order to accommodate the individual situations of each HEN client. Below is a more detailed discussion of the perceived advantages and/or disadvantages of each review process.

#### **Outpatient HEN Clinic**

Of the HEN funded health care facilities profiled, three reported to have specific HEN outpatient clinics in place for review of their clients. The ones that were established were of a multi-disciplinary nature, involving a doctor, dietitian and a nurse. In the clinics that were described, the doctor involved was a gastroenterologist, a surgeon or a doctor with a special interest in nutrition. The Nutrition and Dietetic departments of these hospitals had a dietitian specifically allocated to review and monitor the organisation's HEN clients. The nursing staffs involved were either a stomal therapist or a clinical nurse specialist.

Investigation, during our interviews, into why this type of clinic was not common place revealed that there were some perceived barriers to establishing such a clinic. These barriers included:

- A lack of service funding.
- A lack of interest from non-dietetic disciplines.
- The number of HEN clients at some organisations was seen to be too small to justify establishment of a specific clinic.

Some responses, highlighting potential difficulties associated with a specific HEN clinic, were received from people working in organisations that actually had multi-disciplinary clinic in operation:

*“We have set up a multi-disciplinary clinic for HEN clients. They must come in at least every 6 months even if seen by community dietitian in mean time but occasionally it is hard logistically to get them in.”*

*“We have a HEN clinic for ongoing review. However the failure to attend rate is high. Patients who have multiple appointments at hospital give a low priority to coming in for HEN review.”*

As indicated in the comments above, there might be some potential difficulties with specific HEN clinics. Clients with multiple medical issues might not wish to attend an additional appointment. Hospital based HEN clinics might also be logistically difficult, for the likes of non-ambulatory clients, to attend.

### **Regular Medical / Surgical Outpatient Clinic**

If there was no specific multi-disciplinary HEN clinic established, often the dietitian would try to coordinate review of their HEN clients with the client’s medical/surgical clinic appointments. This might be convenient for the client, however it was pointed out that this could be an inefficient system of review for other health professionals:

*“When discharged patients have review appointments organised with the medical staff and the dietitians appointment is arranged to coincide with this. However often these appointments are changed, cancelled or after discharge patient’s follow up is organised at an alternative hospital. Our patients often ‘get lost’.”*

*“Some difficulties in coordination for patients who attend multiple clinics.”*

*“Coordinating dietetic review with medical review is often difficult.”*

*“There is an issues of distance for some clients to come in for visits. Need to be flexible to fit in with family/other appointments which is not always possible.”*

### **Dietitian Outpatient Clinic**

Contrary to the AuSPEN guidelines (Appendix 1), the most common method of reviewing HEN clients, aside from use of the telephone, was found to be solely with the dietitian. A few Nutrition and Dietetic departments had a specific outpatient clinic allocated for review of HEN.

Alternatively the reviews were made on an individual basis with the client. If the client collected supplies directly from the hospital the review appointment would often coincide with this.

Review of HEN by the dietitian was also seen to have some difficulties as illustrated by the comments below:

*“We tried to set up a separate clinic for HEN review, yet often clients don’t want to make a special trip just to see the dietitian if they are coming on other days to see doctors.”*

*“Would be great to have a continuity type position within the department so HEN patients could be reviewed at home rather than having to come to our ‘HEN clinic’. High failure to attend rate in clinic.”*

As with multi-disciplinary HEN clinics, failure to attend was also seen to be a problem with establishment of a specific dietetic clinic time.

## **Telephone**

As noted previously, dietitians reported in the interviews that the telephone was routinely utilised to maintain contact with HEN clients. It was used to review clients if the time between visits to the hospital was too great. Significant amounts of time have been reported trouble shooting issues with HEN clients over the telephone.

In other cases the telephone had been resorted to as the only possible form of follow-up. This occurred in the situation of HEN clients who were non-ambulatory or HEN clients who were unable to attend hospital outpatient clinics, owing to transport difficulties, or simply distance. If there was no capacity to conduct a home visit, or if there was no local follow up available, then the telephone was the only option with which to maintain contact with these clients. The questionnaire indicated this scenario was quite common:

*“There is no opportunity for us to conduct home visits for bed bound patients. Presently we must review by phone.”*

*“Some degenerative and terminal cases find clinic reviews difficult due to availability of transport and/or difficulty in travelling.”*

*“It is difficult for some patients to come in for review and we don’t have ability to home visit easily.”*

*“Often clients are disabled and find transportation for reviews difficult, or the distance they need to travel for a review, is perceived to be too far.”*

*“Most of our reviews are phone interviews as many of our patients are unable to come into hospital and there is no time for dietitian to do home visits.”*

Review of HEN over the telephone was generally thought to be inadequate without at least intermittent face to face reviews:

*“Some clients do not have to return to the centre for ongoing follow-up (or are unable to because of distance or disability). It is very important to be able to continue face to face follow-up to see how things are really going – not just over the phone.”*

### **Home visit**

Some hospitals were in an area that was serviced by a HACC dietitian. These health care facilities seemed to make full use of the domiciliary role that these practitioners are able to provide and handed over the dietetic management of their HEN clients that were unable to attend the acute centre for follow-up. At one organisation the dietetic management of all HEN clients initiated at the acute centre was handed over to the HACC dietitian servicing the area.

As described in the previous section on the establishment of HEN, one hospital interviewed utilised the Post Acute Program (PAC) to conduct home assessments and education in the initial discharge phase. This program enabled follow-up in the home for up to 4 weeks post discharge. However ongoing follow-up then needed to be addressed after this period. This was often a particular issue for the category of HEN clients who were unable to attend, or had difficulty in attending, a centre for review.

Only a few hospitals had the capacity to conduct home visits. As noted in Section 3.1.1 there was often seen to be inadequate staffing levels to enable such a service from the acute centre. Comments regarding this issue were also received in the questionnaire:

*“Unable to perform unfunded domiciliary visits if clients are unable to attend the centre.”*

*“I am a sole dietitian in a major rural hospital and have minimal time for any outpatients, let alone HEN patients as well. Need a dietitian employed to be able to conduct outpatients and home visits.”*

*“50% of our clients are unable to attend hospital for review. There are no HACC service for dietetics in our area, therefore follow-up is difficult. Not all patients are seen in outpatient clinics, they are managed by GP in community. I find it very difficult to coordinate community resources from hospital base. Ideally a dietitian based at hospital who could go out into the community would be good.”*

### **3.2.3 Domiciliary HEN services**

It would seem, from statements such as those exemplified throughout Sections 3.1.1 and 3.2.2, that the ability to conduct home visits was seen to be integral to the appropriate management of HEN. The extent of this view was explored further in the dietitian survey. Respondents, who were involved in the management of HEN at the time of the survey, were asked directly if they felt the ability to provide a domiciliary service for HEN clients was beneficial. A strong positive response was received with 95% (n=90) agreement. About half (51% n=44) of these respondents actually felt that all HEN clients would benefit from this type of service, while 42% (n=36) thought that the non-ambulatory group of HEN clients would best benefit. ‘Other’ sub-groups of HEN clients perceived to benefit from a domiciliary service were frail elderly or disabled clients and carers who often had multiple issues.

The perceived benefits of a domiciliary service for HEN clients were many. Below are the key benefits as outlined by these respondents.

### **Improved Interventions**

*“It is extremely valuable to view the client in the feeding environment as a lot of issues/concerns are not picked up in the hospital environment, ie technique, cleaning/hygiene, equipment set-up.”*

*“Easier to understand client difficulties and adjust program for client as needed.”*

*“Able to obtain a much better idea of exactly how feeds are given, whether environment is suitable, how well carer is coping. Would be able to respond to queries very practically by showing patient what to do rather than telling them over the phone.”*

*“Improved problem solving and integration of feeding into the clients actual social and living environment.”*

*“More accurate monitoring for non-ambulatory patients.”*

*“The home setting allows for a more relaxed atmosphere – perhaps allowing for better dissemination of information and improved demonstration abilities on the part of the dietitian/demonstrator.”*

These comments suggest that home visits enable more accurate and practical assessment, education and review of the client and HEN clients.

### **Improved Accessibility and Convenience**

*“More convenient for patients, particularly rural, non-ambulatory or clients with no transport.”*

*“Beneficial for non-ambulatory or where families cannot bring child for review. Most families either need to attend for multiple other services and/or manage successfully at home.”*

*“Allows equitable review of patients. Presently non-ambulatory clients are only reviewed by phone.”*

*“Some clients although ambulatory are frail and the trip to a centre such as a hospital can cause considerable distress.”*

*“Reduce load on family/friends/other service providers needed to bring clients for visits.”*

A domiciliary service enables more accessible and convenient face to face review for the client. In the case of many non-ambulatory clients a home visit would be the only way that they could receive a face to face review.

### **More Effective Trouble Shooting**

*“Immediate trouble shooting to minimise unnecessary hospital admissions.”*

*“Able to identify possible problems before they occur. Small problems solved before they become big ones.”*

*“Trouble shooting is easier face to face than over the telephone.”*

Face to face review in the client’s home was seen to enable more effective trouble shooting.

### **Increased Client Confidence**

*“Greater confidence for clients that help is at hand so that they are more accepting of HEN as an option.”*

*“Less threatening for the client and for their carers.”*

*“Client seems to take more control in their own environment and hence a better regimen is often developed.”*

*“Client is more comfortable at home. They are not in an unfamiliar clinical setting which can be daunting. Likely to have a more open discussion in their home environment.”*

Review in the client’s home was thought to increase client confidence and control over their management.

### **Support for Carers**

*“Provide support and training for carers as well as HEN clients.”*

*“Able to communicate with multiple carers.”*

*“All carers can be involved in the consultation.”*

Domiciliary services were seen to provide better support for carers.

## Supply of Product

*“The HEN provider can both review the HEN client as well as provide a delivery service of the HEN products.”*

Home visits could provide an opportunity for supply of formula and equipment.

### 3.2.4 Service Providers

As with the process of establishing a client on HEN, a variety of health professionals were also found to be involved in the ongoing review and clinical management of HEN clients. The number and combination of professionals involved differed from organisation to organisation and often from client to client. From the interviews with dietitians, and the questionnaire, a multitude of personnel were indicated to play some role in the ongoing clinical management of HEN clients. This list included:

- **Dietitians** (hospital dietitians, community dietitians)
- **Nurses** (general hospital nurses, clinical nurse specialists, endoscopy nurses, discharge liaison nurses, RDNS, private agency nurses)
- **Doctors** (gastroenterologists, surgeons, general surgical/medical hospital medical officers, general practitioners)
- **Stomal therapists** (hospital, RDNS)
- **Speech pathologists**
- **Enteral company representatives**
- **Case managers**
- **Social workers**

### 3.2.5 Roles and Responsibilities of Service Providers

Dietitian’s perceptions of what roles these different health professionals play in the ongoing management of HEN were explored in our survey. The same method was used here as that used to explore roles and responsibilities of professionals involved in the initial phases of establishing HEN (Section 3.1.3). Various aspects of the management of HEN were listed and dietitians (who had experience in the management of HEN) were asked to nominate which health professionals they felt should be responsible for the each of the different aspects of management.

In the initial phase of establishing a client on HEN, the roles and responsibilities of the various professionals involved appeared to be relatively clear. Most aspects of care in this phase (nutritional assessment, nutritional requirements, education of formula administration and assessment of swallow) were generally delineated to one or two key professional groups.

In contrast, aspects of care required in the ongoing management phase of HEN were less clearly defined. The findings of our research regarding these aspects of care are presented below. The results from this part of the questionnaire were from respondents with experience in HEN, both in the past and at the time of our survey (n=167).

## Care of Enteral Tubing and Stoma Sites

Ongoing management of enteral tubing and stoma sites were areas that appeared to have less clear professional boundaries. Results from the questionnaire regarding these two aspects of care are presented separately. The combined results are discussed in the latter part of this section in the context of the service system profiles.

### Enteral Tubing

Respondents to the questionnaire were initially asked to rate their attitude to various statements on scale of agree to disagree. The response to a question pertaining to the management of enteral tubing is shown in Figure 9.

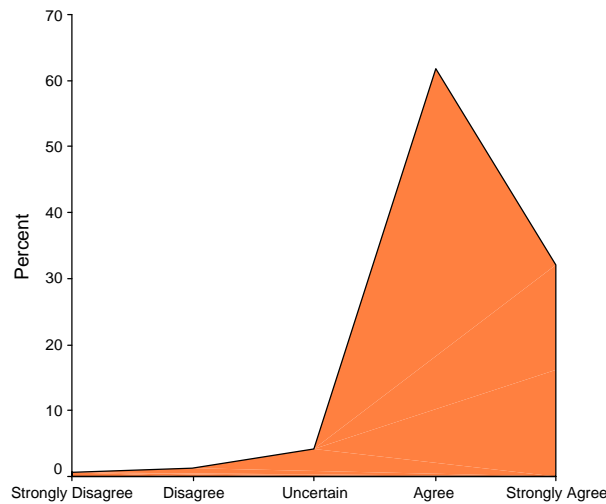
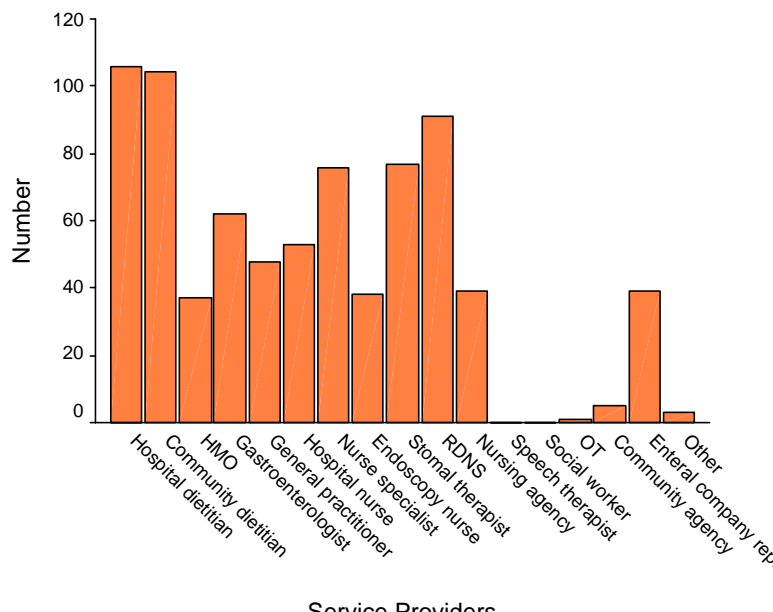


Figure 9 “The dietitian should be able to recognise a problem with tubing and refer on as required.”

Responses to this question indicate that respondents generally agreed (94% n=158) that if working in the area of HEN, the dietitian should be able to recognise a problem with tubing and refer on as required.

In looking at the perceived roles and responsibilities of multi-disciplinary professionals, we divided care of enteral tubing into two components: the assessment of tubing and the actual management of tubing problems. Figure 10 and Figure 11 display the professionals nominated by dietitians as having a role in these aspects of enteral tubing care.

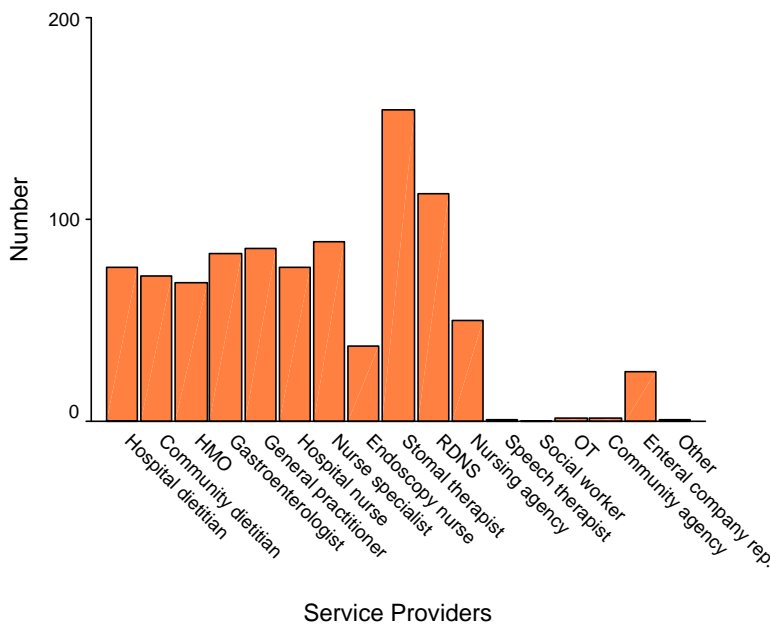




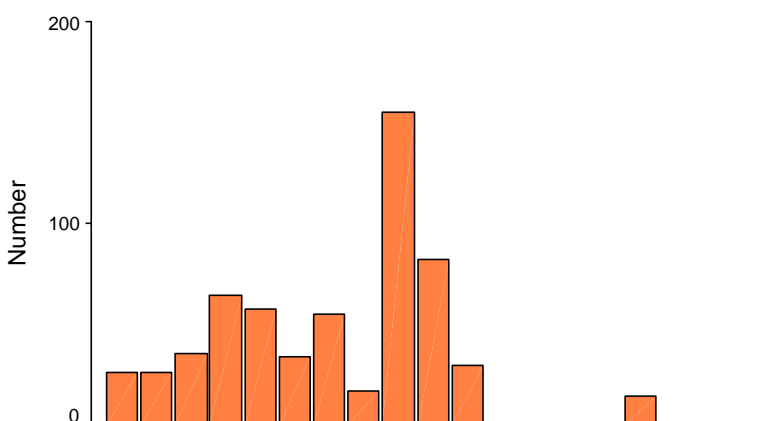
**Figure 12 “The dietitian should be able to assess a stoma site and refer on.”**

The graph in Figure 12 suggests that the majority of respondents (74% n=124) felt that dietitians working in the area of HEN should be able assess a stoma site and refer on as required. However there appeared to be less certainty with the dietitians role in assessment of stomal issues than there was with the dietitian’s role in assessing tubing (74% agreement and 94% agreement respectively).

As with the enteral tubing aspect of care, in looking at the perceived roles and responsibilities of multi-disciplinary professionals, we divided stomal care into two components, assessment and actual management. Figure 13 and Figure 14 display the professionals nominated by dietitians as having a role in these components of stomal care.



**Figure 13 Roles and Responsibilities – Assessment of Stoma Sites**



## Figure 14 Roles and Responsibilities – Management of Stomal Problems

Dietitians rated themselves as having substantially more involvement in assessment of stoma sites than in the actual management. In terms of assessment of stoma sites it appears stomal therapists followed by RDNS were seen as the key professionals that should be responsible for this aspect of management. Other nursing professionals, medical professionals and dietitians were all perceived to have a similar level of input in the assessment of stoma sites.

Actual management of stomal issues was more clearly seen as the role of stomal therapists. RDNS were also perceived to have some responsibility for management followed by gastroenterologists, general practitioners and clinical nurse specialists.

### **Access to Stomal and Tubing Expertise**

Our data collection in both the interviews and the questionnaire suggested that, in some places, accessing professionals with expertise in stomal and tubing care was a problem. It would seem, from the roles and responsibilities graphs above, that in regard to stomal care, stomal therapists were primarily the professionals being referred to.

Our interviews indicated not all health care facilities, or Networks, have access to stomal therapy services for HEN. Comments in the questionnaire supported this finding:

*“Access to stomal therapy is difficult in rural areas.”*

*“Unable to access stomal therapist unless HEN program can pay for her time.”*

*“There is little or no access to a stomal therapist in the community.”*

*“Access to PEG care is difficult.”*

Access in the community to stomal therapy has been noted to be difficult, particularly in rural areas. It was pointed out in the interviews that non-ambulatory clients were a group who seemed most difficult to follow up with regard to these aspects of care. In addition, expertise with regard to dealing with enteral tubes can also be varied in these professionals.

In the absence of a stomal therapist with HEN expertise, it was reported that clients were referred to a range of professionals, namely community based nurses such as RDNS, or the client’s GP. Numerous reports were also received that commercial enteral company representatives frequently

filled this apparent gap in services. One company in particular provided the services of a stomal therapist with expertise in enteral stomas and tubing. Comments received also referred to this option for stomal care of their clients:

*“Need to use enteral company representative or district nurses for stomal care as no stomal therapist attached to the centre.”*

*“Presently many patients are relying on the services of an enteral company stomal therapist.”*

A problem raised in our data collection was the perception that these professionals often have variable knowledge or expertise in dealing with this aspect of care. It was noted that HEN was not necessarily an area that all professionals have had exposure to, or training in. As such, the ability to manage the different aspects of HEN was perceived to vary from individual to individual. Over leaf are some quotes from survey respondents with such viewpoints.

*“There is a lack knowledge regarding replacement tubes, administration, stomal care etc of district nurses, doctors and hospital staff.”*

*“There is a lack of expertise available in the community for management at home.”*

*“There is a lack of expertise with gastrostomy management with RDNS, GPs and some dietitians.”*

*“GP’s have limited knowledge about HEN.”*

*“There is a very strong void of HEN experienced professionals currently within our community at all professional levels.”*

*“There is a lack of understanding by some service providers as to the practicalities of HEN and the issues these present.”*

*“Doctors aren’t aware of their responsibility for following up HEN clients.”*

There was some suggestion made through our data collection, that owing to a difficulty in accessing expertise to review and manage, stomal and tubing issues, this role was, at times, left to the dietitian. The example was given, in a few interviews, that dietitians working in a smaller, or more isolated organisations, quite often did not have access to a multi-disciplinary team to manage HEN. As such, out of necessity, the review of areas such as tubing and stoma became their responsibility, to at least assess. This quote from a survey respondent acknowledges this situation:

*“Generally as the dietitian I am responsible for reviewing the stoma site as well as nutritional status.”*

### **3.2.2 24-hour support**

Of the hospitals profiled, no 24-hour support service, specific to HEN, was noted to exist.

Hospital accident and emergency departments offered a point of contact 24 hours per day. Most medical / surgical units had an on-call rotation available for emergencies. However, no one professional, medical, nursing or dietetic, appeared to be allocated, or funded, to provide expert advice and support for HEN clients by telephone 24 hours per day.

## 3.3 Supply of HEN Products

*Note: In this discussion ‘supplies’ is referring to enteral formula and consumable hardware (eg syringes, pump delivery sets, gravity delivery sets and formula containers). Reference to other enteral products such as pumps and enteric tubing (eg gastrostomy tubes, naso-gastric tubes) is made later in Section 3.3.3.*

In all interviews conducted the response to the introduction of the HEN funding was extremely positive. The general feeling was that the funding program had improved the quality of care for clients by ensuring equal access to appropriate enteral formula and equipment.

Prior to the introduction of the funding scheme for HEN supplies, HEN clients purchased their supplies through a number of sources. Hospitals were the main purchasers and distributors of enteral formula to clients in outpatient settings. Clients were also able to purchase formula directly from individual pharmacies or organisations such as Australian Home Health Care and Slades. Some enteral formula companies also offered a community based HEN supply service. With the introduction of the HEN funding scheme the majority of HEN clients began obtaining their supplies through a HEN funded health care facility.

Some profiles of systems, utilised by HEN funded organisations, to distribute HEN supplies are outlined below. This is followed by an outline of some difficulties or gaps seen in existing supply structures and processes.

### 3.3.1 Provision of HEN Supplies

The HEN service system interviews revealed a number of different supply models in operation. One survey respondent noted that this could potentially cause some confusion:

*“I cover 6 shires and there are 3 hospitals within this area which supply HEN products. All 3 hospitals have different feeds and pumps and also different procedures. It’s very confusing.”*

#### **In-house Supply**

The majority of hospitals distributed supplies to their HEN clients via the in-house supply. The enteral formula and equipment was ordered in by the hospital Supply Department and billed directly to a specific HEN cost centre. HEN clients generally contacted the dietitian, or administrative support staff, for an order. The paper work was completed by the dietitian, or an administration staff member, and/or the order was entered on the HEN database (if in operation).

Point of pick up of supplies varied from organisation to organisation. Often the HEN client or carer collected their order directly from the supply department. Some hospitals utilised Pharmacy as the distributor. Another hospital had an agreement with a privately run shop on the hospital premises whereby the order was dropped off at the shop (by the dietitian or supply staff) for the client to collect. In organisations with smaller numbers of HEN clients, the supplies were collected directly from a store in the Nutrition and Dietetics Department, or from Food Services.

## **Out Sourced Supply**

A few organisations had out-sourced their supply of HEN products. Australian Home Health Care was being used at one organisation to supply and deliver all formula and equipment.

Another model contracted an independent distributor to manage the ordering and supply of product. The distributor purchased the HEN supplies through the hospital supply department, thereby maintaining costs by purchasing product at hospital contract prices. The HEN clients contacted the Nutrition and Dietetics Department to place orders that were then faxed to the distributor. HEN clients either picked their supplies up from the distributor or a delivery service were offered, at a cost, to the client.

## **Home Delivery**

The ability to distribute product to HEN clients, who had difficulty in collecting their supply in person, varied between organisations. Some hospitals had a hospital courier. Others used a commercial courier service. For organisations such as Australian Home Health Care, delivery is incorporated as part of their service. In areas that have a domiciliary service managing the HEN client, the dietitian, or another member of the team, often delivered supplies to the client when conducting a home visit.

With regard to who should bear the cost, the HEN client, the supplying organisation, or the HEN funding program, no clear consensus or guidelines were apparent. At the time of our research all options were being used at one organisation or another.

## **Co-payments**

Collection of client co-payments was again managed in different ways by the various HEN funded organisations. With the change in co-payment structure in the second year of funding the majority of clients were not required to make any co-payment. Subsequently the workload involved in this aspect of the funding program had been reduced for hospital personnel.

For those clients that were required contribute to their HEN, payments were collected a variety of ways. The hospital cashier was generally utilised if the client was picking up an order from the Supply Department. If Pharmacy, or a hospital shop, was being used, these departments might collect payments directly. Some Nutrition and Dietetic Departments billed the client instead, particularly if an external provider was being utilised.

### **3.3.2 Issues**

In the dietitian questionnaire a number of issues regarding current supply systems were raised. Of the respondents who were involved in managing HEN clients at the time of our survey, 63% (n=59) indicated that they had issues. These include:

- Time and workload issues.
- Equity of client access.
- Issues with enteral companies and distributors.
- Issues with policies and protocols.

## Time / Workload

In our interviews, many organisations noted that the HEN funding program, while seen as most positive, had actually created additional demands on Nutrition and Dietetic Departments (dietitians and administrative support staff). With the funding being managed by Networks and hospitals, the responsibility for managing the budget and the logistics of HEN client supplies has fallen, in the majority of cases, to Nutrition and Dietetic Departments. While many Nutrition and Dietetic Departments previously provided and managed this service there were some Departments for which this was a new addition to their service and workloads.

The number of HEN clients managed by individual hospitals was noted to be increasing. Aside from the generic rise in the use of HEN as a nutritional therapy, the introduction of public hospital based funding for HEN supplies initially resulted in an increased number of HEN clients obtaining their supplies through the public hospital system, in order to receive the subsidy. The initial increase in numbers, owing to the introduction of the funding, was at the time of our research reported to be steady.

A number of comments were received surrounding the time and workload associated with the provision of this service. Samples are quoted below:

*“The overall process of supply is coordinated by the Nutrition Department. It runs smoothly but is very time consuming.”*

*“The main concern regarding supply is the workload / time aspect for an ever-increasing service.”*

*“The Dietetics Department is responsible for ordering and stocking product. Therefore there is the need to physically handle product and organise delivery and pick-up. This takes a lot of time.”*

*“Increased workload for dietitians to implement HEN system. No money allocated to improve infrastructure.”*

*“Time consuming process, especially if it is a small dietetics department.”*

These comments suggest that the time and workload associated with the ongoing logistics of supply, for this number of clients was seen to be an issue. Associated with this was the fact that organisations continued to absorb this increased workload without additional financial assistance to resource this service.

The workload demand of supplying HEN product to clients was not only seen to impact on dietitians. Other hospital departments and personnel were also affected, depending on the set-up of the service:

*“Speaking on behalf of the secretary for our department, her work profile has changed considerably with approximately 50% or more of her time devoted to HEN. This impacts on other areas of our work.”*

*“Our hospital supplies product through the pharmacy department, since nutrition department hasn’t the space to store supplies and is often not attended. HEN is extra work for pharmacists with no financial reimbursement to hospital for the extra load.”*

*“It would appear from some problems which have occurred that our Supply Department have trouble meeting the demands of supplying HEN products along with all the other demands made upon their time.”*

## **Client Access**

In discussions pertaining to supply of HEN product, concerns were raised regarding access for certain HEN clients. Clients who are house bound through disability, frailty or lack of transport have no means of collecting HEN supplies in person. It was noted that often these clients do not have anyone who can conveniently collect their supplies for them. Distance from the funded hospital could also be a problem, particularly for rural clients. If these clients were not coming to the hospital for an appointment a special trip would have to be made, which can be quite time consuming and inconvenient. It was also pointed out that travel to a city based hospital could be quite time consuming and inconvenient for clients, owing to traffic and parking difficulties.

Similar comments were made in the questionnaire:

*“Difficult to provide / send HEN products to non-ambulatory patients or patients and/or their carers who have no means of transport.”*

*“Client access from outlying areas is an issue. There are difficulties with supply / delivery.”*

*“Access to rural patients can be an issue.”*

*“Ease of obtaining formulas for clients is often an issue. Free delivery from the hospital would be a solution, or distribution through the local chemist who may deliver drugs, not hospitals as they are often too far away.”*

Many hospitals’ supply systems only operated during business hours. Remarks quoted below indicate this was perceived to create another barrier to easy access for clients.

*“We expect our patients to come into the hospital to collect feeds during pharmacy hours (8.30am to 5.00pm) with no access after hours or on weekends. Sometimes this is very difficult for patients.”*

*“The distribution centre at the hospital is only open 9.00am to 4.30pm Monday to Friday, therefore it is difficult to organise discharge close to the weekend. This also limits times when families can pick up supplies.”*

The storage capacity for stock of some hospitals can impact on convenience for clients. Space may limit the level of stock an organisation might be able to carry which subsequently limits the amount of supply a HEN client can obtain at any one time. This results in more frequent visits to the centre to obtain supplies:

*“Due to limited space we can’t stock too much product which means clients have to visit more often than they might like (especially people who live approximately 1 hour away).”*

*“Our hospital services the entire state but we can only supply 1 months feeds at a time. For stable patients this necessitates many extra trips to Melbourne to collect feeds and equipment.”*

It was also recognised by interviewees that the physical exertion of collecting and unloading their supplies was a problem for some of their HEN clients. The size and weight of the formula, in particular, could be substantial. Some clients or carers have multiple issues. The act of picking up supplies was thought to create an additional stress for these clients.

*“For some clients the physical effort of coming to get feeds is enormous, considering their multiple issues.”*

Home delivery of HEN supplies was raised in our data collection as a solution to overcome all of these issues:

*“Client access overcome by deciding to courier all products.”*

*“Home delivery has been resorted to via courier for simplicity with some patients.”*

*“Patients unable to come in to pick up feed have feed sent by courier which is expensive. Ordering through supplier, ie Slades / Home Health Care and having feed delivered with the supplier sending invoice would be more time effective and a good record of supply of feed and equipment.”*

*“Some HEN clients express difficulties in coming to a major hospital to collect supplies due to inconvenience. A courier service is offered by the hospital but the cost is a deterrent.”*

As noted previously, not all hospitals are able to provide this service. It was also apparent that there was some ambiguity as to which party was responsible for the cost involved in home delivery of supplies.

## **Enteral Companies and Distributors**

Respondents to the questionnaire noted a few issues with the reliability of companies and organisations that were external to the hospital. These issues were surrounding supply of product to the hospital and with supply to the HEN client:

*“The system for the medical centre is fine, however because the clients order in bulk, ie 4 – 6 weeks worth at a time often, the company is unable to keep up with the demand on the product.”*

*“Problems with supply of product secondary to company being unable to provide product in time and of appropriate expiry date.”*

*“No availability of supply system within institution, therefore out-sourced this service to contractor. Problems arising with contractor often lead to extra time to fix.”*

## **Policy and Procedures**

As noted above there appeared to be no policy as to whether the HEN funding should cover home delivery of stock to HEN clients. Other comments received in the questionnaire indicate there was no standard guidelines for the quantity of stock issued to clients. For example the number of pump delivery sets issued seemed to vary from organisation to organisation:

*“HEN clients frequently complain about number of giving sets allowed (3/week).”*

*“Need clarification of what is allowed to be provided by HEN eg equipment / replacement.”*

*“No guidelines for consumable and equipment usage or expenditure.”*

*“Every centre seems to do different things with what they supply.”*

Comments were also received regarding supply of formula and equipment with the transfer of HEN clients from a metropolitan hospital to rural areas (also see discussion regarding transfer of clients under Section 3.1.4):

*“On transfer to rural areas, metropolitan hospitals do not always supply an adequate quantity of feeds and our service cannot guarantee seeing a new client immediately on transfer. It would help to have a standard discharge supply, eg 1 month.”*

*“Clients are sometimes ‘hand-balled’ to rural areas with insufficient feed. It takes time to order special products we don’t have in stock.”*

An issue was seen with inadequate supply being sent with the HEN client when discharged home to the rural setting. Metropolitan-based practitioners were perceived, by rural practitioners, to be unaware of the difficulties and time involved in obtaining specific enteral supplies in rural areas. It was suggested that a standard protocol regarding supplies would be beneficial in this situation.

### **3.3.3 Other HEN Supplies**

In addition to the routine supply of enteral formula and consumable hardware (eg. syringes, pump delivery sets, gravity delivery sets and formula containers), HEN clients often require further equipment such as enteral feeding pumps, replacement pieces for their enteric tube or an actual replacement or spare enteric tube.

#### **Pumps**

Enteral feeding pumps were obtained from a variety of places. Some hospitals had their own pumps, which they provide to HEN clients. Others were hired for a charge from the companies who make the pump. The other alternative was to hire the pump from organisations such as Australian Home Health Care. If there was a charge for hire of pumps, generally the HEN funded health care facility was billed, and the hire fee paid for through the HEN funding program.

These systems of providing pumps to clients generally appeared to work reasonably well. The main issue raised in association with pumps was the time taken to obtain a pump, particularly if discharge was hastened.

#### **Enteral Feeding Tubes**

Interviews with dietitians suggested that supply of enteral feeding tubes, and associated parts, was managed on a rather ad-hoc basis. It was unclear as to whether the HEN funding grant should cover tubing parts and replacement tubing. The original funding was based on estimates of average usage of formula and consumable hardware. It was uncertain whether the cost of enteral tubing parts, or replacements, were entered into the original calculation.

At the time of our research there was disparity between organisations as to who paid and supplied enteral tubing and enteral tubing parts. In some organisations the endoscopy unit was the key provider. In other organisations, particularly in rural areas, this expenditure came out of the Nutrition and Dietetics budget, and ultimately out of the HEN funding budget. There was anecdotal evidence that some HEN clients purchased replacement tubing and parts themselves. This incongruity was seen to have obvious implications on HEN budgets.

## 3.4 Administration

As discussed in the previous section, provision of HEN supplies was the focus of the HEN funding program. This service required substantial administration, from overseeing the stock levels of product, arranging client orders and collection of co-payments. Maintenance of the HEN database was also required as part of the HEN funding program, in conjunction with management of the budget. A number of internal and external parties were often involved in operating the HEN supply services, all bearing some of the administrative load.

### 3.4.1 Issues

The administrative side of HEN service systems also raised some issues. Of respondents to the questionnaire, 62% (n=58) indicated they felt there were some issues with the administrative responsibilities associated with HEN service systems. The main areas of concern related to:

- Database.
- Time / workload.

#### Database

The introduction of the database was perceived to have some difficulties. Some comments received in the questionnaire are quoted below:

*“We’ve had to spend much time on working out how to use the computer database. The non user-friendliness of it in many of its versions has wasted a lot of time and therefore financial resources.”*

*“Database difficult to understand. Time constraints make it impossible to spend time necessary to deal with this.”*

*“No staff training offered by DHS re HEN register.”*

*“Database is not 100% user friendly, but is improving. Unless you have good computer knowledge and understand Access, getting the database started and troubleshooting problems would be extremely difficult.”*

*“There has been no support in working out how to use HEN database computer package. Lots of time is required and consequently other area of my work suffer.”*

The main difficulties noted with the database were with the lack of training and support resources. The time taken to establish the database and learn how to use the program were perceived by dietitians to be too great.

While the database has had some apparent ‘teething problems’, it appeared from some responses that many departments had the database at a functional level and perceived it to be useful:

*“Database has taken some mastering, but is useful.”*

*“Now that the database is up and running there are no real problems (except program is clumsy and not user friendly). However gives good reports.”*

*“Database has required a lot of training but is now working well.”*

### **Time / Workload**

A certain level of administration has always been involved in the management of HEN clients, especially if a supply service was also offered. However some respondents felt the introduction of the HEN funding program had generated some additional administration. For hospitals that did not previously provide HEN supplies, the administration involved was reported to have increased substantially.

Some responses from the questionnaire, with regard to the administration associated with HEN, are shown below:

*“Time consuming to maintain database.”*

*“It is time consuming entering patient data. There are 2 – 3 people in the department who spend a considerable time on HEN (eg secretary) which has been an addition to their workload and this impacts on other areas of work.”*

*“Time, time, time! Limited staff hours already. HEN is very important but is a proportionally draining exercise.”*

*“The paper work involved (and time to do the paper work).”*

*“More administration responsibilities, yet no funding provision for this.”*

*“Workload increase with no infra-structure funding.”*

The perceived increase in workload and time was seen to impact on individuals and departments, particularly with no additional funding for service provision or administration.

## 3.5 Professional Development

In addition to gaining insight into dietitian’s perceptions on current HEN service systems, and the role of various professionals in managing HEN clients, the questionnaire also sought to obtain a self assessment of dietitian’s knowledge, or expertise, in the various aspects of care involved in the management of HEN clients. The rationale behind this was to determine dietitian’s perceived need for professional development in the area of HEN. This section presents the results of the skill base assessment and outlines the demand and suggestions for professional development activities and resources.

### 3.5.1 Dietetic Skill Base

As part of the questionnaire dietitians were asked to subjectively rate their level of knowledge in various aspects of managing HEN. This section was completed by two categories of dietitians: those who were experienced in the management of HEN and those who had no experience in managing HEN, but indicated that it was an area of interest (total n=232). Respondents were asked to rate their knowledge / expertise on a scale of seven ranging from ‘novice’ to ‘expert’. Eight different categories were self-assessed. Results and discussion of these categories follow.

#### Assessment of Nutritional Status and Requirements

Figure 15 and Figure 16 depict dietitian’s (with experience and with no experience in HEN) self rated knowledge or expertise in assessing a HEN client’s nutritional status, and nutritional requirements, respectively.

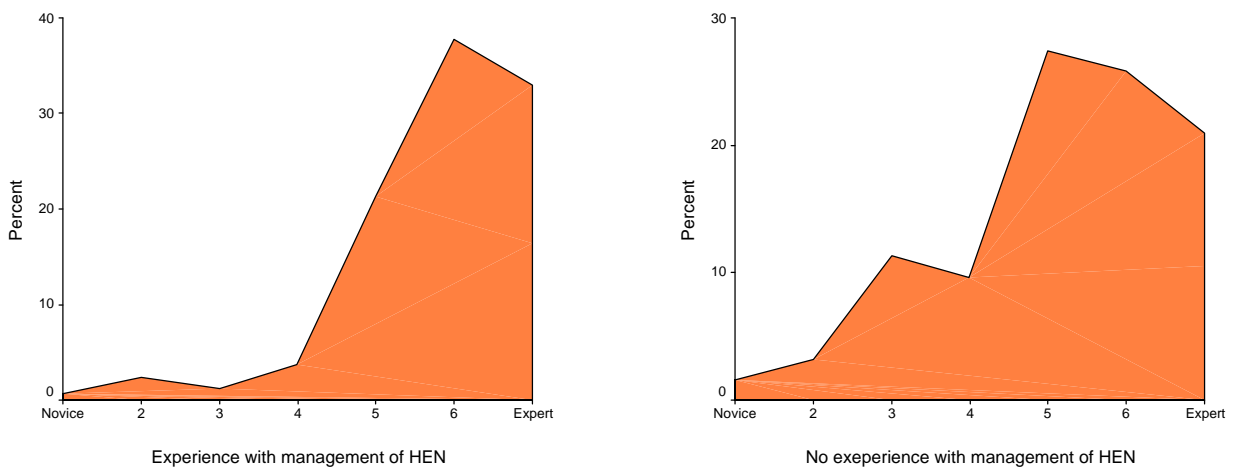


Figure 15 “Assessment of Nutritional Status”

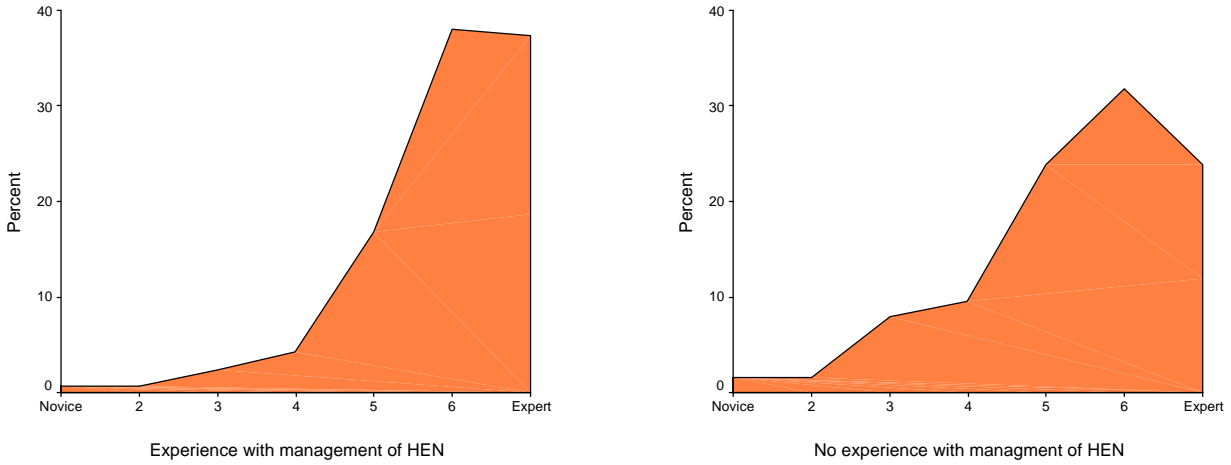


Figure 16 “Assessment of Nutritional Requirements”

Dietitian’s ability to assess nutritional status and nutritional requirements were rated highly, by both groups, on the scale of ‘novice to expert’.

### Demonstration of Formula Delivery

Figure 17 illustrates the self-rated expertise of dietitians (with and without experience in the management of HEN) with the demonstration of methods for formula delivery.

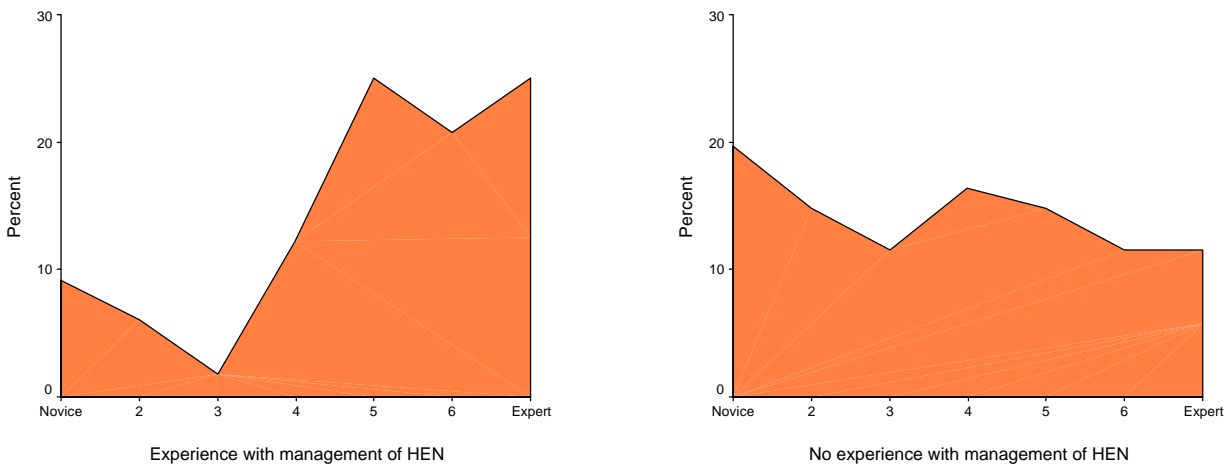


Figure 17 “Demonstration of Formula Delivery”

Dietitians with experience in managing HEN rated their skills, associated with the demonstration of formula delivery, more highly than dietitians with no experience in the management of HEN.

## Tubing Types and Functions

Dietitian’s self-rated knowledge about enteral tubing types and functions are displayed below in Figure 18. Responses from dietitians, with and without experience in the management of HEN, are depicted.

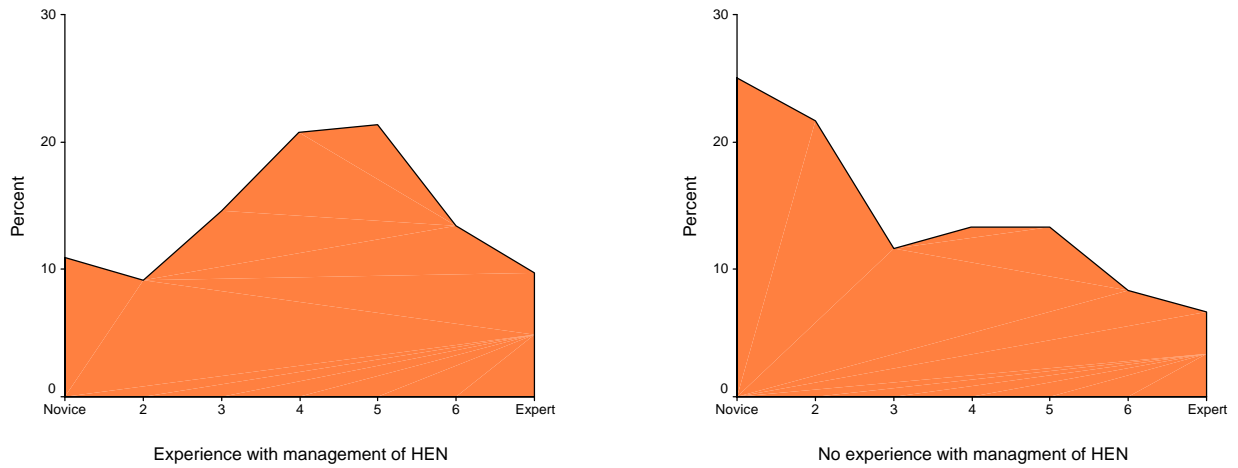


Figure 18 “Tubing Types and Function”

Knowledge of tubing types and functions was rated more highly by dietitians with experience in HEN than those with no experience.

## Stomal Care

Figure 19 illustrates the self-rated expertise of dietitians (with and without experience in the management of HEN) with stomal care.

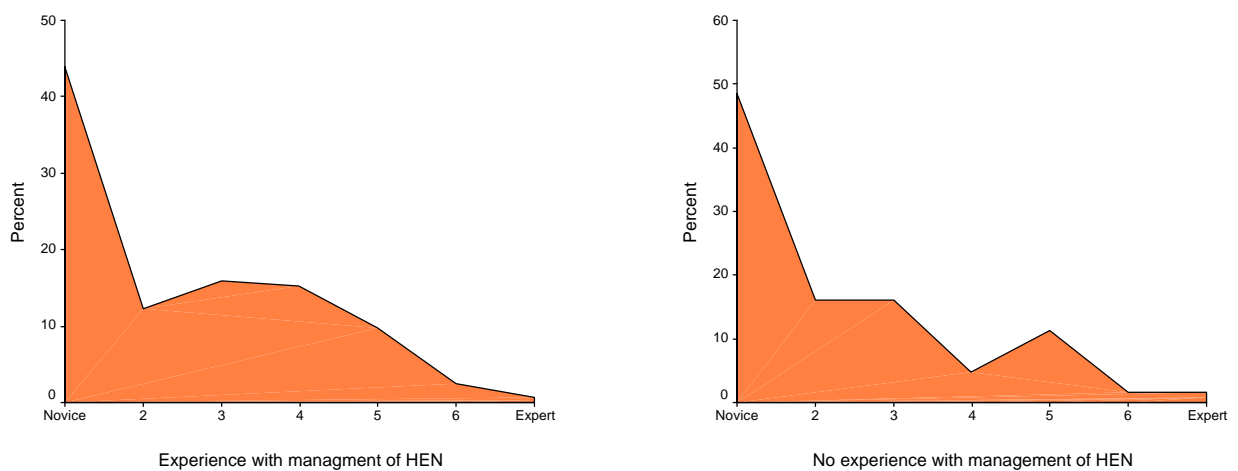


Figure 19 “Stomal Care”

With regard to stomal care, dietitian’s rated their knowledge and expertise strongly towards the ‘novice’ end of the scale.

### Psychosocial Issues

Dietitian’s self-rated expertise with regard to dealing with psychosocial issues associated with HEN clients are depicted below in Figure 20. Responses from dietitians, with and without experience in the management, of HEN are depicted.

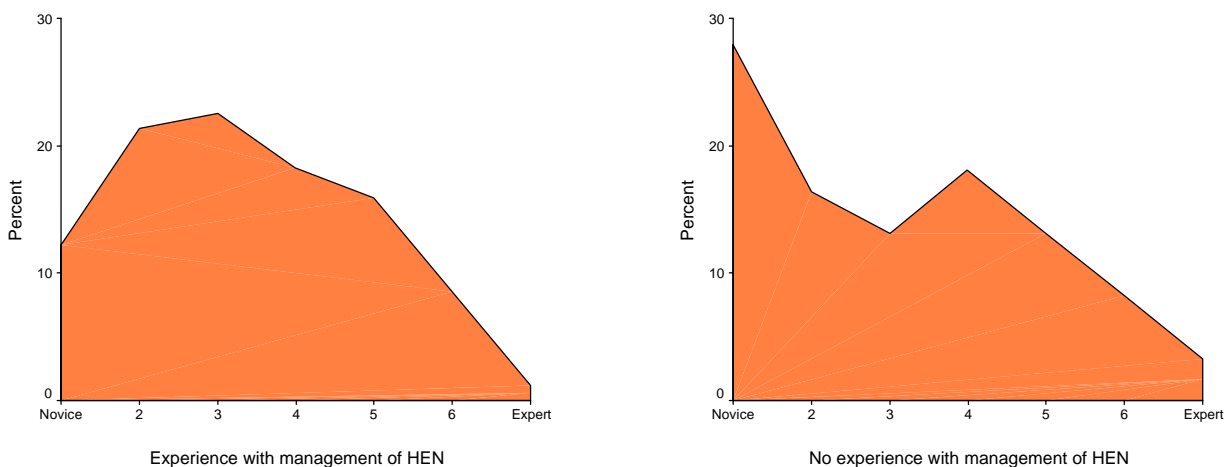


Figure 20 “Management of Psychosocial Issues”

The responses shown in Figure 20 suggest that management of psychosocial issues is an aspect of care that dietitians do not feel overly confident to manage.

### Discharge Planning

Figure 21 depict dietitian’s (with experience and with no experience in HEN) self rated expertise in discharge planning.

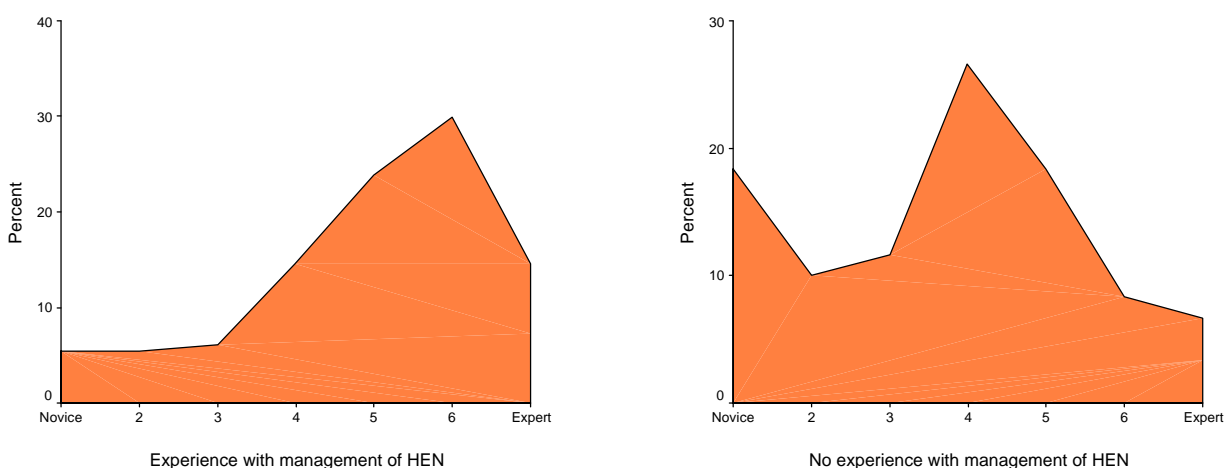


Figure 21 “Discharge Planning”

Ability to discharge plan was rated on the expert side of the scale by the majority of respondents with experience in HEN. The response was a little more scattered by dietitians without experience in HEN.

### Budget Management

Dietitian’s self-rated expertise in budget management is displayed below in Figure 22. Responses from dietitians, with and without experience in the management of HEN, are depicted.

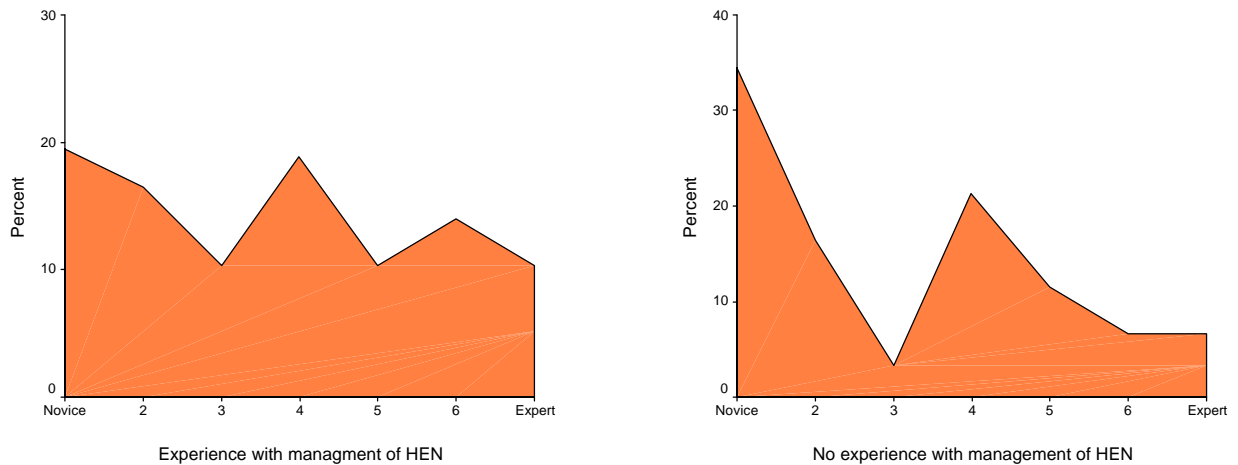


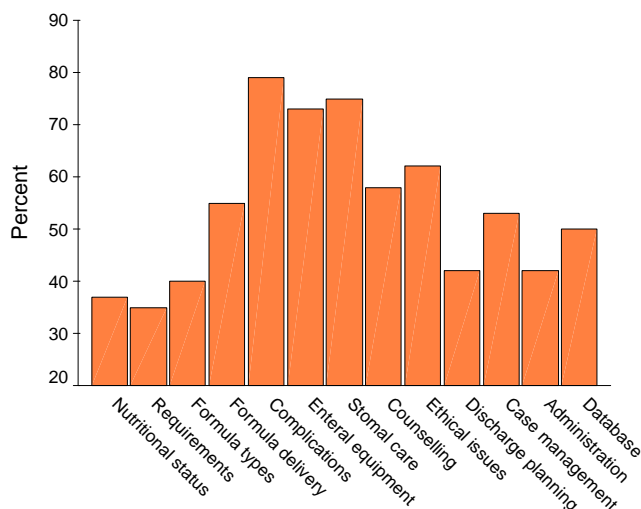
Figure 22 “Budget Management”

Expertise, with regard to budget management, varied along both ends of the ‘novice to expert’ scale. The ratings reflected the position and job description of the individual. Respondents who indicated they had a managerial role in their position of employment rated their ability to manage a budget more highly than did those who indicated no managerial responsibilities.

## 3.5.2 Professional Development Activities

### Topics

Respondents who completed the skill base rating were subsequently questioned about their views on professional development activities and resources. Of these respondents, 86% (n=195) indicated that they would benefit from some professional development in HEN. Respondents were then asked to nominate areas of HEN in which they would be most interested in receiving some professional development. Topics were nominated for both adult and paediatric sub-groups of HEN. The responses are depicted below in Figure 23.



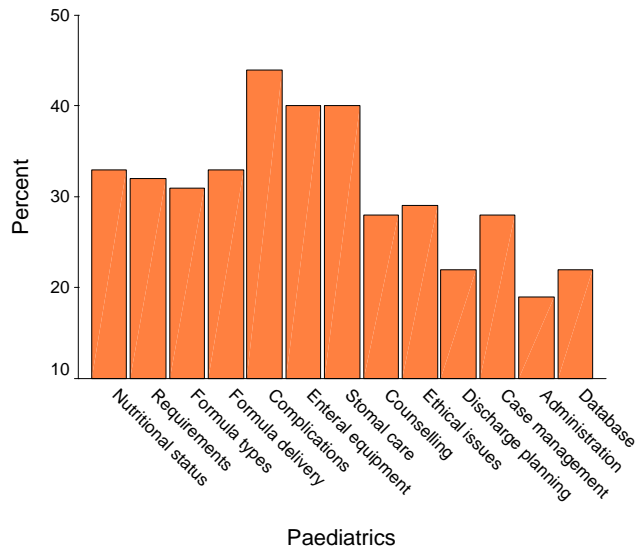


Figure 23 Topics for Professional Development

The top three topics selected for both adult and paediatric clients were:

- Dealing with potential complications of HEN.
- Enteral tubing and equipment.
- Stomal care.

Other topics suggested included:

*“General info on accessing info re HEN. I recently moved from a rural position with very little HEN to a metro position with HEN patients. I had no basic info on how to access pumps/giving sets, who usually pays for what, community contacts etc. It took a lot of time to draw this together. A general info flier re general practices of HEN in Melbourne with contact people would be most useful!”*

*“A regular update of available enteral feeds.”*

*“Roles of other professionals.”*

## Format

Respondents were asked what format for professional development would be most useful to them. The ratings of various formats are shown in Figure 24.

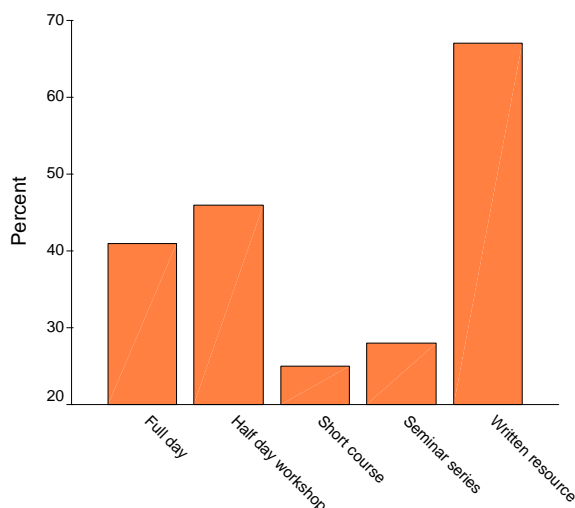


Figure 24 Format for Professional Development

In terms of format for professional development, responses indicated that a written resource would be valuable, along with workshops (full or half day).

Other suggestions included videotaped information or videoconferences. People from rural areas indicated preference for workshops to be held at the beginning or end of the week, should some travel be involved for people to attend. Regular updates, for example annually, were also suggested.

### 3.5.3 Resources

A number of resources were also put forward as suggestions for assisting in the management of HEN. Respondents were asked to rate them on a scale of 'Not Beneficial', 'Uncertain' and 'Beneficial'. Table 1 lists their thoughts in order of 'Beneficial' rating:

Suggested Resources	'Beneficial' Rating (%)
HEN practice manual	93
Access to a 'HEN expert' each Network	88

Standardised client education material	85
HEN 'help-line'	67
HEN web site	54

Table 1 Suggestions of Supporting Resources for HEN

A number of comments were received regarding the resources suggested in Table 1. Samples of these are highlighted in the quotes below.

### **HEN Practice Manual**

*“Manual of equipment / trouble shooting would be more beneficial than generalised information.”*

*“An unbiased comparisons of formulas on costs / ingredients would be useful.”*

*“A HEN practicing manual containing all aspects of care including tubing, stoma care, would be a useful resource to take with you for HEN assessment / follow up.”*

*“Whilst I am only a new graduate I feel that written resources regarding stoma care and feed delivery, including different pump and line types, is essential. As a student I found it very frustrating not being able to respond to questions such as ‘can I have a spa bath if I have a PEG?’ or ‘can I go swimming if I have a PEG?’. Maybe a resource answering commonly or frequently asked questions would be beneficial.”*

### **Standardised Client Education Material**

*“Client education material using simple language and in different languages eg Vietnamese, Slavic, Italian, Greek, Spanish.”*

*“Beneficial if well written and able to be modified for special needs.”*

### **HEN Web-site**

A number of comments were received indicating that access to the Internet was a limiting factor in the benefits of a web site for HEN.

*“Not everyone has access to the net.”*

*“Beneficial if updated regularly!”*

## **Other Suggested Resources**

Other suggestions for resources were made. These included:

- HEN special interest group
- Practitioner contact directory
- Videos
- Resources for other professionals

### **HEN Special Interest Group**

*“Regular meetings from all networks or/ community or/ hospitals. Designated representatives similar to SIG in order to clarify and uniform entire HEN process as a profession.”*

### **Practitioner Contact Directory**

*“A HEN directory naming GPs, gastroenterologists, stomal therapists, dietitians etc with high level of HEN experience.”*

*“Distribution of who to contact, where, for what, in which areas in case of discharge planning for someone not in my own network/region.”*

### **Videos**

*“Videos that we can borrow and view/share.”*

*“Training videos.”*

### **Resources for Other Health Professionals**

*“Resources for other health professionals potentially involved with HEN clients, eg roles and responsibilities, appropriate referrals.”*

*“HEN pocket book that a nurse could use (without dietetic knowledge).”*

*“Standardised education material aimed at other members of the health care team – particularly nursing staff – detailing HEN protocols and support agencies.”*

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## 4. Study 2

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### 4.1 Method

A qualitative approach was taken to this study and as such no statistical inferences have been drawn. The purpose of this study was to gain some insight into consumer perceptions of HEN service systems.

#### 4.1.1 Participants

Clients receiving HEN through the HEN Pilot Program were the chosen target population for this study. Owing to the need for ethics committee approval, the sampling frame was selected on the basis of convenience. As such, only HEN clients managed through the organisations involved in the project were used in the sampling frame:

- Austin and Repatriation Medical Centre.
- Bendigo Health Care Group.
- Southern Health Care Network (Monash Medical Centre, Kingston Centre).

Participants of all ages were selected on a random basis from the HEN databases maintained at each organisation. Clients on the HEN database were screened for exclusion criteria through consultation with dietitians responsible for the nutritional management of the clients. Clients were eliminated from the sampling frame on the basis of the following exclusion criteria:

- Poor health (eg palliative clients).
- Clients with communication difficulties (eg speech difficulties, reduced attention span, dementia) who had no proxy available to participate on their behalf.
- Inappropriate psychosocial circumstances (eg family issues).

Approximately equal numbers were sampled from each of the organisations involved in the study. Bendigo Health Care Group managed the smallest number of clients out of the three organisations. Based on this number, the aim was to sample approximately 10 to 15 clients from each organisation.

A total of 31 HEN clients were interviewed. The breakdown of the participants, in terms of metropolitan versus rural and adult versus paediatric, is described below in Table 2. See Appendix 4 for further demographic data pertaining to the HEN clients interviewed.

	A&RMC	BHCG	SHCN	Total
Adult	11	7	4	22
Paediatric	0	3	6	9
Total	11	10	10	31

Table 2 Location and Age of HEN Clients Interviewed

## **4.1.2 Materials**

Face to face interviews were used to collect the data for this study. The interviews were conducted singularly by the Project Officer. A semi-structured interview format was used to ensure a standard set of topics were discussed with each respondent. This allowed for a free flowing conversation and the opportunity for new issues and ideas to be raised.

The broad topics covered in the interview were as follows:

- HEN details.
- Establishment of HEN.
- Ongoing management of HEN.
- Supply of HEN products.
- General comments.

## **4.1.3 Procedure**

Ethical approval was obtained from the Ethics Committees associated with each of the organisations involved in the project. The HEN clients on the HEN databases at each organisation were screened for exclusion criteria through consultation with dietitians involved in HEN at each organisation. Clients appropriate for the sample frame were then randomly sampled.

A letter explaining the study was sent out to the selected sample, inviting them to participate. The letter was followed-up with a telephone call to make an interview time with those HEN clients who agreed to participate. The subsequent interview was then carried out in the HEN client's home, at the agreed time. Interviews were approximately one hour in length. All clients were informed of their rights as per Ethics Committee guidelines, and a consent form signed.

Data collected in the interview was recorded manually on an interview schedule pro-forma.

## 4.2 Results

Through our interviews a number of valuable insights were gained into consumer's perceptions of HEN services. While there was some variation in reported levels of satisfaction, on the whole the HEN clients interviewed indicated they were relatively satisfied with their HEN management.

Each HEN client had their own individual account of their experiences with HEN. The characteristics of the HEN service received by clients interviewed varied between clients. The services clients received differed, in part, as a result of variations in service structures between organisations. The type of services received also appeared to depend on the client's circumstances and requirements. The time frame that a client had been on HEN also impacted on the types of services they had received, as service structures within each organisation have changed over time.

Owing to the number of clients interviewed no statistical correlations between clients experiences and level of satisfaction could be made. However some interesting issues were raised and some thoughtful solutions to perceived issues and gaps were put forward. These insights and comments have been categorised and presented below.

### 4.2.1 Establishment of HEN

The experiences and perception of services received during the initiation phase of HEN varied from client to client. The circumstances surrounding the initiation of HEN varied between clients. For some people interviewed, their experiences at the time of their tube insertion were quite stressful for reasons both related to and separate to the initiation of HEN. The length of admission varied between clients. The profile of professionals involved in clients' education also varied, as did perceptions of the level of HEN expertise of various staff members involved in clients' care. The post discharge support received also differed from client to client.

#### Education

The amount and adequacy of education client's received was perceived quite differently. Many clients reported having to learn much of their knowledge and skill with regard to HEN, through their own experience. Those clients who had contact with other clients receiving HEN, either through a support group or through introduction at the hospital, found this extremely useful. It was commented that they had learnt more from these contacts than from education received from professionals in the hospital or community setting.

Participants were asked how confident they felt with managing their HEN when they were first discharged home. The responses did vary, however only a few stated that they felt at ease with HEN when they were first discharged. A number of clients noted that once home they had difficulty recalling much of the education received. It was suggested by some that the hospital environment could be quite stressful and some clients felt that they might not have absorbed the information as well as they would normally.

A few clients noted that, in hindsight, they felt that they were not very well prepared for HEN prior to the tube insertion. The potential impact of HEN on their lifestyle was not always discussed. The actual sight of the tube, having not been shown one previously, was also quite

stressful for some. Others noted that it would have been helpful to have prior contact with other HEN clients to prepare them.

Most clients reported receiving education material regarding HEN when discharged.

### **Initial Post Discharge Support**

Some clients received a home visit in the initial post discharge phase. Often this was by community nurses such as the Royal District Nursing Service (RDNS). Some had received home visits from dietitians. Those clients who had home visits from nursing staff or dietitians unanimously reported this support to be most appreciated. These clients stated the knowledge that someone would be visiting them in their home soon after discharge was very reassuring. Benefits of this initial home visit were seen in assisting setting up and storage of equipment. Assistance could also be given with working out the practicalities and logistics associated with individual feeding issues.

Clients that had no follow-up home visits, either by nursing professionals or dietitians, generally stated that they would have benefited from at least an initial home visit. As noted above, many clients felt that they weren't able to remember all the education received in hospital. Client's also found, once home, that they had many more questions they were unaware of at the time of their education in hospital. Often these were practical questions that were difficult to communicate over the telephone or away from the home.

Most clients recalled being given a telephone number of a professional to contact if they had problems. These were mainly business hours telephone contacts. Clients that had multiple needs sometimes were given a 24-hour contact through RDNS.

## **4.2.2 Ongoing Management of HEN**

### **Review Locations**

Clients were reviewed in a variety of settings depending on the options available to them. Some were reviewed in their home. Others attended the hospital, either at a specific HEN clinic or another out-patient appointment. Others were reviewed at a local community centre.

Those clients who received home visits were very satisfied with this service. Generally these clients were physically disadvantaged. In the rural region clients who lived a significant distance from the hospital were accessed through home visits by the rural health team.

Clients who were reviewed in the hospital setting had varying levels of satisfaction with regard to the convenience of this arrangement. Some found it inconvenient to attend the hospital to have their HEN reviewed. Deterrents were parking, waiting times and for clients that had multiple visits this was seen as an additional 'hassle'. This was particularly compounded for those clients who had transport difficulties or were physically frail or disabled. Others were quite happy to have their HEN reviewed in the hospital setting, particularly if they had other appointments to attend.

When questioned as to their preferred place of follow-up, the responses correspondingly varied. Many clients would prefer to have their HEN reviewed at home. The clients that were currently receiving this service would prefer to continue this way. Many of those that were attending the

hospital indicated they would prefer to be reviewed at home, particularly the group who found it physically difficult to attend the hospital. Others who were quite mobile also felt that review in the home environment would be beneficial, for the reasons given above with regard to an initial home visit. Comments were made that the clinician could see practically what the client was doing in the context of their individual environments.

However, in contrast some clients would prefer to visit the hospital for review. These people felt that it was more convenient to go to the hospital and attend to all their appointments and needs in the one day. A home visit was seen to be less convenient as they saw this as an additional appointment.

A few clients commented that review in their home would only be convenient if the review could be undertaken by a single professional with specific knowledge in HEN. They stated that in this context it would not be convenient to have multiple people reviewing their HEN at different times.

### **Enteral Tubing and Stoma Sites**

Many comments were raised during our client interviews with regard to ongoing management and review of enteral tubes and stoma sites. Several situations were described where clients had experienced difficulty in obtaining satisfactory review and management of issues with their enteral tubing or stoma site:

- Often no particular professional reviewed either the tube or the stoma site.
- The client was left to manage and contact someone if there was a perceived problem.
- The client often did not know whom they should contact with regard to these issues.
- Professionals involved in the client's care were seen to have varying levels of expertise with regard to management of these issues.
- Different professionals gave differing advice.

In line with comments noted in the previous section, clients felt that it was reassuring if professionals reviewing HEN in the home were able to deal with all components of their HEN.

A number of clients from all organisations recalled accounts of difficulties with replacement of enteral tubes. The most stressful situation highlighted was that where their tube, most particularly a gastrostomy tube, fell out. Many clients stated that they were not informed of this possibility. Most clients dealt with this situation by going to the closest hospital emergency department. Services here were recalled to be unsatisfactory. Emergency personnel were recalled, in the situations recounted, to have minimal knowledge with regard to enteral tubing and frequently appropriate replacement tubing was unavailable. The waiting time was also seen as an issue.

### **Coordination**

An issue highlighted by some clients was the multiplicity of contacts for HEN. Some clients had experienced difficulty in negotiating the medical system. It was felt in this situation that there was no particular person they could contact to coordinate their HEN requirements and ultimately this became their responsibility. Contacting or coordinating medical review of their HEN was raised as a particular difficulty for a few.

In contrast many clients felt that they could generally contact their dietitian to coordinate their needs or at least refer them to the appropriate person. Clients who were managed by HACC teams seemed to feel that they could make a single contact and have their needs coordinated. This was viewed as most beneficial.

### **4.2.3 Supply of HEN Products**

All clients interviewed were very grateful for the HEN funding program, most particularly those clients who had been on HEN prior to the introduction of the funding grant.

As noted in the previous study (Study 1), systems for supply of HEN products varied between organisations. The main comments made by HEN clients with regard to supply of product were in terms of collection. The option to have supply delivered was seen to be a great advantage. Clients who were receiving their supplies this way were very satisfied with this service. Many clients, or their carers, who were collecting their supplies in person did not find this an issue, as it meant that they could collect their supplies when it suited them. They did not like the idea of having to be at home for a delivery, as might be required with a courier service. However some clients who were collecting their own supplies did think the option of delivery would be beneficial. This view was particularly held if the physical act of collecting and unloading supplies caused considerable exertion. Examples of this were given in the case of people who were physically frail or unwell and in the case where parents had to 'juggle' their children and the collection of supplies.

### **4.2.4 Rural Clients**

As shown in Table 1 (Section 4.1.1), approximately 30% of the HEN clients interviewed were from rural Victoria. The clients here had high praise of the general HEN services provided. Most clients were reviewed at home by one of the dietitians. Dietitians in this rural region were funded to provide domiciliary services to the whole region. As such access to a dietitian was not an issue that was raised by the HEN clients interviewed.

The main issue raised by HEN clients interviewed from the rural region was access to medical support to deal with issues pertaining to their enteral tube. Many of the clients interviewed had their enteral nutrition initiated at a metropolitan hospital. Some of these clients continued to see their physicians in Melbourne intermittently, while others had their care transferred locally. A number of clients had experienced difficulties with their tube, either falling out or needing changing. Most clients felt that their local GP did not have significant knowledge with regard to managing issues with their enteral tube. Experiences were reported to be similar at emergency departments. A number of clients, particularly carers of paediatric clients, stated they had, or would be most likely to, go to their doctors in Melbourne if they had a problem with their tube.

With regard to managing stoma sites, it seemed that local nurses, namely community nurses from the Royal District Nursing Service would deal with queries or issues regarding stoma sites.

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## 5. Discussion

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In recent times, the management of HEN is a topic that has received increasing attention in Victoria with the release of Clinical Practice Guidelines for HEN (Appendix 1) and the introduction of funding for HEN supplies through the Victorian Government Department of Human Services' HEN Pilot Program. Much work and discussion has been undertaken by providers of HEN services, however there has been little documented with regard to current practice in Victoria. This research has attempted to examine service delivery systems for HEN with the aim of identifying and defining best practice in service delivery for HEN in Victoria.

The report from the Ministerial Working Party (DHS July 1997) was the first state-wide review undertaken with regard to the management of HEN in Victoria. Incorporated into this was a study by Winter, Streeton and Kenwood (1999) that investigated usage of HEN in Victoria. This study supported anecdotal evidence of significant increases in the use of HEN in recent years. In their review, the Ministerial Working Party noted an apparent disparity in the service systems established across Victoria for management of this increasing client group. No studies or reports, specifically relating to service systems for provision of HEN in Victoria, have been published to our knowledge.

The research presented in this report was undertaken to profile existing HEN service systems and identify issues or gaps within these systems. Information was collected through two separate studies that examined existing HEN service systems from both a service provider and consumer perspective.

Study 1 focused on service providers involved in the management of HEN. Dietitians were the service providers targeted in this study. Study 1 consisted of two parts, A and B. In Part A interviews were undertaken to profile the structure of some existing HEN service systems. Part B examined perceptions of dietitians with regard to the management of HEN. Study 2 was designed to obtain a snapshot of client perceptions relating to HEN service systems.

Each of the studies undertaken was designed to complement each other. As such the themes and issues that evolved from each study are not mutually exclusive. The discussion that follows integrates the results of both studies.

### 5.1 Structure of HEN Service Systems

HEN service systems are complex, multi-faceted models of care. This was clearly seen in the service system profiles obtained in our research. Multiple professionals from various health care sectors might be involved at various times in a HEN client's episode of care. Multiple support services are also required. The implementation of HEN services requires multiple levels of management from state government through to local level. Financial management is required in conjunction with administrative and clinical coordination

Our research into HEN service systems supported the initial finding of the Ministerial Working Party for HEN; delivery of HEN services is managed in a variety of different ways across Victoria. At the time of our research, with the exception of the HEN funding program, no

standardised infrastructure in Victoria existed to support a generic system for provision of HEN services.

The profile and roles and responsibilities of service providers involved in HEN appeared to differ between organisations. Various systems for ongoing follow-up of clients were reported. This varied in terms of the location of review and the nature of service providers involved. Some organisations managed their HEN clients from the acute setting while others were managed by community based services. Other organisations managed their HEN clients a combination of ways.

The following discussion centres on the key variances and issues in HEN service systems discovered in our research.

### **5.1.1 Domiciliary Services**

A number of sites for service delivery are used for the management of HEN. This is required to meet the varying individual circumstances of the HEN client population. In particular, the ability to provide home visits in the management of HEN was clearly perceived by dietitians, and HEN clients alike, to be integral to provision of best practice care for HEN clients.

However, in spite of this view, it was apparent that, at the time of our research, many organisations did not have the capacity to provide a domiciliary service for the management of HEN. Organisations that were able to conduct home visits most commonly had access to dietitians funded under the Home And Community Care (HACC) program. Other hospitals reported using other DHS funded programs such as Post Acute Care (PAC) or Hospital In The Home (HITH) in the initial post discharge phases. The issue for many organisations however was access to these services or resources. At the time of our research many areas did not fall into catchment areas serviced by HACC dietitians. Not all organisations had access to PAC or HITH. The other issue with these programs was that many HEN clients were ineligible for management under these programs, as per the selection criteria of these programs.

A small number of hospitals had allocated dietetic resources to conduct home visits however the availability of resources was seen to be a barrier to initiation of this type of service.

The other professional commonly reported to provide services in the client's home were community based nurses, such as the Royal District Nursing Service (RDNS). Once again this service was seen to be limited, in most cases, to the initial post discharge phase. In addition this service was not necessarily organised for all HEN clients.

This apparent gap in service structures can present a number of logistical barriers to meeting standards of care for HEN. In the initial phase of establishing HEN, clients may be discharged prior to receiving adequate education regarding management of their HEN. This situation seems to be becoming increasingly common with the pressure to decrease hospital length of stay. The capacity to conduct a home visit in these circumstances is necessary if the client is to be adequately skilled such that they can manage independently.

A view put forward by both HEN clients and dietitians proposed that the ability to conduct a home visit in the initial phase was something that would benefit all HEN clients. It was suggested that more effective client education could be achieved in the home environment. Further support was received for a domiciliary service with the opinion that more accurate

assessments can be made in the home, enabling development of care plans that better meet the needs of the individual.

Similarly the lack of domiciliary services for management of HEN presents issues for reviewing HEN clients. Many clients, particularly non-ambulatory clients, have great difficulty in attending the hospital for review of their HEN. Consequently those clients living in an area not serviced by a domiciliary team can only be reviewed by telephone. Telephone review was generally perceived to be inadequate. Face to face review was seen as a necessity for a complete assessment and trouble shooting.

### **5.1.2 Multi-disciplinary Support**

HEN clients need to be managed by a team of professionals. This is the recommendation made by AuSPEN in their clinical practice guidelines (Appendix 1) and is subsequently assumed in the implementation of the funding program. However in practice this did not always seem to be occurring. Very few organisations had a specific team established to manage HEN either through provision of an outpatient clinic or as a domiciliary service. Management was commonly reported to be left to a single professional, often the dietitian. Alternatively a variety of professionals might be involved, however this was often managed in an uncoordinated manner.

An aspect of care that was perceived to cause particular difficulty for many organisations managing HEN clients was the management of stoma and tubing issues. This was an issue raised by both HEN clients and dietetic practitioners. There was an apparent gap in many existing service structures in terms of access to professionals with expertise in these areas. This was seen to result in untimely or poor management of tubing or stoma sites, often placing unnecessary pressure on hospital emergency services.

### **5.1.3 Roles and Responsibilities**

Our research revealed an apparent lack of clearly defined roles and responsibilities for the various professionals that might be involved in the management of HEN. While this was not the case for all aspects of care, such as assessment of nutritional status and requirements, or assessment of a client's swallow, there were a few aspects of care for which there was no clear delineation of professional responsibility. This was seen most particularly in regard to the management of tubing and stomal issues. The delineation of responsibility for managing these aspects of care was spread across a range of professionals. While it seemed that stomal therapists were perceived by dietitians to be key professionals in these aspects of care, the fact that a number of other professionals were also nominated, suggests some ambiguity in roles and responsibilities.

This could be interpreted a number of ways. It might indicate these areas are not perceived to require specific knowledge or expertise. However, more likely, it is an indication of the way HEN service systems were operating at the time of our research. It has already been highlighted that access to professionals with expertise with in the management of enteral tubing and stomal problems was perceived as an issue for both HEN clients and dietitians. The fact that this was raised as a problem would suggest these aspects of care were considered to require professionals with specific training or extensive practical experience in this area of enteral nutrition therapy. As such the 'confusion' in designating responsibility of these aspects of care to particular

professionals might be a reflection of the various solutions that have attempted to fill this apparent gap in HEN service structures.

Dietitians' role in the management of enteral tubing and stomal care was an area that received considerable attention in our data collection. It was suggested that, owing to difficulties in accessing multidisciplinary expertise, the responsibility for reviewing these aspects of care might fall, by default, to the dietitian. In light of this the suggestion was made that, while care of stoma sites and enteral tubing was not traditionally a role dietitians are trained in, it might be an area that these professionals should at least have some knowledge in. Results obtained from the survey appeared to reflect this view. Dietitians indicated quite strongly that, if working in the area of HEN, dietitians should have the knowledge or expertise in these areas to enable them to assess and identify stomal or enteral tubing issues. The actual management of these issues was perceived to require the expertise of other health professionals such as stomal therapists, specialist nurses or medical professionals, access to which was clearly perceived to be a gap in existing HEN services.

#### **5.1.4 Coordination**

In many cases it appeared that over the course of a client's episode of HEN, a variety of professionals might be involved. It was noted that often the involvement of these professionals was managed in an uncoordinated manner. A lack of centralised coordination was seen to result in poor communication and subsequently a disjointed and inefficient plan of care for the HEN client.

From a consumer's perspective this situation might also cause some difficulty. An issue raised by HEN clients interviewed was the multiplicity of contacts associated with the management of their HEN.

HEN clients faced with this issue suggested that a single point of contact, to either manage or coordinate their HEN management, might be a better alternative. Similarly it would seem from a professional's perspective that centralised coordination might have the potential to facilitate a more streamlined service for HEN.

#### **5.1.5 24-hour Support Services**

An area of concern raised, by a number of HEN clients interviewed, was the lack of a specific 24-hour contact for HEN. The main concern for clients was the scenario of their enteral tube falling out. At the time of our research it seemed that hospital emergency departments were the only points of contact in this situation. However there was a feeling of dissatisfaction, or lack of confidence, amongst HEN clients interviewed, in the ability of these services to adequately manage issues associated with HEN. This suggests that new options or modification of existing systems might need to be explored for managing such situations.

#### **5.1.6 Equity of Access to Supply of HEN Products**

An issue raised, by HEN clients and dietetic professionals alike, was equity of access to HEN supplies for clients. Access difficulties can occur for non-ambulatory clients, for clients with no

means of transport and for clients who live in geographically isolated areas. Access restricted to business hours was also a limitation of many supply systems.

Home delivery of HEN supplies offers a solution to overcome this issue, however it was not a service generically integrated into supply structures at the time of our research.

### **5.1.7 Resourcing of HEN Service Systems**

Access to appropriate levels of professionals with the relevant expertise was clearly perceived, by dietitians and HEN clients, to be an issue for many organisations. The clinical workload associated with the increasing numbers of HEN clients and the corresponding administrative requirements was seen to cause strain on existing dietetic resources.

Implementation of best practice is impossible without adequate support structures.

Consideration needs to be given to appropriate allocation of human resources so that there is equitable access to quality services.

### **5.1.8 Policy and Procedures**

In association with the HEN Services Pilot Program numerous policies and procedures have been introduced to guide the administration of HEN under the funding program. The state-wide coordination and standardisation resulting from these guidelines was seen as beneficial, however a few ambiguities were noted, particularly pertaining to supply of product. In addition a number of issues were raised that were seen to require review and subsequent development of policy statements to standardise practices.

Ongoing state-wide management of HEN was perceived to be important to the facilitation of continuous quality improvement and standardisation of HEN practices throughout Victoria.

## **5.2 Professional Development**

Responses from dietitians throughout our research suggested that the development of some ongoing professional development activities in the area of HEN would be well supported. As noted previously (Section 2.0), owing to the scope and time frame of the project, dietitians were the only health professionals targeted in this needs assessment. It is, however, well recognised that other health professionals also have significant involvement in the management of HEN and as such it would be recommended that the professional development needs of these professionals be pursued in future projects.

At the time of our research no formalised training or qualification was available to support the development of knowledge and expertise for professionals involved in the management of HEN. Some education and training in HEN is incorporated into discipline specific training courses, however anecdotal evidence suggests this is minimal. As such short courses in HEN rated well as a resource option.

Strong support was also received for the development of additional resources, to assist the management of HEN. A paucity in the availability of good resources was highlighted. Examples

of suggestions for development included practical handbooks, videos, web-site and professional directories.

Particular topics for professional development were also explored. Management of stomal and enteral tubing issues rated highly. It was interesting to note this response in light of previous results. Managing stoma sites, in particular, has not traditionally been a role of the dietitian. However respondents strongly supported the view that dietitians involved in HEN, should have the knowledge and expertise to be able to assess (as opposed to manage) issues with stoma sites, or enteral tubing, so that referral could then be made to professionals with the appropriate expertise. Yet when these same respondents were asked to rate their level of expertise or knowledge in these areas, the ratings were distinctly towards the novice end of the scale. As such development of training opportunities in the particular areas of assessment of enteral tubing and stomal sites would appear to be priority areas for dietitians.

### **5.3 Recommendations**

The aim of this phase of the project was to determine the characteristics and gaps in HEN service structures in Victoria that both facilitated and created barriers to the implementation of practice guidelines for HEN, as described by AuSPEN (1997). The findings from the research undertaken have been used to guide the development of a proposed model, and concurrent recommendations, for best practice in service delivery of HEN. These are outlined in the document entitled: 'Development of a Best Practice Model for Service Delivery of HEN: Phase II, Best Practice Model and Recommendations'.

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# Appendices

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## Appendix 1 – Clinical Practice Guidelines for HEN in Australia (AuSPEN 1997)

### Introduction

The aim of these guidelines is to achieve better health outcomes by improving the practice of health professionals involved in the care of patients requiring home enteral nutrition (HEN).

### Multi-disciplinary Nutrition Teams

Nutrition support teams operating within hospitals have demonstrated that their involvement improves standards of care and increases cost-effectiveness of artificial nutrition support.

The best care of the patient receiving HEN will occur when the primary care physician working with a nutrition support team (comprising medical practitioner, nurse, dietitian, stomal therapist) takes responsibility for the initial and ongoing care of the patient receiving HEN.

All members of the team have specialised knowledge and experience in HEN. The team familiar with HEN liaises with all other health professionals involved with all other health professionals involved with other aspects of clinical care. The team makes a joint decision regarding patient selection and ongoing management.

The team approach can:

- Improve standard of care
- Increase cost-effectiveness
- Ensure appropriate training and counselling of patient / or carer
- Reduce complication rates

# Indications

Home Enteral Nutrition can be considered in the management of the following conditions, including:

## 1. Impaired ability to ingest nutrients

- Oropharyngeal, oesophageal tumours
- Neurological disorders, eg cerebrovascular accident, multiple sclerosis, motor neurone disease, trauma

## 2. Impaired absorption of nutrients

- Surgical resection / bypass, eg gastrectomy, small bowel resection
- Malignancy of GIT, eg Ca pancreas
- Inflammatory disorders, eg Crohn's disease
- Short bowel syndrome
- Gastrointestinal fistulae
- Radiation enteritis

## 3. Miscellaneous

- Chronic pulmonary disease, eg Cystic Fibrosis
- Chronic renal failure
- Anorexia nervosa
- Congestive cardiac failure

HIV / AIDS

## 4. Paediatric indications

- Neurological disorders, eg Cerebral Palsy
- Failure to thrive
- Short bowel syndrome
- Chronic pulmonary disease, eg Cystic Fibrosis
- Inflammatory bowel disease
- Gastro-oesophageal reflux
- Metabolic disorders
- Chronic renal failure
- Malignancy

# Contraindications

Patient / carer not motivated or able to maintain the discipline involved in delivering HEN.

# Selection of patients for HEN

- Inability to meet nutritional requirements by oral intake as documented by dietitian's nutrition history.
- Clinical status is stable and allows discharge to the home.
- Quality of life will be maintained / improved by nutrition support.
- Patient has the ability to comply with and tolerate the nutrition therapy.
- The patient and the carer are able to cope with changes in lifestyle and demonstrate ability to perform procedures to acceptable standards.
- The home environment is appropriate for the safe and effective use of nutrition support.
- The patient and carer understand the cost of nutrition support and are aware of financial responsibilities.

# Assessment

## 1. Clinical History

The following clinical data will be assessed:

- Underlying disease
- Age
- Metabolic demands including growth requirements
- Fluid requirements

## 2. Medications and Supplements

Consideration will be given to the method of delivery of medications and supplements.

## 3. Nutrition History

The dietitian, through appropriate dietary methodology, will assess the nutrient intake of the client.

## 4. Anthropometry

The following anthropometric measures will be assessed:

- Weight, height, BMI
- Weight history
- In children, include percentile growth data and head circumference in young children and infants
- If body weight cannot be measured, an estimation of body weight should be obtained from family or carer.

## 5. Biochemical Data

The following biochemical data will be assessed:

- Liver function, renal function
- Serum electrolytes, glucose, phosphate and calcium

## 6. Social Considerations

The home environment and the patient / carer's ability to cope with the necessary procedures shall be assessed.

## 7. Activity Pattern and Lifestyle

The recreational and relaxation activities of the client will be considered including how these will impact on home feeding regimen.

# Planning

A care plan will be based on the results of the assessment and should include the following:

## Selection of Most Appropriate Route of Administration for HEN

The selection of the most appropriate route of administration for HEN will take into account the expected duration of support, the conscious state and clinical condition of the patient. Possible routes include:

- Nasogastric
- Nasoduodenal
- Nasojejunal
- Gastrostomy
- Jejunostomy

## **Methods of Delivery of HEN**

The safest and most efficient method of delivery of HEN must be determined clinically for each patient. Enteral feeds may be delivered by intermittent bolus, gravity infusion or pump-controlled techniques.

## **Selection of Formula and Timing of Feeds for HEN**

- The selection of formula will be based on a balance between the clinical requirements, mode of delivery tolerance, long-term cost and availability.
- The formulae will be appropriate for the disease process and be adjusted according to metabolic requirements.
- Formula will meet estimated nutritional and fluid requirements, with consideration for other sources of fluid / restrictions.
- The cost implications of type and quantity of feeds and the availability of government subsidies for HEN should be considered in the selection process.
- Rate and timing of administration of solutions shall be based on patient tolerance and home routine.

## **Implementation**

There shall be written guidelines (an instruction manual) for the education of patient / carer.

### **Upon discharge from hospital, the patient / carer will know:**

- How the function of GIT has changed and the reason for enteral nutrition.
- How to manage the delivery system; pump or gravity drip or syringe.
- The principles of hygiene.
- How to prevent and recognise complications such as infection, aspiration, and mechanical complications such as occlusion or misplacement of the tube.
- How to irrigate a blocked tube.
- How to change malfunctioning parts of the tube.
- Storage, hang-time, and means of provision of feeds.
- Names of personnel to contact 24-hours/day.

### **The patient / carer will be able to:**

- Check tube position.
- Prepare feed ready for administration.
- Connect feed to feed tube.
- Program feeding pump.
- Administer a bolus feed down the tube.
- Administer medication down the tube.
- Disconnect feed and flush water down the tube.

## Documentation

1. There will be a written staff protocol for initiating, monitoring and terminating HEN.
2. The nutrition support team will document in medical history all relevant aspects of assessment and management of HEN, and send information to all involved in health professionals upon discharge.  
In the medical history, the following will be documented:
  - Nutrition care plan including;
  - Initial assessment
    - anthropometry, biochemistry, nutrient requirements
    - route and method of administration of HEN
    - delivery times or duration of feeding period
    - formula
    - nutrient and fluid composition
3. There will be a patient / carer instruction manual for HEN, which is regularly updated in order to reflect developments and innovations in tube feeding, access, nutrients and delivery systems.
4. There will be a written prescription for the enteral feed, and other prescribable items.
5. There will be a list of the required equipment eg syringes, pump, drip stand.
6. There will be a written patient / carer learning goals for HEN.

## Monitoring

- Protocols shall be developed for the periodic review of the patient's clinical and biochemical status, and quality of life.
- There is an agreed time-frame for follow-up and reassessment by the nutrition support team.
- Patients receiving HEN feeding shall be reviewed by the nutrition support team after the first 3 months of initial treatment. After this review at no longer than 6 monthly intervals.

The patient will be monitored for:

- Effectiveness of therapy.
- Adverse effects
- Clinical changes.

Routine monitoring should include:

- Continued need for HEN.
- Nutrient intake.
- Review of current medications.
- Signs of intolerance to feeds.
- Weight changes.
- Biochemical, haematological data.
- Adjustment to therapy.
- Psychosocial problems.
- Changes in home environment.

- There will be an on-call system for providing expert medical advice and support to the patient / carer by telephone 24 hours a day.

## Termination

- Protocols will exist which indicate when feeding should be stopped, and what alternative action should be taken.
- Enteral nutrition should be stopped when the nutrition support team and patient / carer judge that the patient no longer benefits from the therapy.

## Transitional feeding

- If the patient is changing over to oral intake, they must be seen to be achieving adequate nutrition by this method before HEN is stopped.
- Close dietetic involvement is important to ensure adequate nutrient intake.
- An intermediate period of increasing oral intake and decreasing enteral feeding will be often necessary to assess this.
- If swallowing difficulties are present, a speech pathologist will be required to assist in transition from enteral feeding to oral intake, and to minimise aspiration risk.

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## **Appendix 2 – Recommendations of the Ministerial Working Party on HEN (July 1997)**

The Working Party recommended that:

### **Recommendation 1**

A small sub-committee comprising of HEN service providers be convened to identify a HEN minimum dataset and to consider how this dataset should be best funded, monitored and maintained.

### **Recommendation 2**

The Department of Human Services considers funding Victorian-based research trials into the outcomes and cost-effectiveness of HEN therapy.

### **Recommendation 3**

The provision of HEN in Victoria should be based on the best practice framework detailed in the 'Clinical Practice Guidelines for HEN in Australia' developed by the Australian Society for Parenteral and Enteral Nutrition (AuSPEN). This incorporates:

- Written criteria for the selection, initiation, monitoring and termination of HEN therapy.
- Standards for HEN care including discharge planning guidelines and education protocols
- Adoption of a multi-disciplinary team approach or a case management approach for HEN clients.
- Regular clinical review of HEN clients, at least within the first three months of discharge and every six months thereafter (at a minimum) with clinical reviews to be undertaken by a dietitian and a medical specialist.

### **Recommendation 4**

The Minister writes to the Commonwealth Minister for Health and Family Services seeking Commonwealth assistance for HEN costs for clients in community settings.

### **Recommendation 5**

The Department of Human Services invites Health Care Networks and hospitals to apply for funding for HEN services, contingent on agreement to meet the following conditions:

- Assumption of demand risk.
- Compliance with AuSPEN 'Clinical Practice Guidelines for HEN in Australia'.
- Collection of patient co-payment for enteral formula.
- Distribution of enteral formula.
- Collection of an agreed minimum dataset.
- Provision of all necessary aids and equipment for all HEN clients.
- Participation in ongoing monitoring and review by the Department of Human Services.
- Maximise access for rural clients.

### **Recommendation 6**

The Working Party reconvenes to review the impact of changed funding arrangements, outcomes or research and changes in clinical practice on the provision of HEN services in Victoria, with particular emphasis on the equity of co-payment arrangements and on accessibility for rural clients.



## Appendix 3 - Participants in Study 1, Part A

### Austin and Repatriation Medical Centre

- |  |   |
|--|---|
| Austin and Repatriation Medical Centre | <ul style="list-style-type: none"><li>• Ms Leonie Pearce</li><li>• Ms Helen Longton</li></ul> |
|--|---|

### Inner and Eastern Health Care Network

- |                                  |   |
|----------------------------------|---|
| Alfred Hospital                  | <ul style="list-style-type: none"><li>• Ms Ibolya Nyulasi</li><li>• Ms Vanessa Carter</li></ul> |
| The Angliss Health Service       | <ul style="list-style-type: none"><li>• Ms Adriene Jardine</li></ul>                            |
| Bethlehem Hospital               | <ul style="list-style-type: none"><li>• Ms Kate Desnevovs</li></ul>                             |
| Box Hill Hospital                | <ul style="list-style-type: none"><li>• Ms Helen Gray</li></ul>                                 |
| Maroondah Hospital               | <ul style="list-style-type: none"><li>• Ms Anita Wilton</li><li>• Ms Julie Viney</li></ul>      |
| The Peter James Centre           | <ul style="list-style-type: none"><li>• Ms Rhonda Gilbert</li></ul>                             |
| Peter MacCallum Cancer Institute | <ul style="list-style-type: none"><li>• Ms Gwenda Roberts</li></ul>                             |
| St George's Hospital             | <ul style="list-style-type: none"><li>• Ms Jenny McDonald</li></ul>                             |
| St Vincents Hospital             | <ul style="list-style-type: none"><li>• Ms Angela Herd</li></ul>                                |

### North Western Health Care Network

- |   |   |
|---|---|
| The Northern Hospital<br>Bundoora Extended Care | <ul style="list-style-type: none"><li>• Ms Helen Sheehan</li></ul>  |
| Royal Melbourne Hospital<br>Western Hospital    | <ul style="list-style-type: none"><li>• Ms Kathryn Pierce</li></ul> |
| North West Hospital                             | <ul style="list-style-type: none"><li>• Ms Claire Martin</li></ul>  |

### Peninsular Health Care Network

- |                    |   |
|--------------------|---|
| Frankston Hospital | <ul style="list-style-type: none"><li>• Ms Libby Morrel</li></ul>   |
| Mt Eliza Centre    | <ul style="list-style-type: none"><li>• Ms Yvonne Coleman</li></ul> |

Southern Health Care Network	
Dandenong Hospital	<ul style="list-style-type: none"> <li>Ms Elizabeth Frew</li> <li>Ms Barbara Villani</li> </ul>
Kingston Centre	<ul style="list-style-type: none"> <li>Ms Alison Stewart</li> <li>Ms Cathy Toyas</li> </ul>
Monash Medical Centre	<ul style="list-style-type: none"> <li>Ms Carol Cameron</li> <li>Ms Julie Woods</li> </ul>
Berwickwide Community Health Centre	<ul style="list-style-type: none"> <li>Ms Meagan Murray</li> </ul>
Women's and Children's Health Care Network	
Royal Children's Hospital	<ul style="list-style-type: none"> <li>Ms Jodie Bond</li> </ul>
Barwon South Western Region	
Geelong Hospital	<ul style="list-style-type: none"> <li>Ms Dianna Primrose</li> </ul>
Gippsland Region	
La Trobe Regional Hospital	<ul style="list-style-type: none"> <li>Ms Jacqui Bailey</li> </ul>
Hume Region	
Goulburn Valley Base Hospital	<ul style="list-style-type: none"> <li>Ms Linda McWhae</li> </ul>
Loddon Mallee Region	
Bendigo Health Care Group	<ul style="list-style-type: none"> <li>Ms Jenny Bacon</li> <li>Ms Kate Brown</li> <li>Ms Sally Mitchell</li> <li>Ms Jenny Harriott</li> </ul>

Table 3 Participants in Study 1, Part A

## Appendix 4 – HEN and Other DHS Programs

In our research a number of existing service delivery and funding programs and were noted to interface with HEN services. These were:

- Post Acute Care Program
- Hospital in the Home
- Home and Community Care

### **Post Acute Care**

PAC is a joint initiative of the Acute Health and Aged, Community and Mental Health Divisions of the Department of Human Services. PAC projects are gradually expanding to extend coverage in metropolitan areas and rural regions across Victoria. The resources allocated to PAC projects are dedicated to coordination and service provision following discharge.

Post Acute Care is a time limited short term intervention designed to assist patients to recuperate following an acute hospital admission and to facilitate their independence or transition to continuing care where required. Funding enables the purchase of individually tailored packages of health and community care services such as home nursing, personal care, childcare, allied health services and home help following discharge from hospital. The PAC program provides funding for the provision of additional post acute care services as required, and in doing so acts to augment the current service system, not substitute existing services (DHS June 1999, Appendix 6).

PAC has been used by a few organisations to manage HEN clients in the initial post discharge phase. This has generally been used to purchase community nursing services and has enabled domiciliary dietetic services.

The limitations with using PAC as a funding source of service provision for HEN is the fact that it is a short-term service. The provision of continuing care must still be addressed.

### **Hospital in the Home (HITH)**

Hospital in the Home provides consumers with more health care options by incorporating a home based component in, or providing a complete home based alternative to, an episode of acute care (DHS June 1999, p.51). For some short-term HEN clients undergoing specific treatment, eg radiotherapy and chemotherapy clients, HITH is a useful alternative. HITH is not however available for HEN clients with particular conditions who require long term HEN.

### **Home and Community Care (HACC)**

The HACC Program is a national, cost-shared program between Commonwealth and State governments. The aim of the HACC Program is to provide a comprehensive and integrated range of support services for frail aged and other people with a disability, and their carers. Multi-disciplinary services are provided to assist people to be more independent at home and in the community and to assist carers in their caring role. The aim is to prevent inappropriate admission to long-term residential care and to enhance the consumer's quality of life.

Home and Community Care (HACC) teams, namely HACC dietitians have become involved with the care of non-ambulatory HEN clients. The present limitations with this program are that not all areas are serviced by HACC teams, or HACC dietitians, and not all HEN clients fall under the Program's eligibility criteria (DHS May 1998).

## Appendix 5 – Demographics of HEN Clients Interviewed

	A&RMC	BHCG	SHCN	Total
Total Number	11	10	10	31
<b>Age</b>				
Adult	11	7	4	21
Paediatric	0	3	6	10
<b>Condition</b>				
GIT	2	0	2	4
Neurological	5	7	6	18
Cancer	4	1	0	5
Genetic	0	2	1	3
Abnormal Development	0	0	1	1
<b>Time on HEN</b>				
< 3 months	2	1	2	5
≥ 3 months	9	9	8	26
<b>Enteral Tube</b>				
PEG	8	10	8	26
Other	3	0	2	5
<b>Residence</b>				
Home	10	9	9	28
Supported Residence	1	1	1	3

Table 4 Demographics of HEN Clients Interviewed in Study 2