FINAL REPORT

In relation to Services for
Development of a Consumer Guide and
Information on Continence Products

on behalf of the
COMMONWEALTH OF AUSTRALIA
as represented by the
DEPARTMENT OF HEALTH AND AGED CARE

Submitted by
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Introduction ................................................................................................................... 101
Research approach .......................................................................................................... 101
Proposed content and formats of the Guide ................................................................. 101
Pilot testing of draft samples of the Guide ................................................................. 102
Results ........................................................................................................................ .... 102
Conclusion ..................................................................................................................... .1 04
Description of the Draft Consumer Guide to Continence Products ...................... 105
DEVELOPMENT OF RECOMMENDATIONS ....................................................... 107
Research approach .......................................................................................................... 107
Recommendations .......................................................................................................... 107
APPENDICES ................................................................................................................ 111
Appendix 1. Ethics participant information sheet and consent forms (Focus Group
Interv iews) .................................................................................................................... .. 111
Appendix 2: Systematic review search strategy for CINAHL database ................. 116
Appendix 3: Systematic review proforma ................................................................. 117
Appendix 4: Spreadsheet template for data collection from grey literature on continence
products ....................................................................................................................... ... 118
Appendix 5: Survey form for continence industry ................................................... 119
Appendix 6: Evaluation form for pilot testers ........................................................... 123
EXECUTIVE SUMMARY

Overview of the project

A Research Consultancy Team was convened to develop the tender submission and to carry out the research and development of a Draft Consumer Guide and Information on Continence Products. The Research Team consisted of Professor Sandra Dunn (principal consultant), Dr Jan Paterson and Ms Leigh Pretty (all from Flinders University), Ms Rae Winter and Ms Rosalie Donhardt (both from the Independent Living Centre of South Australia) and Professor Irene Stein (from Newcastle University). The Senior Research Manager was Dr Inge Kowanko, and the Administration Officer was Mrs Helen Murray. Collectively the Research Team had world class expertise in continence management, gerontology, health research, indigenous health issues, facilitation of independent living through continence aids and appliances, and management of information provision in variety of media to a wide range of consumer groups. The Research Team had a detailed understanding of the cultural, community and organisational issues relevant to the project. The project was funded by the Commonwealth Department of Health and Aged Care as part of the National Continence Management Strategy. Flinders Consulting Pty Ltd was the tenderer on behalf of the Research Team.

Background

Incontinence, whether urinary or faecal, is a multifaceted problem with many potential causes and treatments. The stigma associated with being incontinent limits social and professional activities and may detrimentally affect health. Many people suffering from incontinence rely on concealment techniques or continence products to manage their condition in the short or long term. There is a bewildering choice of hundreds of continence products on the market today. Choice of appropriate products for an individual with incontinence will be influenced by individual characteristics and needs, resources and care available. Without comprehensive and current information on the range of products available, informed choice and advice is not possible.

Research approach

The premise of the Research Team was that an evidence based, consultative approach would enable the development of a comprehensive Guide that best meets the needs of consumers. A mixed method approach to data collection and analysis was used, including: ongoing consultation with a Reference Group of key stakeholders; comprehensive review of published and unpublished research literature and other documents; interviews and focus groups with individuals and key organisations to determine the needs and views of clients and their carers (inclusive of culturally and linguistically diverse groups from around Australia), health professionals, health services, manufacturers, distributors and suppliers of continence products; and analysis and triangulation of qualitative and quantitative findings. Draft samples of the Guide in several versions were pilot tested by a wide range of consumers and stakeholders. The final content and format of the Guide was a compromise between what consumers wanted and what industry could provide. Recommendations for expanding, updating, marketing and distributing the guide were developed in consultation with the Reference Group. The Draft Consumer Guide to Continence Products accompanies this report.

The Research Team has undertaken this project as a fully consultative and open process, to optimise the quality and utility of the project output, providing the Commonwealth Department of Health and Aged Care, clients, carers and health professionals with current, comprehensive information regarding continence products, enabling informed choice and advice.
Perspectives of people who have incontinence and their carers

A qualitative approach involving thematic analysis of interviews and focus group discussions with a wide range of people with incontinence and carers across Australia was chosen as an appropriate way to explore the needs and views of these consumers, in particular to find out what information consumers want in a continence product guide and how it should be presented. The Reference Group facilitated access to a wide range of consumers from all states and territories, ages and genders, culturally and linguistically diverse groups including indigenous Australians, and special interest groups. A total of eleven focus groups and six individual interviews were held.

The findings of this aspect of the project highlight the need and provide a framework for a consumer guide and information on continence products. Issues raised by consumers included the paucity of written information available, ignorance amongst health professionals concerning continence products and the lack of readily available information concerning sources of financial or physical help. Most consumers selected products by trial and error. They wanted a product guide that is user friendly and easily accessible, with product information on availability, cost, quality, comfort and design. They also wanted more general information on incontinence, sources of help and how to select, care for, and dispose of products. It was important to the consumer groups that the Guide be made available in different languages, in large print and simple language.

Perspectives of health professionals

Health professionals were identified as potential consumers of the Guide, and therefore their views were also sought. The Reference Group facilitated access to health professionals from across Australia, including continence nurse advisors, medical specialists, allied health professionals and others.

The health professionals were broadly supportive of the Guide as a useful reference to aid their practice, although some questioned their personal need for a Guide. They strongly advocated professional assessment of individuals to explore treatment options and optimise management strategies. A comprehensive guide to products in book or CD-ROM format, in simple language and including full purchase details, was preferred.

Systematic review of research into the effectiveness of continence products and related consumer issues

A systematic review of research literature concerning the effectiveness of continence products and related consumer issues was conducted. More than 350 items of literature were considered for the review, but it is apparent that there is a lack of high quality research into the effectiveness of continence products or the needs and contexts of consumers. A recurrent theme in the literature is the importance of individual assessment to find products to suit the particular needs of each consumer. The review highlights that people with incontinence, their carers and health professionals lack knowledge about the condition and treatment options, and that selection of continence aids and appliances is difficult in the absence of comprehensive information.

Review of grey literature on continence products

Grey literature is a term used by researchers for the many sources of information apart from those in the scientific and healthcare literature. For this project, grey literature included consumer information from special interest groups and a variety of catalogues, advertising brochures and other documents from manufacturers, suppliers and distributors of continence products. As grey literature is generally more accessible to lay consumers
than the scientific literature, it may influence consumer choice of product.

An incidental sample of grey literature on continence products was analysed in terms of content and format to determine what information is provided and how useful it might be in aiding product selection. Literature from consumer groups mostly sought to inform consumers about incontinence, stressed the need for professional advice and gave limited but unbiased information about products. In contrast, literature from industry sources assumed a more informed audience and promoted particular brands of product. The results suggest that consumers could obtain very basic general information about incontinence from consumer organisations’ documents. However, most of the available grey literature would not be helpful to consumers selecting between or within product categories.

**The market for continence products**

International market research indicates that demand for continence products is expanding with increasing longevity and activity in old age, improved health awareness and advancing medical technologies. The Australian market is dominated by eleven large companies of which only three manufacture products onshore, and over thirty smaller companies. The preponderance of international companies manufacturing products used in Australia, coupled with the lack of internationally recognised and meaningful quality standards, makes it difficult for consumers to compare products on the basis of product documentation.

There are no clear cut mechanisms in place to enable tracking of supply and demand for continence products in Australia. There are three main demand sectors: retail, health care (hospitals and aged care) and public assistance schemes. Estimates of demand for continence products were derived from data collected from hospitals, the aged care sector, national and state public assistance schemes and industry. The estimated national expenditure on continence products in Australia was $69.1 million Aus per annum excluding the retail sector ($41.6 million Aus per annum in aged care facilities, $11.4 million Aus per annum in public and private hospitals, and $16.1 million Aus per annum through public assistance schemes).

**Collection of detailed product information from industry**

Detailed product information and other data was collected from industry by means of a survey and follow-up telephone calls. Twenty four companies provided information for the Guide. Data was entered into a relational database which enables export into word processing software. Draft samples pages from the guide were prepared from the product information for pilot testing.

**Development and pilot testing of the guide**

The findings of all the various aspects of the project were integrated, highlighting their similarities and differences, and informing the development of a Draft Guide. From these integrated findings, a full text version of the Draft Guide, including general information, detailed product information and supplier contacts, was developed. Additionally, and in response to consumer demand, a series of brochures giving brief introductory information was proposed.

Samples of pages from the Draft Guide and a draft brochure, both in several layouts and with varying content, were developed and printed for pilot testing. Packages of pilot test materials were sent to over 60 evaluators, comprising Reference Group members and consumers. The results indicated the final format and content of the Draft Guide.

The Draft Guide has been produced in two versions, a looseleaf full text print version and a CD-ROM containing identical information in pdf format. At this point a single brochure
Recommendations

Recommendations for improving, maintaining, marketing and distributing the Guide were developed in a consultative manner throughout the project. Most of the recommendations were implemented in the Draft Guide and other materials accompanying this report. Further recommendations are listed below.

1. Produce the Guide in a variety of print and electronic versions, including brochures, full text printed copy in a ring binder, a searchable CD-ROM and on the internet. These materials should build upon each other, offering different levels of complexity.

2. Produce a series of brochures which provide brief general information, and refer the consumer to sources of help and support and to the Guide itself. There should be separate brochures aimed at males and females with different severities of incontinence, and other brochures on continence products. Brochures should be translated into other languages. One draft brochure ‘Mild urine loss in females’ has already been produced as part of this project.

3. Produce a full text print version of the Guide in looseleaf format which includes general information about incontinence, assessment, treatments and management with products; comprehensive information about all available continence products; and contact details of suppliers and distributors. A ring-bound full text printed version of the Draft Guide has already been produced as part of this project. This Draft Guide should be updated, edited and sent to suppliers for checking before publication.

4. Produce a CD-ROM of all the information in the print version, plus colour graphics, audio and videoclips and a variety of search strategies. As part of this project the pdf files of the full text Draft Guide and brochure have been recorded onto CD-ROM.

5. Post the complete Guide on the internet, and include sophisticated search strategies, improved access and hyperlinks to related sites.

6. Create a central consumer resource in both print and electronic forms which comprises the research outputs of all the National Continence Management Strategy projects (including this project).

7. Expand the product information section of the Draft Guide to include product categories (eg commodes, enuresis alarms and toilet modification devices) omitted from this edition, and products from suppliers who did not participate in this project.

8. Expand the introductory section of the Draft Guide to provide general information about all product categories, focusing on issues that consumers might consider when selecting a product.

9. Include an index of products and keywords for the Guide, a comprehensive list of relevant national and international resources and organisations, a bibliography and references to research, handy hints section and a mailing slip to request updated copies. Some of these are already part of the Guide.

10. Encourage further research and development work regarding international standards, provision of relevant product information eg cost, quality assurance, allergenicity and packaging options; standardisation of icons used in packaging and catalogues.

11. Develop a variety of search strategies for the electronic versions, including both simple and advanced word searches with boolean operators.

12. Develop a process for continual updating of the Guide, with annual revisions of the...
full text print and CD-ROM versions and online updates of the internet version.

13. Outsource the maintenance contract to an organisation with specialised knowledge and skills relevant to continence products, professional advice and consumer assistance, database management, as well as strong links with the continence industry.


15. Aim all marketing and evaluation of the Guide at its consumers, including a wide range of people who have incontinence, carers, health care professionals, and industry.

16. Market and promote the Guide widely in the public arena, eg pharmacies, groceries, libraries, health centres, yellow pages, community health services, and the National Continence Helpline.

17. Distribute the brochures (translated where appropriate) widely in a range of public venues and community centres for people to take away and read in privacy. Provide such venues with the full text printed version and CD-ROM for reference. Publicise the web address for the internet version widely.

18. Evaluate the impact of the Guide 12 months after release in terms of consumer use, acceptance and perceived benefit.

19. Create a central database for tracking supply and demand for continence products.
REFERENCE GROUP

This project was guided by a Reference Group comprising representatives of relevant professional and consumer groups and national and international experts in the field. The role of the Reference Group in the project was to guide and provide feedback to the Research Team, and to facilitate access to consumers and other stakeholders to obtain their views. The Reference Group met formally on three occasions. Their assistance was essential to the project and greatly appreciated. Members of the Reference Group and the organisations they represent are listed below.

Ms Leigh Pretty, Australian Urological Nurses Society
Prof Paul Finucane, Department of Rehabilitation and Aged and Extended Care, Flinders University
Ms Cheryl Keatley, Nursing for Continence (SA) and Aged and Community Services (SA & NT)
Mr Geoff Walsh, Pharmaceutical Society of Australia Inc
Ms Pam Dawson, Alzheimer’s Association (SA) Inc
Ms Jenny Turner, Royal District Nursing Service (SA) Inc
Mr Andrew Sayer, SAYCO Pty Ltd
Mrs Carolin Gray, Carer’s Association of Australia, Inc
Ms Karen Richardson, Council on the Ageing (SA) Inc
Mr Hugh Carter, National Caucus of Consumer Disability Organisation
Ms Dalila Vellotti, MALSSA
Ms Di Semmler, Continence Foundation of Australia and Physiotherapist
Ms Rose Bonnin, Migrant Health Service
Ms Bernadette Roberts, Women’s Health Service
Ms Brenda Sando, Australian Association of Stomal Therapy Nurses
Ms Gail McLlwain, Australian Urological Nurses Society
Ms Janine Haynes, Council of Aboriginal Elders of SA (Inc)
Prof Alan Cottenden, international expert on continence products
Mr Paul McCudden, continence product industry
Mr Paul Franche, Australian Retired Persons Association
PERSPECTIVES OF PEOPLE WHO HAVE INCONTINENCE AND THEIR CARERS

Authors: Jan Paterson, Ann van Loon, Irene Stein, Sandra Dunn, Inge Kowanko, Leigh Pretty

Introduction

The Research Team used an evidence-based, consultative approach to developing the Draft Consumer Guide to Continence Products. For this project, consumers were defined as people with incontinence, carers of people with incontinence and health professionals. Extensive discussions with consumers from across Australian society were held to inform the content and format of the Draft Guide. This section of the Final Report on this project concerns the perspectives of carers and incontinent people. The perspectives of health professionals are summarised and discussed elsewhere in this Final Report.

Study design, participants and methods

The consumer data was gathered using qualitative methods that involved semi-structured interviews and focus groups followed by thematic analysis. Informed consent was obtained from all participants. Letters of approval from the relevant institutional research ethics committees, participant information sheets and consent forms appear in Appendix 1.

A series of open-ended questions was developed to guide the semi-structured interviews. The same questions were used for all interviews of individuals and focus groups, but some additional discussion ensued in several of the focus groups. The questions were developed collaboratively by the Research Team and the Reference Group. They were:

- How and where do you usually get information about your health?
- Which of these sources have information about continence products?
- Would you feel comfortable seeking information about continence products from these sources?
- Do you know anyone (yourself, friend, relative, acquaintance) who has needed to use products to contain bowel or bladder incontinence?
- Please tell us about how that person found out about the range of available continence products and where to get them.
- Please describe any problems that person had in getting information about continence products.
- What types of products does that person use?
- Is that person satisfied with their continence products?
- How did that person decide which product to use?
- What factors influenced the choice?
- What advice/information did that person get about how to use and care for the products?
- Please describe any difficulties that person had in obtaining, using or caring for the products.
• Please describe that person’s experience of seeking help from a health professional for their incontinence.

• What information would be helpful in managing that person’s continence needs?

• What type of information should be included in a Consumer Guide for Continence Products?

• How could the information be arranged to make the Guide user-friendly?

• What words would you use to find products in the Guide that suit that person’s needs?

• What form and location for the Guide would be most accessible to that person?

• Would it be useful to have a section in the Guide about how to access health professionals for assessment of incontinence and advice on managing the problem?

• Are there any other issues that you would like to raise about continence products?

The participants were selected to include people who had incontinence, cared for someone with incontinence, or were part of an advocacy group that had significant numbers of incontinent people in its membership. A combination of purposive and snowball sampling was used to gain the widest possible range of consumer voices from different cultural and linguistic backgrounds, and who were coping with various types and severities of continence conditions.

Members of the Reference Group assisted with recruitment by inviting their clients or members of the groups they represented to participate. Reference Group members made the initial contact with their members or clients, explained the project, and ensured that potential participants had all the facts they required to make a fully informed decision to participate in the project. As recruitment began the researchers were given names of other groups and individuals who might also be interested in taking part, and these contacts were followed up also.

The members of the Reference Group negotiated a convenient venue and time. The interviews and focus groups were tape-recorded and written notes were taken. A continence nurse adviser was present at the focus groups to answer any questions related to continence and to act as a scribe (apart from the Melbourne focus group where the researcher was a continence nurse advisor and the scribe was a consumer). The participants were given an opportunity to comment upon, add to, or modify the scribed outcomes of the focus group interviews.

After each interview and focus group the tape recording was transcribed and the data analysed thematically as follows. The researchers listened to the tapes and transcribed key issues from each interview. These were added to the notes scribed during the interview. The data from each interview and focus group were entered into a computer for further thematic analysis. Three researchers undertook data collection and findings were cross-validated by another researcher, to ensure no points were missed and meaning was clarified.

The language the consumers used was employed at all times in this report to reflect common language around continence. Consumers repeatedly requested that the Guide be written in ‘layman’s terms’ and ‘simple’ language. For this reason several verbatim quotes have been used throughout this report to illustrate the issues consumers wanted to highlight.

Recruitment to participate in the study ceased once no new themes were being located. People had many different experiences around product usage, and their personal experiences of being incontinent were astounding. The data continued to reveal new information in this area which was of great interest but not the focus of the product guide. When it became apparent no new data relevant to the development of the Guide was being uncovered the focus groups and interviews ceased.
A letter of thanks was sent to the many people responsible for assisting us to locate the participants, and to the individual participants. The level of cooperation from these advocacy groups was outstanding, and the researchers are grateful for their wonderful efforts.

A total of eleven focus groups were undertaken in four states, and six individual interviews were conducted in South Australia. Focus groups were held with the following communities:

- Aboriginal community- Metropolitan New South Wales
- Aboriginal community- Remote New South Wales / Queensland
- Council Of The Ageing (COTA) group - South Australia
- Metropolitan carers group- South Australia
- Rural carers’ group - South Australia
- People with disability – Tasmania and Melbourne
- People with disability – South Australia
- Parents of children with disability, chronic illness or congenital disease - South Australia
- Muslim Women’s Association - South Australia
- Polish community carers’ support Group - South Australia
- Vietnamese Community Association - South Australia

Individual clients were interviewed that represented various consumer groups in the community, including:

- The carer of a woman (wife) with advanced Multiple Sclerosis (Australian)
- The carer of a man (husband ) with Alzheimer's disease
- The carer of a woman (mother) with Alzheimer's disease
- The carer of a woman (mother) with Alzheimer's disease
- A woman with Poliomyelitis and permanent disability caring for herself
- A man with advanced Multiple Sclerosis caring for himself

The participants were drawn from various culturally and linguistically diverse groups to gain a broad perspective of the needs of consumers from different backgrounds. In addition to participants of dominant Anglo-Australian background, the project included people from indigenous Australian (Aboriginal), English, Chinese, Dutch, German, Greek, Indian, Italian, Lebanese, Pakistani, Polish, Russian, Turkish, Ukrainian and Vietnamese backgrounds. The reason for incontinence varied widely and included congenital malformations such as spina bifida, chronic debilitating diseases such as multiple sclerosis, spinal cord injuries leading to paraplegia and quadriplegia, and degenerative disease such as Alzheimer’s disease.
Description and interpretation of results

Seeking information

How do I begin?

Participants told how they did not know how to begin to search for information about incontinence and continence products. Comments such as these were heard in all the groups:

‘I didn’t know where to go.’
‘I didn’t know where to start.’
‘I had no idea where to begin.’
‘I had no idea what was important and what was not.’
‘You have no prior knowledge, therefore no idea where to start.’
‘I had no idea what was available.’
‘I didn’t even know what to call the products.’

Need for information on incontinence

The level of interest in self-care and appropriate management of incontinence was very high among all participant groups. Consumers noted that the best way to manage their health is to understand it. They wanted answers to their questions about the causes of incontinence, the short and longer term consequences of incontinence, the full range of possible treatments and therapies, sources of help including self-help, ways to manage and cope with incontinence, and detailed product information.

Problems in finding information

Consumers found they had to travel far and wide to get the information they needed. When they found information, there were always gaps, which they continued to fill through their own research efforts. Clients who were less capable of travelling had very limited product knowledge. Most consumers gathered information by themselves, and were usually unaware of the wide range of available products and the assessment procedures and management techniques used to assist in product selection. The following comments illustrate these experiences:

‘There are gaps in all the sources.’
‘You cannot find everything in one place.’
‘There is no central place to get it all from.’
‘You search for it yourself and muddle through.’

Sources of information

Consumers gleaned information themselves from product packaging, leaflets, catalogues, samples and advertisements associated with continence products. These were found in chemists, supermarkets, general stores (in country areas), and surgical and medical suppliers. Books, women’s magazines & newsletters of special interest groups (eg ParaQuad), were other sources of print information. The internet was mentioned by a small but enthusiastic minority. The brochures and other consumer information from the Continence Foundation of Australia and the Independent Living Centres were known to
many participants. Carer networks, community service providers (eg domiciliary care) also provided information. Participants mentioned seminars and workshops on incontinence held by special interest groups such as Alzheimer’s Association, Carers Association, Older Women’s network and service clubs eg Probus. Social clubs and churches were especially important sources for multicultural groups. Many participants obtained information about continence management from health professionals such as GPs, medical specialists, nurses, physiotherapists, community workers (particularly for Aboriginal communities) and continence nurse advisers. This occurred in hospitals, rehabilitation centres, specialist units eg spinal injuries unit, community health centres and home nursing services. Some information was available from subsidy schemes eg CAAS and ILEP and organisations such as DVA.

Feeling Vulnerable

Most participants felt that discussing incontinence management and shopping for incontinence products was very personal and embarrassing, and therefore valued sensitivity when speaking to health professionals and shop assistants. Almost all consumers approached their local doctor for information and advice in the early stages. Aboriginal women and many of the women from multicultural backgrounds preferred to go to a female doctor about issues such as incontinence. Participants often spoke about the problem to trusted relatives and friends in the first instance. Several people approached professionals on behalf of relatives, but were more reluctant to approach professionals regarding their own incontinence.

Lack of confidence in health professionals’ knowledge

The vulnerability that consumers experienced was magnified by their lack of confidence in their health professionals. The participants said they had not received much helpful product advice from health professionals, nor were they referred to sources of information, yet they relied on them to assess them and refer them on to appropriate resource people. The following quotes illustrate these perceptions:

‘You are reliant on medical and nursing in the first instance.’

‘You are dependent on the health professionals advice.’

‘You need people to tell you where to get things.’

‘You have trouble getting people who are honest about the problem.’

‘You end up finding the sources yourself.’

‘Quite frankly they know bugger all about the problem.’

The participants consistently noted that the most satisfactory help they received was from specialist continence nurse advisers. The majority commented that their local doctor knew little about incontinence assessment and management. Many consumers were very dissatisfied with their general practitioners’ ignorance about incontinence. According to their experiences, there is still a pervasive ‘grin and bear it’ attitude amongst generalist health professionals. Many participants were told to accept incontinence as a part of ageing, to purchase a supermarket product and learn to live with the problem because nothing could be done about it. Such inappropriate advice was devastating to people with incontinence and their families, severely hampering social activities and reducing quality of life. It is notable that during the focus groups several participants became angry when they heard (for the first time) that there are many options for incontinence management, and many product choices that may provide individuals with social continence.
Assessment and management issues

Consumers were largely unaware of the fact that they could and should be professionally assessed to develop the most appropriate personalised management plan. This was especially evident for the carers of people with chronic degenerative diseases such as Alzheimer’s disease. They saw incontinence as yet another part of the disease process and accepted it as something they could do little about. Very few consumers had been given a thorough assessment by a professional educated in continence management.

Another issue raised by consumers was a lack of consistency in professional advice. Several participants noted they had similar injuries and diseases yet the assessment and management of their incontinence was vastly different. They commented that the differences probably depended on the professional’s preference rather than the patient’s problem. Many participants expressed a need for a standardised and coordinated assessment and management strategy, so that professionals managing various aspects of their care could all follow best practice care plans. These care plans could be individualised and made available to all care providers. This was of particular concern to consumers with a disability such as advanced multiple sclerosis, paraplegia or quadriplegia. They noted that their continence management involves a delicate balance of multiple factors which can be easily disrupted when care is divided between multiple professional providers unfamiliar with the client, for example following an unplanned hospital admission.

Finding a suitable product

How will I begin?

Many participants used the supermarket or chemist as the first place to search for products, because they felt anonymous there. They usually scanned the shelves, and seldom asked for advice during the early stages. They tried out the products at home and eventually found something that suited them and which they could afford. In this way, the majority of participants found a product, or combination of products, that enabled social continence, that is the product contained their loss sufficiently to feel safe moving around in the community. However a significant number of participants, particularly carers of older people with chronic illnesses or Alzheimer’s disease, used inadequate products that they bought from the supermarket, and were unaware of the availability of a larger range of products elsewhere.

One consumer described her long search for an adequate product and when she found ‘the right thing’ she described it as ‘heaven’, such was the desperation in the search for products to enable social continence. Unfortunately, however, for many consumers the product simply “patches the problem, but does not solve it”.

Sources of advice for product selection

Most consumers told us that they had scant product knowledge in the early stages of incontinence, and so they selected from the very limited range of products that was accessible to them. In most cases this was restricted to those available in shops, recommendations of professionals, or those available to them through product subsidy schemes and hospital suppliers. The following quotes demonstrate this:

‘You get what you are told to get from hospital and CAN.’ (disabled child)
‘I got samples from the (RDNS) nurse and tried them all.’
‘I got advice from the Continence Nurse.’ (most long term clients)
‘I use what I am given.’ (DVA client)
People with incontinence and carers who were in support networks stated they obtained publications about products from them. Support groups facilitated exchange of information about ‘what is good and cheap’, and sometimes products, as these quotes illustrate:

‘I hear from other people what works for them.’ (carer)

‘I swap products with other consumers.’ (client with MS)

Many participants from all groups did not know about the professional help and support available from continence product subsidy schemes, were unaware of the range of incontinence products available outside the shops. They did not know that professional assessment of incontinence was recommended to devise an optimal treatment and/or management strategy. A continence nurse adviser was present in each focus group to scribe notes of the discussions and many participants met with the nurse afterwards to make an appointment for further help.

Products used by participants

The types of continence products used varied widely among groups. They included disposable and reusable absorbent bodyworn pads, pants and pouches; bowel products (eg anal plugs, enemas, gloves, deodorants), internal and external urinary catheters, drainage bags and accessories; bed pads and furniture protection; urinals, commodes and modifications for toilets; skincare and laundry products.

There were a number of participants who were unable to find any product that suited their needs and these people modified products or made their own. They gave examples of improvised condom drainage devices, pads being cut in half and sewn on the machine, nappies being lengthened with duct tape, and several other innovations. It was interesting that several male carers from multicultural backgrounds had developed innovative ways of caring for their wives. They made and/or modified equipment such as toilet chairs, shower chairs and various articles of clothing so that their wives could be as independent as possible. Some had stopped using their ‘home made’ equipment after domiciliary care workers advised against it. Others commented they resorted to ‘home made’ equipment because of the outrageously inflated costs of equipment.

What factors influence product choice?

Most participants chose products that contained their loss and suited their budget. They usually experimented with products until they found one that suited them and then continued to use that product.

It is notable that consumers chose products according to the individual needs and circumstances of the incontinent person. However carers’ needs and constraints were also considered when selecting products. For example we were told that some people with Alzheimer’s Diseases are easily aggravated by disposable pads or pants and tend to ‘shred the pads and roll them into little balls’. Thus product selection in such cases means finding a comfortable product that the client will keep on and which the carer can readily apply and change. Consumers seldom mentioned carer considerations as part of the decision making process, treating it as a taken-for-granted aspect of product selection.

According to the interviews and focus groups with consumers, there were five key factors influencing selection of continence products: availability, cost, quality, comfort and design.
Availability

The key factor in decision making concerning products was availability. The range of products that consumers used was limited to those that were easily available from local suppliers, shops, or subsidy schemes, as illustrated by these excerpts:

‘I can get Depend at a supermarket but I order them from wholesaler.’

‘I get what is available through the hospital, so we get it cheaper.’

‘I get whatever I can get easily up here.’ (country)

‘What I can get at the supermarkets - but they don’t sell bigger sizes.’

‘I get whatever the nursing home supplies.’

‘I order stuff but then they don’t always supply what is available, so I have to make do with what is around the place here.’

‘I had a 6 month wait for MASS scheme delivery, so I had to get whatever I could’ (Remote aboriginal community)

‘Many agencies will only supply one type of product and will not tell you about products from their competitors, so you never know of what else exists.’

Cost

Another major factor in decision making concerning products was cost. Consumers pointed out that they could not always afford the products recommended by professionals, and made their choice based on cost. Some consumers had a small supply of specific (usually more expensive) products for special occasions such as bus trips and social activities, but used cheaper, less effective brands when at home to stretch their budget. Spending on continence products varied, but most consumers were concerned about the cost of continence products. The following quotes illustrate these issues:

‘Our nappy bill for the year is $3,800 so anything that does the job cheaper is always welcome.’

‘I get whatever is cheapest (like home brand) because I can’t afford more.’

‘It is not cheap- $16 for 8 pads for my wife and I can go through 3 in one night sometimes 6 per day. This is impossible with our pension.’

‘Cheaper is good, but only if the quality is also there.’

‘You may have to use more of the product, so it can be false economy.’

‘Sometimes I have to compromise, and make a choice between the health risk of infection and what I can afford.’

‘I use whatever she is not allergic to. That does not leave much choice because everything cheap creates allergies.’

Quality

Clients wanted a quality product which would do what it claims to do, each and every time, and do it well. Consumers had experienced faulty seams in some products, inaccurate sizing, pads that did not adhere, adhesives which dried hard and chaffed the skin, and other problems that could be considered as quality control issues for manufacturers.

‘I look to see if the product does what it says it will do.’

‘It needs to do what it claims to do, and do it well.’
‘You need have the assurance that the product will work and you will not embarrass
yourself. That improves your confidence.’

‘I buy what stays on.’

For some consumers, quality was more important than price:

‘I buy boxes of 30 pads that used to cost $35 two years ago. The exact same product and
the same quantity now cost me $60. I still get them, because I know they work.’

More often, the quality of the product selected was limited by costs, for example:

‘Some do not fit well but they are affordable.’

‘Some not as absorbent, but affordable.’

**Comfort**

All consumers wanted the product to be comfortable, but for some carers this was a
particularly important issue, as the person with incontinence could become very difficult
to manage when agitated. One participant with incontinence said that comfort was a
prime consideration for him because being comfortable enabled him to perform his work.

‘It must be a good fit and comfortable, or they get aggravated.’

‘I want my child to be comfortable.’

‘I use what is most comfortable, but the price is higher as a result.’

**Composition and design**

The design issues consumers raised included suitable fit for larger women, materials for
people with allergies, discreetness and noise, and particular design features that suit
individual needs, as the following quotes demonstrate:

‘I use a shield with a gutter on the side and other products don’t have that.’

‘I look at what design fits her best and what sizes she needs, so it is not so obvious that
she is wearing a pad.’

‘I look for non plastic materials that don’t make noise.’

‘I need to find non irritating materials as she has very sensitive skin.’

Many consumers wanted products to be displayed at the point of sale so they could check
design features, such as the following request:

‘The chemist should have a sample hanging in the shop to show people how big it is and
what it looks like and so on’.

**Problems with continence products**

Poor design and inferior quality compromised consumers, which they found frustrating,
and a large number of complaints were voiced during interviews and focus groups.

‘They don’t offer complete protection, especially at night.’

One participant mentioned his experience with penile sheaths and drainage bags that ‘do
not last full day, they fall off, don’t stick, are expensive, problems with keeping it on,
leaking night bags’. Another talked of pads ‘leaking around the edges’.

There were problems with poor fit and sizing:

‘Sizes are too big and don’t always fit ... have to put safety pins in them in.’
‘They fall off when you exercise.’

Claims of capacity to absorb urine absorbency were misleading, for example:

‘They might tell you it holds 150 ml, but it does not hold 100 ml if it comes out in a gush, only if it comes out in a dribble. Particularly pouches will not hold urine if it comes out quickly.’

Many other complaints were heard about uncomfortable, bulky, noisy, absorbent garments that were very obvious under clothing. Poor workmanship and cheap materials were other criticisms.

**Information about product use, care and disposal**

**Instructions for use and wear**

Most participants agreed that there is insufficient information about how to use and care for products. Most learned about the correct use of products by reading the manufacturer’s instructions. However, several female participants noted some products have no instructions for use and wear on the packaging:

‘Do you need a belt, or special pants?’

Many older participants noted that such information may be printed too small to read. Several older people and disabled people with limited mobility and flexibility stated their preference for video advice on how to use and care for the products. Carers particularly liked video advice on such issues as catheter insertion and care. Other sources of information about product use and care were health professionals such as continence nurse advisers; Independent Living Centres; and support networks and groups of other people in a similar situation.

**Care of products**

Most participants stated that they received little information on cleaning and caring for products. This information was seldom included in the manufacturer’s information. Consumers who managed their incontinence with catheterisation were particularly keen to get more information on correct use, care and storage of products to prolong the product’s life, decrease the risk of infection, and avoid the unnecessary extra costs of product replacement. Many participants stated it is too expensive to dispose of and replace single use items, even though single use is recommended and consequently many consumers were soaking and ‘sterilising’ single use catheters daily and disposing of them after one week.

**Laundry**

Another major issue raised by participants was the need for good information about laundering reusable products. One participant told how she ruined the first Kylie (reusable absorbent bed pad) she bought because she was given no instructions on how to wash it correctly. Later she found that groups such as Domiciliary Care provide fact sheets on washing these products, which could have helped her avoid a costly mistake. Another consumer commented that she could not afford to wash the Kylie all the time, so she hung it out by a window to air. Most elderly participants found Kylies very difficult to launder due to their considerable weight when wet. Some clients used a laundering service offered by Domiciliary Care, but others were not aware of the existence of this service, or were ineligible.
Disposal

Consumers wanted information on the most hygienic and environmentally friendly manner of disposing of products. According to the participants, directions for appropriate disposal were seldom discussed by professionals and often absent from the product literature. Comments were made about the lack of facilities for disposal of penile sheaths and catheters in male public toilets, and the small size of disposal units for larger incontinence pads in female toilets. Disposal in public places was a significant concern for all clients.

Other issues about raised by consumers about products

It was evident that consumers had major concerns about supply of products. They included issues such as quotas on the number of products an individual can order each month through hospital suppliers and product subsidy schemes. This posed problems for many consumers who could not order enough products for their needs. Consumers were also concerned about changes to suppliers without notice, and the limited access to suppliers particularly in country Australia. The following quotes illustrate these concerns:

‘Hospital suppliers do not give enough supplies in the quota.’
‘Suppliers close down or change without warning.’
‘Distributors only carry limited lines, then change lines without warning.’
‘There are limited suppliers of specialist equipment- eg chemist only stocks pads but not much else. Some will get it in stock, but others will not.’
‘Sometimes suppliers send the incorrect products eg wrong size.’

There was a litany of complaints from consumers about product subsidy schemes. It should be noted that there were consumers in all focus groups who may have been eligible for subsidy but were unaware of the existence of product subsidy schemes.

Participants in receipt of subsidy complained that it did not cover their actual product costs. Some spoke of the indignity of having to ask charities for assistance to get the continence equipment required. Participants felt that the amount of subsidy should be based on assessed need, rather than a fixed amount. Participants told how some schemes use up their funds before the end of each financial year so that consumers who have not accessed their final entitlements run out of products.

The eligibility criteria for subsidy schemes were inconsistent between states and regions, such that some consumers may be subsidised, while others with the same needs may not described. The eligibility criteria were described as discriminatory for people with degenerative diseases. The lack of access to subsidy schemes for children under 16 years and people over 65 years was noted, as was the lengthy waiting list for joining most schemes.

Consumers commented they were not informed by subsidy scheme administrators when suppliers changed and products altered. This can create great difficulty for consumers who must make major alterations to personal continence management strategies and need time to find a suitable alternative products. Participants said that schemes did not always supply competitively priced products. People complained that they needed to buy their own products if they wanted something out of the mainstream.

There was widespread anger and numerous complaints about the Continence Aids Assistance Scheme. Consumers told of serious and extensive delays in supply (eg a four months delay in filling routine order of penile sheaths). In many cases, delays led consumers to create make-shift aids or reuse products while waiting their deliveries. Other complaints mentioned poor service (eg cannot answer consumers’ questions, incorrect supplies sent), and impractical catalogues or catalogues not received despite
numerous requests). Throughout the focus group interviews there was a clear perception that consumers living in the country are disadvantaged compared to urban consumers. This was particularly so in relation to access to information and services, availability, range and prices of continence products.

**Designing the consumer product guide**

**Product information**

Consumers were asked what information they would like to see in the Guide. They wanted detailed product descriptions including name, product code number(s), available sizes (and how to choose the right size) and country of origin. They also wanted explanations of products intended use and function, what types and severities of incontinence the products are suitable for. Consumers wanted to know what the products look like, and how they should be worn, and so diagrams or photographs were popular suggestions.

Clients wanted a meaningful indication of working capacity, that is how much urine can be absorbed without leaking during use. They commented on the difficulties they faced in selecting products for different rates and volumes of loss. A quality rating was suggested on many occasions, for example ‘a uniform standard rating or a rating by an impartial panel of accredited experts like Choice magazine.’

They wanted to know if products could be reused and how long they are expected to last, if they are biodegradable or harmful to the environment. Instructions for use, care, laundry, disposal and storage were requested. Information about product composition was required, especially for those with allergies to latex and plastics, and to people with environmental concerns.

Consumers needed to know how to obtain the products and so they suggested including full contact details for manufacturers, suppliers and distributors, product prices and other information needed to order supplies.

Consumers wanted the Guide to include details of design features like colour and fabric options, with/without fly, suitability for swimming. They wanted to avoid bulky, noisy products that are detectable under clothing, and discomfort from seams and joins, and ideally would have liked the Guide to include sufficient detail to choose products without these problems.

**General continence information**

Consumers requested the inclusion of information on subsidy schemes such as CAAS, ILEP and other government assistance like domiciliary care, community care packages, carers schemes, respite programs. Additionally they wanted contact details of key support and advocacy groups (including help lines and toll free telephone numbers), health professional contacts, equipment loan and hire services

Consumers expressed the strong wish to be more informed about incontinence in general, why it occurs and what can be done about it now and in the longer term, where to go for help, treatment and management options.

Another request was for a ‘handy hints’ section, with tips on management strategies for travel, economical home-made devices and remedies, and so on.

**Language**

There was an overwhelming response from consumers that simple layman’s language should be used throughout the Guide. Comments included
Avoid using medical language.’

‘Keep it simple’

Consumers discussed the words and terms that would be most easily understood. Most participants were familiar with the terms ‘continent, incontinent and incontinence’. Other terms that participants used, and which were recommended for the glossary, included bladder and bowel, male and female, urine and faeces and their colloquialisms (poo, wee, pee, piss, shit, number one, number two were all mentioned). It was agreed that a glossary of colloquial, technical and medical terms be included.

Consumers from non-English-speaking backgrounds requested that the Guide be translated into other languages, taking into account cultural sensitivities. Consumers were concerned that the Guide should be available to people with visual impairment (eg video).

Arrangement of information in the Guide

Participants were asked what would be the most appropriate method of arranging the material to assist information retrieval. It was apparent that there was a need for different levels of information, ranging from brief introductory pamphlets to a detailed directory of product information. It was suggested that the Guide could be built up in ‘layers’ from simple pamphlet to an extensive guide.

Consumers wanted the complete Guide to be divided into general information and detailed product information. Good indexing and cross-referencing, and the inclusion of a glossary of lay and technical terms were considered essential. Consumers wanted to be able to search the guide in different ways, depending on their needs and questions. Suggested topics for inclusion in the general information were: bowel incontinence, urinary incontinence, male and female incontinence, and mild, moderate and severe incontinence, incontinence resulting from spinal injury, assessment and advice, and contacts for other continence related resources. These topics were considered suitable for abridging into leaflets.

The consensus of the focus groups and interviews was that the product information section should be grouped into categories of similar products such as absorbent pads, catheters. Each product group could include general information relevant to all products in the group. Detailed information specific to each product in the group would follow, crossreferenced to the complete contact details of suppliers.

Views were mixed about the use of icons and symbols. It was agreed that if symbols were to be used they would have to be standardised across the industry and recognisable by consumers and health professionals. Consumers wanted meaningful and standardised measures of functional (working) capacity and absorbency rate, and were frustrated by the inconsistent, irrelevant or absent measures currently given by manufacturers.

Print formats

The overwhelming preference of all consumers for the complete Guide was a printed format, simple to read, in layman’s language, using large print. This was agreed across all focus groups. Use of humour, eg cartoons, was suggested.

There was also strong support for multiple levels of information in different formats, to suit the various information needs of consumers. These might range from pamphlets or fliers giving basic introductory information, more detailed booklets about particular conditions or product types, to the complete version in printed or electronic versions.

Widely available pamphlets were a popular way of obtaining information discreetly. It was suggested that pamphlets be designed to build upon each other, and that they should
refer consumers to the complete version of the Guide, as well as to other sources of help and support.

Electronic formats

There were only a few participants in this project who had access to the Internet. Most older people interviewed were not computer literate and had no time or desire to learn at this stage in their lives. Carers noted they had little time to use a computer, and reported having insufficient funds to pay for Internet access, but they acknowledged there are probably individuals who will want to access the information this way. Clients in the spinal cord injury group, and some individuals with chronic illness, were extensive computer users and these groups believed that electronic versions of the Guide would be desirable. They suggested using an accredited registered internet site and a good search engine, include on-line links to relevant organisations and sites, make disk versions available as CD-ROM and floppy disk (as some have no CD-drive in their computer). Discussion about keywords for searching electronic versions of the Guide stressed the importance of being able to search using colloquial terms.

Marketing and distribution of the Guide

Consumers were invited to share their ideas about ways to advertise and promote the Guide. Posters and fliers inviting people to ring or write for a copy were considered the best way to advertise the guide. However, care with wording is needed to avoid misunderstanding. For example one participant said she saw a continence poster in Sydney that said “Waterworks” - but she thought it was about the Sydney water system!

Advertisements and segments on television, in magazines and community newspapers were suggested. Radio was suggested as an important means of publicising the guide, particularly for people from multicultural groups who listen to programs in their own language.

Consumers wanted the Guide to be available widely from health care facilities and health professionals’ rooms, pharmacies, government and community services (eg libraries, day care centres, council offices), social clubs and societies (eg senior citizens clubs), churches, support groups and advocacy networks, retail outlets, . They also suggested promoting the Guide in newsletters of relevant organisations (eg COTA, Alzheimer’s Association, RSL).

Other issues raised by consumers about the Guide

There was considerable concern among consumers about the need for careful use of government monies allocated for continence supplies. Most consumers see the worth of a consumer product guide, but are very concerned that maintaining such a guide up to date, may be difficult and costly. They are concerned that the funding required to maintain the guide will come out of the budget allocation for product subsidies.

The comment is also raised that there is little point to a catalogue or product guide if the consumer cannot get such a product on the subsidy scheme, or the product is so expensive they cannot afford it. As such there is concern that the guide is not the best use of government funds.

Summary

The findings of this aspect of the project highlight the need and provide a framework for a consumer guide and information on continence products. Issues raised by consumers included the paucity of written information available, ignorance amongst health professionals concerning continence products and the lack of readily available
information concerning sources of financial or physical help. Most consumers selected products by trial and error. They wanted a product guide that is user friendly and easily accessible, with product information on availability, cost, quality, comfort and design. They also wanted more general information on incontinence, sources of help and how to select, care for, and dispose of products. It was important to the consumer groups that the Guide be made available in different languages, in large print and simple language.
PERSPECTIVES OF HEALTH PROFESSIONALS

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Introduction
There is no single profession within the health arena that has sole responsibility for the assessment and management of people with incontinence, due to the multiple causes and variety of treatments. While it is likely that many sufferers of incontinence will access the Guide themselves, in many instances they will request the help of a health professional to identify suitable options and find information about access and product care. Therefore the Research Team believed that it was essential to consult health professionals who have contact with the incontinent community and their carers about the proposed Guide. Given the expectation for health professionals to be involved with continence care, there is a need for them to keep their knowledge of products in the market up to date.

Study design, participants and methods

Interviews
Qualitative methods were used, involving semi-structured interviews and focus groups to collect data from health professionals and thematic analysis of the data. A series of open-ended questions were used for all interviews and focus groups were developed collaboratively by the Research team. The questions were:

1. Could you explain briefly the type of practice you work in and the range of clients that you consult with?
2. What influences your product selection when recommending these for clients?
3. How do you advise clients who only want advice regarding aids and appliances but decline a formal assessment?
4. Are you able to provide these clients with information to enable them to select products directly? What materials can / do you provide?
5. Do you have any data available regarding the demand for and supply of incontinence products (aids and appliances)?
6. If so, would you be willing to share this information?
7. How do you usually access information about products?
8. A comprehensive guide about continence products is being developed to be accessible to consumers, carers and health professionals. What information would you want in this?
9. Can you describe the ways you would like the information presented?
10. Have you seen or used any information guides that were useful and user friendly? Would a similar framework / layout be useful and if so could you provide details so we might view this?
11. What do you feel would be the ideal consumer guide?
12. What limitations do you foresee with this?
13. Do you have any suggestions for overcoming any identified limitations?
14. Any other comments that may be useful?
Face to face interviews of groups of four to five people were conducted in metropolitan Adelaide. The remaining participants were interviewed by telephone with specific consent to tape the conversations. Two participants who were unable to interviewed responded in writing to the questions.

Ethics approval was obtained from the Flinders University Social and Behavioural Ethics Committee. Participant information sheets were sent to potential interviewees and all participants completed consent forms. Appendix 1 contains the ethics documentation for this project.

**Participant selection**

An attempt was made to obtain a broad cross section of health professionals working in the field of incontinence to ensure that the guide would cater for all consumers’ needs. A combination of purposive and snowball sampling was used to gain a range of participants. Members of the Reference Group facilitated contact with a variety of national health professional bodies. Contact was then made with the professional bodies through their national or state chairpersons who agreed for their members to be interviewed and provided contact details. The chairpersons were kept informed during the project.

The interviewer contacted key people to arrange suitable times for either face to face interviews or telephone interviews. Telephone interviews were generally conducted with 1-5 health professionals from the same region gathering at a speaker phone as arranged by the main contact person. Everyone contacted was most willing to participate, however due to a variety of circumstances including leave, emergency work commitments or insufficient time, not all were able to proceed with involvement. One general practitioner in part-time clinical practice declined as he did not believe he could contribute to any discussion about incontinence. Health professionals from all states were invited to take part with metropolitan, rural and remote regions being represented.

**Participants and their practices**

A total of twenty three health professionals participated. Interviewees included urogynaecologists, urology nurses, physiotherapists, pharmacists, geriatricians, occupational therapists and stomal therapists. Continence nurse advisors made up the largest group and reflected a variety of practices including women’s health, aged care and urology in acute hospital or community settings. Participants practiced in metropolitan areas mostly, but several were located in rural and remote areas including Alice Springs, Kalgoorlie and Bairnsdale and their surrounding. All states were involved in the interviews, except NSW where a major public event at the time of data collection interfered with usual work schedules and availability.

Participants’ clients included men, women and children, and migrant and indigenous groups. The range of services offered by the interviewed health professionals covered a broad range of disabilities, obstetrics, gynaecology, conservative and surgical options. Both acute and long-term institutionalised, nursing home & hostel patients were catered for in either clinic, inpatient or community environments. In some instances the health professionals provided support for primary nurses and also in all instances gave varying degrees of phone support to patients. Pharmacists are often the first point of contact for sufferers and carers of incontinence and are frequently expected to have some understanding of continence products which may provide the social continence that is being sought and supply those required.

Most health professionals stated that their clients primarily wanted to achieve continence and not just receive products, however they recognised that clients also needed advice on these products. Education about continence management was a significant part of their practice, particularly for the continence nurse advisors and where necessary, all those
interviewed referred their clients on to specialists. Aspects of participants’ practice included: conservative therapy, assessment and management; referral; urogynaecological surgery; pharmacy supplies; occupational therapy needs; long term care of people with physical disabilities; limited advice on aids and appliances, provision of a limited range of products with ability to access anything that can be purchased (pharmacy); answering questions about clients’ incontinence problems, and patient education.

Results

Influences on product selection

Health professionals selected products based on a range of criteria and generally all were considered prior to the recommendation. However, the knowledge base of the health professional limited the factors considered. The criteria used by the health professionals included individual client needs and product characteristics.

Individual Client Needs

Continence nurse advisors in particular based any recommendations for products on the individual’s requirements and a full assessment. Where a complete assessment was not possible because the client declined or because advice for products was sought by telephone or by a carer, sufficient information could often be elicited to enable a suitable choice of product. A holistic approach was considered necessary, particularly by the continence nurse advisors, as multiple and complex medical and social problems could impact on the recommendations.

In tailoring the right aids and appliances for individual clients, comfort, product fit, lack of bulkiness and discreteness were said to be important. Client characteristics assessed included allergies with particular mention made to latex and synthetic products. Cognitive ability, including mental alertness and intellectual deficits, mobility, dexterity and need for carer support or living alone were all mentioned as influencing product choice. Understanding of the cognitive state and carer support often predicted whether reusable or disposable items were recommended, both because of ability to launder but also due to a sometimes seen trait of attempting to dispose of absorbent products via the sewerage system. Statements such as ‘I prefer disposables but recommend reusables to a high percentage of patients with dementia’ were made.

Carer ability was an important consideration as the need for continence care is often demanding and places extra burdens that can be exhausting. While using reusable items may seem appropriate they may be impractical due to the workload involved with laundering. Before recommending Kylie sheets a standard question was ‘Who washes them and puts them on the bed?’

The degree and type of incontinence was the most significant client factor for product selection, in particular urinary or faecal loss, rate and volume of leakage, and time of incontinence. As many clients were also being treated to either eliminate or reduce the incontinence, periodic reassessment of the need for and type of product was felt to be part of good continence management.

Where clients lack insight or deny the problem of incontinence and ‘don’t want to be involved’, items that perhaps were not considered ideal or optimal by the health professionals were often suggested as they felt it was preferable to have a less than adequate product rather than nothing at all. ‘Poverty and living in squalor are harder to manage’ and the health professionals agreed that this made achieving social continence more challenging.
The clients provided input into the product choice through trial and feedback as well as by suggesting or requesting specific items they had previously been made aware of. In most instances a choice was given, eg different sizes and brands. Most health professionals believed that the client should be given the opportunity to try a variety of products to ensure satisfaction and effectiveness and to prevent the purchase of a larger quantity of unsatisfactory items.

**Product characteristics**

Availability of product was a primary consideration by all health professionals with statements such as ‘if I can’t get it I don’t want to know about it’. One country based nurse admitted that she would ‘beg, borrow or steal from the hospital’ to obtain penile sheaths and catheters for her clients. Lack of delivery or at least delivery within a reasonable time restricted some items being used especially in the rural and remote areas. Participants spoke of the problems of maintaining confidentiality in a small town, and said that men in particular may be afraid to go to a chemist to purchase incontinence products for fear of being seen by others in the community. However buying quantities in bulk and having them delivered also created storage difficulties for them, according to participants.

Knowledge of suppliers, or lack of this knowledge, dictated where products were purchased and consequently which brands were available as evidenced by statements such as: ‘I go to PQ lifestyles for all products, don’t know where else to go’. Several interviewees, in particular the doctors, advised their clients to go to the supermarket or chemist for products. Furthermore they recommended these locations as the preferred suppliers of products as they believed that they would be the most convenient and economical for the client, but were usually unaware of alternatives.

Continence nurse advisors were more likely to direct clients to wholesale outlets or refer clients to funding schemes if eligible, and recommended the products supplied by these bodies. Participants told how clients who were eligible for assistance by a subsidy scheme tended to use only products available within the scheme, despite not being restricted to it, generally for economic reasons.

Of products available, cost was a very significant factor with the health professionals acting in most cases as an advocate for the client. They kept cost in mind as a limiting factor for clients needing to purchase their own products, but given the unavoidable costs to being incontinent, even the most economical choice might not be affordable for some clients. Cost alone was regarded as probably the major determinant of whether the recommended products ultimately get purchased.

Another strong influence on product suggestion by most of the health professionals was the availability of samples. The issue of samples to clients usually meant they could try a product and if satisfied would proceed with the purchase. The health professionals frequently commented that they ‘love samples’.

Qualities such as ‘user-friendly’ and ‘easy to use’ influenced health professionals’ product selection for clients. Product characteristics including volume, capacity, size, type and material and product knowledge ultimately determined the selection that matched the client’s needs.

**Advice on Aids and Appliances**

The underlying theme to emerge from the health professionals’ interviews was that they wanted to prevent ‘a culture of padding up only’ and where possible attempted to encourage people with incontinence to be assessed. They also realised that assessment must be wanted by the client. Some of the community continence nurse advisers asked the primary nurses to ‘encourage patients to be assessed’ and through education helped
people to appreciate the benefits of assessment.

In some circumstances, funding schemes will only provide products following assessment and while formal assessments were not always undertaken, several continence nurse advisers would establish a picture through general conversation. For example:

‘If I got rung and asked for pads, I’d ask questions.’

‘Sometimes incontinence is only a small part of a bigger problem, they can’t cope at that moment with more issues in life.’

Nurses were regarded as good at triaging and identifying the level of further assessment required and what the patient’s immediate needs were. Participants told how interim measures would sometimes suffice until further assessment could take place, with a priority being given to achieving social continence. For example one participant said she liked to ‘set them up so they can live life socially and comfortably’.

A pharmacist spoke of referring approximately 30% of customers to the local continence nurse adviser or doctor. Other participants made the point that they tried to make their clients feel comfortable about returning for further help as needed.

Materials provided to clients with information to enable product selection

Predominantly, participants gave their clients a demonstration of the products being recommended. However, a continence nurse adviser working in the aged care field who demonstrates and guides choice said that some clients ‘can cope with decisions, but some get confused’ and ‘they get confused by too much choice’. She felt that much of the written literature was mostly advertising and confusing for her clients.

The Independent Living Centres were recognised as being a very useful resource with written information, products on display and samples available. Those clients who contact the Independent Living Centres but are unable to visit are sent written product information. Written brochures were generally available from the nurses and physiotherapists on specific aids and appliances, however the doctors interviewed did not usually have this information on hand, but referred clients on to others.

Samples are usually given out whenever possible and these were well received by clients. Contact details of suppliers were provided and while reference to websites and CD-ROM were mentioned, computers were not used or recommended as a resource by the majority.

Access to information about products

Health professionals were asked how they usually accessed information about incontinence products and detailed a variety of means and a strong ability to seek out information needed. Virtually all health professionals found that the brochures and catalogues received through the mail formed a primary resource for keeping them up to date with product information. In some instances these included brochures and advertising in journals and in some instances catalogues were directed at particular health professionals such as occupational therapists.

Conferences most notably received mention as being a major source of information with continence nurse advisers from the rural and remote areas in particular using these to maintain the currency of product knowledge. Trade displays at seminars were also highly acknowledged as being very useful.

Continuing education programs for pharmacists were regarded as an opportunity for obtaining information about continence products, but there is very little information available as continence products only represent about 2% of pharmacy products and therefore need to complete with other lines and topics.
Manufacturers, suppliers and their representatives kept the majority of participating health professionals well informed through regular visits and provision of written information. A good relationship was maintained with acknowledgment that there is very good support from the companies who try to ensure that their current products are kept at the forefront when considering choice. It is also expected that they provide samples where possible and the reliance on their support was confirmed by one participant who demands they come or they ‘will get shot at dawn’.

In some instances the clients were seen as a source of information as they often introduced new products to the health professional. Resource centres such as the Independent Living Centres and Continence Help Line were used. One participant found that membership of the Association for Continence Advice in UK was a good resource for information about validated products and research. Evidenced based practice provided some information with research articles being scanned and continence journals being accessed. The network both inter and multi-disciplinary is used by everyone readily and particularly within regions.

**Information wanted in a guide**

Health professionals were asked what information they wanted in a guide and outlined the following areas.

**Education**

The Guide was seen by the health professionals as an opportunity to be an educational guide with information about incontinence including what it is, symptoms, major problem areas and causes. It was seen as a chance to promote ‘seeking help’ and encouragement for people with incontinence to have an assessment. A suggestion was made that there could be information about how to go about choosing the right product, having considered the individual consumers needs of a product.

**Product information**

Specific product information that participants thought should be in the guide included:

- **Availability:** Information on where to access products including samples, the easiest way to get them and how to purchase directly from the manufacturer was suggested.

- **Capacity and absorbency:** While there was full agreement about the need to include this data, there was disagreement about the measure of capacity to be used (i.e. total capacity or working capacity or both). It was considered that consumers may want capacity represented in terms of suitability for ‘light, moderate or heavy’ loss, whereas the continence advisors preferred to know the capacity in millilitres. They felt that this would only be a guide in any case as the absorbency rate may differ between products of similar capacity. It was suggested that a standard for capacity for Australia would be very useful.

- **Use:** A number of participants believed that a section on how to apply the product was necessary as consumers frequently were confused and consequently did not use products effectively.

- **Cost:** There was a strong call to include the prices – ‘we really need them’ but there was little consensus in how this could be done to ensure accuracy. One participant suggested that the product information could be regionalised to better ensure the information such as price was relevant to them. It was acknowledged that prices were likely to change frequently. It was also suggested that value for money be incorporated but no ideas as to how this should be done were offered.

- **Disposable versus reusable:** Participants wanted each product to be marked as either disposable or reusable. It was suggested that an indication of the longevity of reusable
products would be useful along with information about washing or disposal.

Material: Information about product composition was regarded as useful, particularly for people with allergies.

Pictures / photos / icons: It was generally agreed that pictures or diagrams of the products should be in the guide, with some feeling that icons may help. An icon for ease of use was suggested (one hand for simple and three hands for hard). Drops could represent capacity with explanatory terms such as soaked/wet/damp or high/medium/low.

Ordering details: It was agreed that details should be included to aid in ordering of products, eg code numbers of products, specifications and names.

Product size: There was agreement that the different sizes needed to be included as well as dimensions such as crotch width of pads.

Suppliers: Names and contact details for ordering of products was considered essential.

**Resources**

Participants wanted a section of the guide to contain information about available resources such as the details of the local Continence Nurse Advisor, support groups, the Continence Foundation of Australia and the Continence Helpline phone number.

Suggestions were that the guide needs to be non-biased, consisting simply of a database about products with no advice. However others suggested that a section of 'reviews of products' along with anecdotal comments about products would be a useful addition. It was also mooted that products be given a star rating following evaluation by a peak body of relevant people.

**Presentation of guide**

**Layout**

It was agreed that the guide needs to be well indexed, preferably with colour coding, and the products should be categorised eg. pads, pants.

**Currency**

Keeping the guide current was considered to be essential for it to be of value. To do this several participants believed that a ring binder would allow new material to be added periodically without incurring the full costs of replacing the guide completely.

**Format**

While the majority of health professionals interviewed did have at least some access to a computer, most felt that they would not access the guide electronically but would be more likely to use a print version. It was considered quicker to flip through a hard copy than to access a computer which might not be in the immediate clinical area or may be shared by others within the department. Not everyone felt completely comfortable with their computer skills and so did not believe they would use an electronic version of the guide to its full potential. Nevertheless it was generally agreed that the Guide should be placed on the internet and be available on CD-ROM.

It was thought that the knowledge of people using the guide would be variable, and so two guides were suggested with one directed at clients in the public arena and the other for health professionals and the Continence Nurse Advisor.

A number of the health professionals, particularly those working with the aged, did not
believe that consumers would want to access a complete guide as it was more likely they would see someone for advice and direction. Brochures with limited information sufficient to enable consumers to ask pertinent questions of health professionals were considered a good option for consumers.

**Concerns**

Several concerns were expressed by health professionals regarding the proposed Guide. Most were concerned that the guide would be outdated quickly and a print version in particular would be more difficult to update than an electronic version. They realised that both the availability of products and costs would aggravate this issue and suggested that a distribution list be kept to advise holders of the guide of updates and deletions. One participant asked:

‘Who will do it? Who will pay for the guide and the updates and who will do the updating?’

A suggestion was made that manufacturers may contribute to this, however not everyone agreed as this could introduce an element of bias.

Another concern was that as a national guide there would be a lot of superfluous information that would not be relevant to all areas of Australia. It was suggested that the resources section and list of manufacturers and suppliers could be arranged by region so that people could access resources and suppliers in their area.

**Recommended framework**

Various frameworks were suggested including those used in the RELPAR catalogue, pharmaceutical guides, industry brochures, MASS catalogue, Independent Living Centre database and the Australian Medicines Handbook. Relevant aspects of these were considered in the discussion of the possible frameworks for the proposed Guide to continence products.

**Distribution of guide**

The comment as made that if the guide was only available in health care services it would be considered ‘too exclusive’. Most agreed that the Guide should be freely available in public areas such as: pharmacies, information centres, public resource centres, GP surgeries, hospitals, main street shopping centres, hospital wards, allied health areas and libraries. Private areas within pharmacies were also suggested because the ‘client can search themselves, they are often happy to do so and save time for pharmacists who are often busy’. Widely available brochures were suggested for provision of introductory information about incontinence, contact and resource details and where to access the full guide.

**Other comments**

General comments relevant to the Guide and the role of health professionals included:

‘Lots come to the service expecting that we will simply advise them what product to use and don’t realise that we will assess their incontinence with the view to working to an improvement or cure’.

‘People are dependant on health professionals’.

‘We can decide what’s best for them’.

‘Health professionals can help with product choice’.

Participants were somewhat ambivalent about purchasing the Guide, and made comments
such as:
‘I would be prepared to buy it but it would depend on how helpful it is.’
‘…would buy it if I got more information but I don’t see a need at present.’
‘…don’t think I would use it as can get all the information I need.’
‘Good luck.’
‘Great idea.’
‘Good to have.’

‘When people join CAAS, they don’t have a clue based on pricing description, the catalogue needs deciphering by a Continence Nurse Advisor.

Summary

Health professionals interviewed were drawn from practitioners whose practices involved continence promotion as either the predominant or a large component. A group not consulted included nurses who have no specific continence education but whose everyday practice is likely to include caring for people with incontinence. Their voice is not present here. The sample of doctors was somewhat biased with most having easy access to continence services to whom they could refer clients and this tended to relieve them of the need to provide all the information about incontinence products. The continence nurse advisors demonstrated a greater understanding of products and appropriate questions to consider when selecting and recommending them.

This group supported the concept of the Guide, however they did not feel an overwhelming need to access it as they believed that their network provided information adequate to their needs. They felt that a guide should be educational, promote continence, and direct consumers to appropriate products. They wanted the guide to include detailed product information such as availability, capacity and absorbency, use, cost, disposable versus reusable, material, pictures/photos/icons, ordering details, product size and suppliers. A list of resources with the opportunity to add local information was also considered necessary.
Introduction

What is incontinence?

Urinary incontinence was defined by the International Continence Society Standardization Committee as "a condition in which involuntary loss of urine is a social or hygienic problem and is objectively demonstrable" 1 (p551). This definition has been adopted widely among health professionals 2-4. Urinary incontinence is always symptomatic of another underlying problem 2, 5, 6. Five main types of urinary incontinence are now recognised: stress, urge, reflex, overflow and functional 2. Factors associated with incontinence include: impaired mobility and cognition, female gender, childbirth, menopause, age, psychological distress, certain medications and medical conditions, obesity, smoking, faecal impaction, low fluid intake, environmental barriers, high impact physical activities, pelvic muscle weakness, sleep difficulties and living alone 6-9.

Faecal incontinence may be defined as involuntary loss of faecal material, and almost always causes social and hygiene problems. It may result from an intrinsic bowel disorder, neurogenic problem or faecal impaction 3, 10.

Urinary and/or faecal incontinence varies in severity and duration, and therefore its impact on sufferers and their carers also varies considerably. The social stigma of being incontinent means that people with the condition may go to great lengths to conceal the problem, may not seek help, and often become isolated 11-14.

Who suffers from incontinence?

Incontinence is prevalent in all societies, and may affect both men and women, young and old. Some estimates of prevalence are: 21% of urban Swedish women 15, 68% of USA rural community-dwelling women aged over 55 16, and 42% of acute-care patients in the USA 17. A recent cross sectional population survey of 3000 South Australians found a prevalence of urinary incontinence of 4% of men and 35% of women, increasing to 50% in older women 18. Prevalence is higher in nursing homes than in the community, eg 77% in an Australian study 19, 20 and 84% in a Swedish study 21.

Treatments for incontinence

For the majority of sufferers, incontinence is curable with a range of conservative therapies, surgery and drugs. Research evidence about the effectiveness of these treatments is accumulating, eg. pelvic floor exercise 22-28, bladder training 24, 29-36, mechanical devices 37, 38, electrical stimulation 24, 25, 34, 39, drugs 24, 40-42 and surgery 43, 44.

Management of incontinence

About 50-70% of people with incontinence respond to conservative therapies, surgery and drugs. Research evidence about the effectiveness of these people include containment of loss, maintenance of skin integrity, concealment of the problem and maintenance of quality of life 11, 13, 46-49. These continence management issues are also relevant to people undergoing or waiting for curative treatments, and for those for whom curative treatments have not been fully successful, as well as those who elect not to try treatment.
Product options for containment and/or concealment of loss comprise absorbent products such as pads, pants and bed pads, or collection devices such as indwelling or external urinary catheters, urinals and faecal collectors. The range of continence products and their features have been summarised in several articles. Directories of continence products are available from continence organisations in some countries eg from the Swedish Handicap Institute, Canadian Continence Foundation, UK Continence Foundation, and in the USA the Simon Foundation and the National Association for Continence.

**Importance of professional assessment**

Knowledgeable and experienced health professionals can assist incontinence sufferers through investigation of symptoms and diagnosis of the underlying problem, planning of optimal short and long term treatments and developing management strategies to suit individual needs and contexts. In Australian studies 70% of elderly community-living people attending a continence service significantly improved or resolved their incontinence. While undergoing therapy, or if therapy is not an option, aids and appliances may be necessary, and clients may also require assessment to choose an appropriate product for their particular needs. Selection of continence aids and products will depend on client characteristics including type of incontinence; frequency, amount and rate of loss; cognitive ability; dexterity; available care; cost and many other factors. Therefore initial assessment and periodic review is advisable to match individual and changing client needs and contexts with appropriate products.

**Methods**

**Review protocol**

A systematic review of the scientific and healthcare literature concerning effectiveness of continence products, and the needs of consumers was conducted. The review was systematic in that pre-determined and documented steps were followed to find, appraise, and summarise published and unpublished evidence. Journal articles were identified by searching electronic databases including Medline, CINAHL, Sociological Abstracts, PsycINFO and the Cochrane Library from 1982-2000. The search strategy used for CINAHL is typical, but was modified slightly to suit other databases. Further literature was obtained from the bibliographies of relevant identified articles, and by searching the internet, contacting leading researchers in the area for unpublished research, from manufacturers’ documentation and from the personal libraries of the investigators.

Potentially relevant literature was selected on the basis of the title (and abstract if available), and full text copies were obtained. Articles were classified and summarised using a proforma developed for this project. Articles were classified as research if they described the participants, continence products, methods and outcomes sufficiently to enable readers to draw their own conclusions. Research articles included experimental, quasi-experimental, descriptive or interpretive studies conducted in clinical, community or laboratory settings using qualitative or quantitative methodologies.

For this review the research literature on product effectiveness was summarised in narrative and tabular form. ‘Expert opinion’ papers are occasionally cited in the narrative in the absence of research articles.

**Clarification of terms for the systematic review**

- Consumers were broadly interpreted as users of continence products, their carers and their health professionals.
- Continence products include absorbent bodyworn pads, pants and nappy-style
garments; absorbent bed pads and chair pads; urinary catheters, drainage bags, valves and accessories; penile sheaths; urinals and commodes; faecal collectors; penile clamps; anal plugs; odour control and perineal skin care products; and enuresis alarms.

- Effectiveness was broadly interpreted as performance under clinical or laboratory conditions, encompassing subjective and/or objective measures such as consumer preference, absorbing capacity, cost, maintenance of skin integrity and prevention of leakage.
- Needs of consumers encompassed personal and social requirements and expectations, and the contextual factors that influence them.

**Results**

**Scope and quality of the literature**

Over 350 potentially relevant articles were identified from the literature search. Of these, 167 were classified as relevant research articles and are included in this review. A further 48 items from the literature are included here to provide context and background.

The quality of most of the research evidence was low level according to scientifically accepted criteria with most studies involving only small numbers of participants, lack of randomisation and blinding, and limited control of confounders. The research literature varied widely in terms of the products studied, the outcomes measured, client characteristics and research methodologies, making statistical meta-analysis inappropriate and integration of the results difficult. It should be noted, however, that randomised controlled trials to evaluate the effectiveness of products may not always be appropriate since products are continually being modified and outcomes of importance to consumers are multiple and mostly subjective. Furthermore, it is methodologically difficult to compare products from different categories.

**Consumer issues**

There is a social stigma associated with incontinence and people with the condition reported feeling incompetent, guilty and infantile and had low self-esteem. Their quality of life was significantly reduced and their anxiety, isolation and depression increased with severity of incontinence. People with incontinence felt that the psychosocial implications of incontinence were more important to them than the actual urine loss. It has been suggested that the social and emotional costs of being incontinent may be so high that nothing short of a cure is satisfactory, although others suggest that the willingness to pay for potential reduction in symptoms is related to the extent of the problem. Being incontinent affected sexuality, employment and leisure activities and financial security. Carers of incontinent people also experienced personal, social and financial disadvantage.

Adult incontinence is a taboo subject in most societies, and people with the condition may be too embarrassed to seek help and hence suffer needlessly. In a survey of US senior citizens, 60% of those who had experienced incontinence had not sought professional help. In contrast, studies of Dutch women indicated that most incontinent respondents had sought help and coped well with their incontinence. Research demonstrated that careful professional assessment enabled the selection of continence aids appropriate to individual client characteristics, leading to increased client comfort. It has been suggested that individual consumers should be involved in making decisions about their continence management options in order to select products to suit their particular needs and circumstances. There is little published research on consumer needs and requirements with respect to continence products, although ‘expert opinion’ papers abound in the health care literature.

Research shows that misconceptions about incontinence were widespread in the
community. Many wrongly believed incontinence to be an inevitable consequence of aging and were unaware of the range of treatment and management options available. Other research has centred around the continence management strategies used by people with the condition. People who coped well took charge of the situation and developed ways of managing that protected self esteem and enabled a ‘normal’ life. Concealing the problem from others was the priority. Managing incontinence was reported as a burden and hard work.

Research on the incontinence knowledge and practices of health professionals suggested widespread deficiencies and variations. A need for more knowledge about treatment options and roles of health professionals regarding continence care has been identified. In the last decade practice guidelines have been developed and disseminated by the Agency for Health Care Policy and Research in the USA and the International Continence Society. The National Health Service in the UK has implemented and evaluated consensus guidelines on continence promotion. Provision of a handbook about continence nursing improved nurses’ knowledge. Other health care institutions have developed procedure manuals. However, no published evidence of improved practice by health professionals associated with practice guidelines was identified.

Organisations such as the International Continence Society, the Continence Foundation of Australia, the National Association for Continence, the Simon Foundation, the Canadian Continence Foundation, the Association for Continence Advice, the Continence Foundation (UK) and others have worked to raise public awareness about incontinence, and have produced a range of leaflets and websites in simple language providing general information about incontinence symptoms, treatments and services. Most recommend early professional assessment for best treatment and/or management.

There is a bewildering array of continence products, aids and appliances available for managing incontinence, however there are very few directories of continence products and aids to assist or inform consumer choice. In Australia the Independent Living Centre (SA) has developed a database of aids for independent living, which includes a limited range of continence products, and which is available on the internet. A similar directory aimed at health professionals is available on the Swedish Handicap Institute website. In the North America, the National Association for Continence and the Canadian Continence Foundation have published directories of products. The Continence Foundation (UK) advertises a comprehensive directory of products, where to get them and how to use them. Dr Alan Cottenden and his group in the UK has produced a review of a large range of disposable absorbent continence products which was evaluated and found useful by continence advisors. Cottenden’s group has also produced a draft review of reusable absorbent products.

Absorbent continence products

Absorbent products are the most commonly used devices to contain incontinence. These products include absorbent pads, insert pads and male pouches that are worn inside close-fitting and sometimes specially designed underwear; absorbent pants; nappy-style garments usually with resealable fastenings; and absorbent bed pads and chair pads. They may be reusable (designed to be washed many times) or disposable and are made in a variety of sizes, shapes and materials. Whether reusable or disposable, most contain an absorbent core, a waterproof outer covering and an inner cover which draws fluid away from the skin. There are many brands and variants available, which are continuously being modified, introduced to the market or discontinued, and which vary in availability in different countries around the world. Most absorbent continence products have not
been rigorously evaluated in controlled clinical trials and consumers rely largely on manufacturers’ claims of effectiveness or the recommendation of health professionals. For all of these reasons informed product selection may be difficult.

**Standards**

There are few internationally recognised standards for absorbent continence products. Laboratory tests of capacity are commonly cited by manufacturers, but may bear little relation to clinical performance \(^{113}\). For example, there was little difference in clients' subjective assessment of wet comfort of several different pads although the pads had widely differing laboratory absorbent capacities \(^{114, 115}\). Some meaningful standards are being developed, for example certain laboratory tests of absorption which correlate with pad leakage performance under clinical conditions \(^{116-124}\). Other important clinical characteristics are comfort, maintenance of skin integrity, ease of application and removal, discretion and aesthetics \(^{119, 125, 126}\).

**Composition**

The cores of disposable absorbent products are made of fluffed cellulose wood pulp with or without superabsorbent polymer material that binds urine. The inclusion of superabsorbent material in body worn absorbent products is associated with less leakage \(^{16, 127-131}\) and less skin irritation \(^{16, 129-133}\). However, other research suggests that superabsorbent cores do not necessarily guarantee that the product will not leak in clinical usage \(^{134}\). Modern disposable pads almost all contain superabsorbents. The absorbent cores of reusable absorbent products are usually made of multiple layers of cotton, polyester or rayon \(^{112}\).

**Disposable vs reusable absorbent products**

The choice between reusable and disposable products is not simple. Although reusable products may seem an environmentally sound choice the energy, resources, effort, inconvenience and cost associated with washing and drying these products, and the high initial cost to clients must also be considered \(^{135}\). Community-dwelling clients who choose disposable products need to be able to afford the ongoing cost of purchase, dispose of used products safely and have access to a reliable supply of goods \(^{135}\). Therefore choice of reusable, disposable or combination must be tailored to the individual needs and circumstances of incontinent people and their carers. Similarly, decisions about reusable or disposable continence products in hospitals and nursing homes need to based on each institution’s resources as well as their clients' characteristics. Some consumers find the concept of reusable continence products unacceptable \(^{136}\). There is no demonstrable risk of cross-infection from reusable bed pads in hospital settings providing appropriate laundering protocols are followed \(^{137}\).

Research literature which compares effectiveness of reusable and disposable absorbent products is summarised in Table 1. The quality of the research is mostly low level and subject to bias, there is conflicting evidence, and therefore it is inconclusive overall. Some consumers preferred disposable products \(^{138, 139, 140}\), Philp, 1993 #76 whereas others preferred reusables \(^{141, 142}\). Skin integrity may be better maintained with disposables \(^{131, 132, 143-145}\), yet other research demonstrated no difference in skin condition \(^{141, 146}\). Research into cost effectiveness is also conflicting, showing that disposables increased costs \(^{138, 141}\) or decreased costs \(^{143-149}\). Possible reasons for the discrepancies in the results include differences between studies in the products compared, the measures of effectiveness, client characteristics, sample size and study designs.

**Table 1. Summary of research articles about disposable vs reusable absorbent continence products**
<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>131</td>
<td>Comparison of various absorbent bodyworn pads, pants, underpads. Disposable or reusable.</td>
<td>Incontinent adults. N=345, from 5 studies published in 128, 132-134, 141, 143-145</td>
<td>Systematic review of RCT and quasi RCT</td>
<td>Inconclusive. May be less skin problems with disposables. Superabsorbent materials may be preferred by clients, leak less and be cheaper, compared to fluff pulp.</td>
</tr>
<tr>
<td>143-145</td>
<td>Disposable bodyworn pad (Promise) in reusable stretch mesh pants vs reusable snap-fastening cloth pants used with reusable underpad.</td>
<td>Incontinent adults in nursing home. N=68</td>
<td>Random allocation to 2 treatment groups</td>
<td>No differences in total costs or number of products used. Significantly lower laundry cost with disposable product. Significantly better skin condition with disposables.</td>
</tr>
<tr>
<td>132, 133</td>
<td>Comparison of disposable and reusable products with/without superabsorbent polymer, ie polymer nappies vs nonpolymer nappies vs polymer underpads vs nonpolymer underpads vs cloth underpads.</td>
<td>Incontinent adults, hospital setting. N=166</td>
<td>RCT</td>
<td>Skin integrity better with both polymer products, worst with cloth underpad. Urine absorption best with the polymer products. Polymer products most expensive.</td>
</tr>
<tr>
<td>62</td>
<td>Comparison of disposable and reusable absorbent products, ie: underpads (Kylie, Buddies, Medipant plain, Medipant stripe, washable sheet), bodyworn pads used with mesh pants (Sancella, Moliform, Buddies, Smith &amp; Nephew) and absorbent pants (Medipant).</td>
<td>Incontinent people in an Australian nursing home N=94</td>
<td>Clinical evaluation Within subject comparison</td>
<td>Effectiveness (freedom from leakage, fit, comfort, maintenance of skin integrity, aesthetics) depended on individual client characteristics (gender, severity of incontinence)</td>
</tr>
<tr>
<td>Page</td>
<td>Comparison</td>
<td>Study Type</td>
<td>Study Details</td>
<td>Summary</td>
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<tr>
<td>138</td>
<td>Comparison of disposables and reusable bodyworn pads, ie Peaudouce Slipad or Molnlycke Tenaform bodyworn pad and stretch pants vs ACS Medical insert pad and stretch pants</td>
<td>Clinical evaluation, within-patient comparison</td>
<td>Patients and nurses preferred the disposable product (Peaudouce Slipad or Molnlycke Tenaform), although more expensive.</td>
<td></td>
</tr>
<tr>
<td>146</td>
<td>Reusable pads vs disposable nappies</td>
<td>Paired clinical study</td>
<td>Residents in a psychiatric ward, severe incontinence N=30</td>
<td>No significant differences in nursing time, cost, skin condition, safety or aesthetics</td>
</tr>
<tr>
<td>141</td>
<td>Disposable vs reusable absorbent pants</td>
<td>Crossover trial</td>
<td>Hospital setting N=46</td>
<td>80% preferred reusable product (cheaper, environmentally friendly). No difference in skin condition</td>
</tr>
<tr>
<td>139, 140, 150</td>
<td>Evaluated 42 reusable bodyworn absorbent pads, pants, all-in-ones, pull-ups.</td>
<td>Clinical evaluation, uncontrolled</td>
<td>Community-dwelling people with incontinence N=37</td>
<td>Overall, reusable pads &amp; pants were not very successful, and most consumers opted to discontinue use and revert to disposables. Some consumers found a reusable product to suit their particular needs. Acceptability more likely for light incontinence.</td>
</tr>
<tr>
<td>151</td>
<td>Evaluation of 27 disposable and reusable absorbent pads and pants</td>
<td>Clinical evaluation, uncontrolled</td>
<td>Incontinent people from community and hospital settings N=137</td>
<td>Inconclusive Kanga single pad and Tenaform performed well. Individual consumer needs (severity of incontinence, dexterity, mobility, dependence) influenced acceptability of products.</td>
</tr>
</tbody>
</table>
Evaluation of reusable absorbent pants and underpads (Medipant range vs ‘disposable pads and linen changes’).

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Community and long stay hospital residents N=70</th>
<th>Crossover trial</th>
<th>Kylie bedsheets most effective as sole protection. Bodyworn pads inconvenient to change</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=4</td>
<td></td>
<td>Uncontrolled evaluation</td>
<td></td>
</tr>
</tbody>
</table>

Comparison of 7 combinations of bed pad and bodyworn pad, disposable and reusable

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Hospital study</th>
<th>Clinical cost-benefit evaluation</th>
<th>Staff opted to continue using reusables</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=70</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Comparison of 5 bed pad systems, reusable and disposable (Kylie, Hygi Everdry, Polyweb, Undercover Bedpad)

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>Hospital based. N=14</th>
<th>Crossover study, multicentre</th>
<th>Kylie product was preferred by nurses. Increased patient comfort. Reduced disturbance, wetness and costs</th>
</tr>
</thead>
</table>

Absorbent bodyworn pads

Body worn pads are worn inside closefitting underwear or special reusable mesh pants. The pads may be disposable or reusable and come in a variety of sizes to suit different severities of incontinence. Some bodyworn pads are designed to be inserted into pouched pants (marsupial pants).

Research literature concerning the effectiveness of bodyworn pads is summarised in Table 2. Research has demonstrated that using bodyworn absorbent pads is a cost-effective means of containing urine loss 

A systematic review of randomised controlled trials and quasi-randomised trials of various types of disposable and reusable body worn pads has recently been published. Five studies met the selection criteria, but taken together, the results were inconclusive. These and other research articles about bodyworn pads are summarised in Table 2, but no firm conclusions can be made because much of the research was of poor quality (eg. inadequate control of confounding variables, lack of randomisation, small samples), and was highly variable in terms of participants, interventions, methods and outcome measures.

Most of these studies compared different styles or brands of bodyworn pad. Some studies considered the effectiveness or acceptability of the special stretch mesh or pouched pants that hold some pads in position but results were inconclusive. The consensus is that assessment of individual consumer requirements is the
key to appropriate product selection. Indeed, many research articles have emphasised that the particular needs and contexts of individual consumers should guide selection of an appropriate bodyworn pad 62, 64, 131, 134, 139, 140, 150, 151, 153, 161, 162.

Some men with slight or dribble incontinence use a pouch-shaped pad that fits around the penis 3, 4. No research on the effectiveness of male pouch-style pads was identified.

### Table 2. Summary of research about effectiveness of bodyworn absorbent pads

<table>
<thead>
<tr>
<th>Citation</th>
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<th>Participants</th>
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</tr>
<tr>
<td>127, 128</td>
<td>Comparison of various designs of disposable bodyworn pads.</td>
<td>Incontinent elderly women, hospital residents. N=45</td>
<td>RCT, crossover.</td>
<td>Design features that reduce leakage were inclusion of superabsorbent material, elastic edges, use of net pants to secure pad position, larger size</td>
</tr>
<tr>
<td>159</td>
<td>Comparison of 2 reusable ‘marsupial pants’ (Hygi vs Urocare), both used with disposable pad insert</td>
<td>Community-living incontinent people. N=76</td>
<td>Crossover trial</td>
<td>Inconclusive, possible Hawthorne effect. Hygi performed better in one geographical area, no difference in another.</td>
</tr>
<tr>
<td>Page Ref</td>
<td>Study Details</td>
<td>Patient Details</td>
<td>Study Type</td>
<td>Findings</td>
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<tr>
<td>134, 163, 164</td>
<td>Comparison of 6 disposable bodyworn pads (Tenette extra (Molnlycke), Serenity regular (Johnson and Johnson), Conveen Regular (Coloplast), Super Strola large (IPS Hospital Supplies), Cumfie small (Vernon Carus), Restful 200 (International Disposables Corporation) ).</td>
<td>Community living women with mild incontinence N=20</td>
<td>Randomised clinical trial, within-patient comparison</td>
<td>Individual clients had their own preferences &amp; issues. Comfort, leakage, confidence in use, aesthetics best for Tenette &amp; Serenity. Superstrola &amp; Conveen better than Cumfie &amp; Restful. Presence of superabsorbent polymer did not always guarantee clinical effectiveness.</td>
</tr>
<tr>
<td>153</td>
<td>Comparison of various bodyworn incontinence pads, pantyliners, menstrual pads, home-made devices</td>
<td>Continent female N=1</td>
<td>Laboratory evaluation</td>
<td>Comfort, fit, cost and leakage (of water!) varied markedly. Some home-made pads (washcloths, tissue) are cheap &amp; effective for small losses.</td>
</tr>
<tr>
<td>64, 161</td>
<td>Comparison of 4 disposable bodyworn pads</td>
<td>Elderly women, confused N=20</td>
<td>Single case design</td>
<td>No ‘best’ pad. Best pad for each client determined from individual needs.</td>
</tr>
<tr>
<td>116, 118-120, 125, 126</td>
<td>Comparison of disposable body worn pads &amp; pants</td>
<td>Incontinent people N=112, from 16 test centres in 7 countries.</td>
<td>Multicentre clinical trial</td>
<td>Clinical performance best for pads with elastic sides, bodyform shaping, high absorbency polymer core.</td>
</tr>
<tr>
<td>Page</td>
<td>Comparison of disposable and reusable absorbent products, ie: underpads (Kylie, Buddies, Medipant plain, Medipant stripe, washable sheet), bodyworn pads used with mesh pants (Sancella, Moliform, Buddies, Smith &amp; Nephew) and absorbent pants (Medipant).</td>
<td>Incontinent people in an Australian nursing home N=94</td>
<td>Clinical evaluation Within subject comparison</td>
<td>Effectiveness (freedom from leakage, fit, comfort, maintenance of skin integrity, aesthetics) depended on individual client characteristics (gender, severity of incontinence)</td>
</tr>
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</tr>
<tr>
<td>138</td>
<td>Comparison of disposables and reusable bodyworn pads, ie Peaudouce Slipad or Molnlycke Tenaform bodyworn pad and stretch pants vs ACS Medical insert pad and stretch pants</td>
<td>Incontinent people in residential care N=11</td>
<td>Clinical evaluation, within-patient comparison</td>
<td>Patients and nurses preferred the disposable product (Peaudouce Slipad or Molnlycke Tenaform), although more expensive.</td>
</tr>
<tr>
<td>165</td>
<td>Disposable body worn pads, Depend (Kimberley Clark) vs Softeze (Sancella)</td>
<td>Incontinent psychiatric hospital residents (Australian) N=6</td>
<td>Clinical evaluation</td>
<td>Softeze slightly better in terms of nursing time</td>
</tr>
<tr>
<td>162</td>
<td>Comparison of 8 disposable bodyworn pads: Free and active regular’ (Humanicare), ‘Store brand menstrual pad’ (Confab Companies) and ‘Serenity guard’ (Johnson and Johnson), ‘Always menstrual pad’ (Procter and Gamble), ‘Surety shield’ (Confab Companies), ‘Tranquility shield’ (Principle Business Enterprises, Inc), ‘Attends insert pad’ (Procter and Gamble) and ‘Depends shield” (Kimberley Clark),</td>
<td>Community-dwelling women with mild to moderate stress or urge incontinence N=65</td>
<td>RCT, within-client comparisons</td>
<td>‘Serenity’ pad rated highest performance by women. Menstrual pads rated as well or better than more expensive incontinence pads and women more willing to buy them. High cost did not correlate with good performance.</td>
</tr>
<tr>
<td>Page</td>
<td>Study Description</td>
<td>Participants</td>
<td>Study Design</td>
<td>Findings</td>
</tr>
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<td>------</td>
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</tr>
<tr>
<td>114</td>
<td>Comparison of bodyworn pads of different materials</td>
<td>Women with light stress or urge incontinence N=20</td>
<td>RCT and clinical comparison</td>
<td>All pads had similar ‘wet comfort’ as perceived by women although lab results varied.</td>
</tr>
<tr>
<td>146</td>
<td>Reusable pads vs disposable nappies</td>
<td>Residents in a psychiatric ward, severe incontinence N=30</td>
<td>Paired clinical study</td>
<td>No significant differences in nursing time, cost, skin condition, safety or aesthetics</td>
</tr>
<tr>
<td>129, 130</td>
<td>Comparison of disposable infant nappies with or without superabsorbent material and cloth nappies</td>
<td>Infants, community N=1614</td>
<td>RCT</td>
<td>Nappies containing superabsorbent material keep skin drier and less dermatitis.</td>
</tr>
<tr>
<td>154</td>
<td>Disposable bodyworn pads (Softeze) vs no pads</td>
<td>Nursing home residents (Australian study) N=10</td>
<td>Clinical evaluation</td>
<td>Pads reduced costs.</td>
</tr>
<tr>
<td>166</td>
<td>4-hourly vs 8-hourly pad changes, using ‘Moliform extra’ bodyworn disposable pads</td>
<td>Incontinent people in residential care N=131</td>
<td>Crossover study</td>
<td>Less frequent pad changes associated with wetter skin, but no effect on dermatitis or sleep disturbance</td>
</tr>
<tr>
<td>157</td>
<td>Comparison of 3 reusable bodyworn pads (Wellcross, Holbrooks, Medipants)</td>
<td>Severely incontinent nursing home residents N=28</td>
<td>Clinical evaluation, uncontrolled</td>
<td>All the pads leaked, and pads were modified during trial. Medipants was best of the three</td>
</tr>
<tr>
<td>139, 140, 150</td>
<td>Evaluated 42 reusable bodyworn absorbent pads, pants, all-in-ones, pull-ups.</td>
<td>Community-dwelling people with incontinence N=37</td>
<td>Clinical evaluation, uncontrolled</td>
<td>Overall, reusable pads &amp; pants were not very successful, and most consumers opted to discontinue use and revert to disposables. Some consumers found a reusable product to suit their particular needs. Acceptability more likely for light incontinence.</td>
</tr>
</tbody>
</table>
Evaluation of 27 disposable and reusable absorbent pads and pants

Incontinent people from community and hospital settings
N=137

Clinical evaluation, uncontrolled

Inconclusive
Kanga single pad and Tenaform performed well.
Individual consumer needs (severity of incontinence, dexterity, mobility, dependence) influenced acceptability of products.

Comparison of 2 systems of reusable pants with disposable insert pads (Kanga pants/pad vs Sandra pant with Bambi pad)

Women with incontinence
N=51

Within patient control, crossover trial

Equally effective in keeping dry.
Greater patient comfort with Sandra

Comparison of 7 combinations, of bed pad and bodyworn pad, disposable and reusable

Community and long stay hospital residents
N=70

Crossover trial

Kylie bedsheets most effective as sole protection.
Bodyworn pads inconvenient to change

Comparison of disposable and reusable absorbent products

Hospital study
N=…?

Clinical cost-benefit evaluation

Staff opted to continue using reusables

Evaluation of reusable pants (3 from Kanga range, used with disposable insert pads)

Long stay geriatric patients
N=12

Uncontrolled evaluation

Kanga pants well accepted by patients and staff.
Problem with insert pads disintegrating when wet.

Evaluation of 3 pads (flat vs T-shaped vs shaped elasticised)

Elderly care patients
N=63

Uncontrolled evaluation

Shaped pads leaked less than flat pads, and elasticised edges improved performance further.

**Absorbent pants and nappy-style garments**

Absorbent nappy-style or pant-shaped products are also very popular. These may be similar in design to infant nappies with fastenings (usually resealable adhesive tapes for disposables and snaps or hook-and-loop tape for reusables) and are known as all-in-ones. There are also absorbent pants or ‘pullups’, which resemble padded underwear. These
products are available in reusable or disposable form, in a wide variety of styles, sizes and capacities.

Absorbent pants and nappies were effective in containing incontinence in hospital settings 167, 168 and in the community 169. Table 3 shows that research results were conflicting regarding the relative merits of pants and nappies compared to bodyworn pads, and the effectiveness of different designs and materials. Again, it is evident that individual consumers have particular needs and issues which must be considered when choosing an incontinence garment.

**Table 3. Summary of research on the effectiveness of absorbent pants, pull-ups and all-in-ones**

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>143-145</td>
<td>Disposable bodyworn pad (Promise) in reusable stretch mesh pants vs reusable snap-fastening cloth pants used with reusable underpad.</td>
<td>Incontinent adults in nursing home. N=68</td>
<td>Random allocation to 2 treatment groups.</td>
<td>No differences in total costs or number of products used. Significantly lower laundry cost with disposable product. Significantly better skin condition with disposables.</td>
</tr>
<tr>
<td>132, 133</td>
<td>Comparison of disposable and reusable products with/without superabsorbent polymer, ie polymer nappies vs nonpolymer nappies vs polymer underpads vs nonpolymer underpads vs cloth underpads.</td>
<td>Incontinent adults, hospital setting. N=166</td>
<td>RCT</td>
<td>Skin integrity better with both polymer products, worst with cloth underpad. Urine absorption best with the polymer products. Polymer products most expensive.</td>
</tr>
<tr>
<td>116, 118-120, 125, 126</td>
<td>Comparison of disposable body worn pads &amp; pants</td>
<td>Incontinent people N=112, from 16 test centres in 7 countries.</td>
<td>Multicentre clinical trial</td>
<td>Clinical performance best for pads and pants with elastic sides, bodyform shaping, high absorbency.</td>
</tr>
<tr>
<td>Page</td>
<td>Study Description</td>
<td>Study Population</td>
<td>Study Design</td>
<td>Study Findings</td>
</tr>
<tr>
<td>------</td>
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</tr>
<tr>
<td>62</td>
<td>Comparison of disposable and reusable absorbent products, ie: underpads (Kylie, Buddies, Medipant plain, Medipant stripe, washable sheet), bodyworn pads used with mesh pants (Sancella, Moliform, Buddies, Smith &amp; Nephew) and absorbent pants (Medipant).</td>
<td>Incontinent people in an Australian nursing home N=94</td>
<td>Clinical evaluation Within subject comparison</td>
<td>Effectiveness (freedom from leakage, fit, comfort, maintenance of skin integrity, aesthetics) depended on individual client characteristics (gender, severity of incontinence)</td>
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<td>146</td>
<td>Reusable pads vs disposable nappies</td>
<td>Residents in a psychiatric ward, severe incontinence N=30</td>
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<td>Clinical evaluation, uncontrolled</td>
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</tr>
<tr>
<td>167</td>
<td>Disposable absorbent pants (Attends, Proctor &amp; Gamble) vs nothing</td>
<td>Hospitalised incontinent people N=29</td>
<td>Clinical evaluation</td>
<td>Use of disposable absorbent pants reduced nursing time and amount of soiled linen/clothing significantly</td>
</tr>
<tr>
<td>170</td>
<td>Disposable incontinence system (pants and bed pads with superabsorbent material, Tranquility, Principle Business Enterprises) vs other disposable products</td>
<td>Incontinent people in nursing homes N=95</td>
<td>Clinical study, uncontrolled</td>
<td>The test system was effective, with less skin wetness and irritation (nurse assessment)</td>
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<tr>
<td>141</td>
<td>Disposable vs reusable absorbent pants</td>
<td>Hospital setting N=46</td>
<td>crossover trial</td>
<td>80% preferred reusable product (cheaper, environmentally friendly). No difference in skin condition</td>
</tr>
<tr>
<td>151</td>
<td>Evaluation of 27 disposable and reusable absorbent pads and pants</td>
<td>Incontinent people from community and hospital settings N=137</td>
<td>Clinical evaluation, uncontrolled</td>
<td>Inconclusive Kanga single pad and Tenaform performed well. Individual consumer needs (severity of incontinence, dexterity, mobility, dependence) influenced acceptability of products.</td>
</tr>
<tr>
<td>171</td>
<td>Evaluation of 36 disposable all-in-one absorbent pants (not named by brand)</td>
<td>Incontinent people N=192</td>
<td>Uncontrolled clinical evaluation</td>
<td>Marked differences between best and worst in terms of capacity, leakage, consumer preference, but no detailed results reported. Price unrelated to performance.</td>
</tr>
<tr>
<td>168</td>
<td>Disposable absorbent pants vs usual care (urinary catheters, pads, etc)</td>
<td>Hospital residents N=32</td>
<td>Pre-post clinical study</td>
<td>No deterioration in skin condition with disposable briefs. Reduced cost Nurses liked the pants</td>
</tr>
</tbody>
</table>
Evaluation of reusable absorbent pants (Healthdri)

Community-living
N=175

Consumer satisfaction survey.
Uncontrolled

Most consumers satisfied with comfort, performance, Increased confidence

Absorbent underpads for beds and chairs

Underpads may be used alone but more often are used in conjunction with additional incontinence aids such as bodyworn pads or pants. The research into effectiveness of reusable and disposable underpads was reviewed and is summarised in Table 4. All the identified research concerned bed pads and none was found about chair pads. Some studies showed that bed pads were an effective means of containing urine loss 147, 152, 172-175, particularly for bedridden people, those with limited mobility or for night use. There was no demonstrable risk of cross-infection from reused bed pads laundered according to the hospital’s standard ‘foul wash’ procedure 137. In contrast, other research comparing different bed pads demonstrated that there were problems with the performance of all the bed pads and that only 60% of consumers were satisfied with the highest rated bed pad 117, 176. As with the research for other absorbent products, no firm conclusions can be made from this review due to variability in studies. Again, several researchers highlighted the need to match individual needs and contexts to suitable products 62, 177.

Table 4. Summary of research about effectiveness of bed pads

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
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<th>Outcome</th>
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<td>Random allocation to 2 treatment groups.</td>
<td>No differences in total costs or number of products used. Significantly lower laundry cost with disposable product. Significantly better skin condition with disposables.</td>
</tr>
<tr>
<td>Reference</td>
<td>Study Details</td>
<td>Sample Size</td>
<td>Study Design</td>
<td>Key Findings</td>
</tr>
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</tr>
<tr>
<td>132, 133</td>
<td>Comparison of disposable and reusable products with/without superabsorbent polymer, ie polymer nappies vs nonpolymer nappies vs polymer underpads vs nonpolymer underpads vs cloth underpads.</td>
<td>Incontinent adults, hospital setting. N=166</td>
<td>RCT</td>
<td>Skin integrity better with both polymer products, worst with cloth underpad. Urine absorption best with the polymer products. Polymer products most expensive.</td>
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<tr>
<td>62</td>
<td>Comparison of disposable and reusable absorbent products, ie: underpads (Kylie, Buddies, Medipant plain, Medipant stripe, washable sheet), bodyworn pads used with mesh pants (Sancella, Moliform, Buddies, Smith &amp; Nephew) and absorbent pants (Medipant).</td>
<td>Incontinent people in an Australian nursing home N=94</td>
<td>Clinical evaluation Within subject comparison</td>
<td>Effectiveness (freedom from leakage, fit, comfort, maintenance of skin integrity, aesthetics) depended on individual client characteristics (gender, severity of incontinence)</td>
</tr>
<tr>
<td>170</td>
<td>Disposable incontinence system (pants and bed pads with superabsorbent material, Tranquility, Principle Business Enterprises) vs other disposable products</td>
<td>Incontinent people in nursing homes N=95</td>
<td>Clinical study, uncontrolled</td>
<td>The test system was effective, with less skin wetness and irritation (nurse assessment)</td>
</tr>
<tr>
<td>147</td>
<td>Evaluation of reusable absorbent pants and underpads (Medipant range vs 'disposable pads and linen changes).</td>
<td>multiple sclerosis patients N=4</td>
<td>Uncontrolled evaluation</td>
<td>Reduced laundry costs with reusable system</td>
</tr>
<tr>
<td>117, 176</td>
<td>Comparison of 6 disposable bed pads</td>
<td>Severely incontinent, mostly hospitalised N=95</td>
<td>Crossover study, within participant control.</td>
<td>Acceptability of leakage performance was variable. Most performed poorly, top-scoring bed pad was acceptable to only 60% of consumers.</td>
</tr>
<tr>
<td>Page</td>
<td>Study Description</td>
<td>Study Design</td>
<td>Results</td>
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</tr>
<tr>
<td>152</td>
<td>Comparison of 7 combinations, of bed pad and bodyworn pad, disposable and reusable</td>
<td>Community and long stay hospital residents N=70</td>
<td>Crossover trial</td>
<td>Kylie bed sheets most effective as sole protection. Bodyworn pads inconvenient to change</td>
</tr>
<tr>
<td>172</td>
<td>Comparison of reusable bed pads (Kylie) vs none</td>
<td>Community study N=12</td>
<td>Pre-post clinical study</td>
<td>Use of bed pads reduced linen changes, odour. No change in skin condition, bed wetness, comfort, restlessness</td>
</tr>
<tr>
<td>142</td>
<td>Comparison of 5 bed pad systems, reusable and disposable (Kylie, Hygi Everdri, Polyweb, Undercover Bedpad)</td>
<td>Hospital based. N=14</td>
<td>Crossover study, multicentre</td>
<td>Kylie product was preferred by nurses, increased patient comfort, reduced disturbance, reduced wetness and lower costs</td>
</tr>
<tr>
<td>173</td>
<td>Comparison of 3 reusable bed pads (all from Kylie range)</td>
<td>Hospital based. N=5</td>
<td>Crossover trial</td>
<td>Modifications to bed pad made by manufacturer in response to clinical experience were effective.</td>
</tr>
<tr>
<td>177</td>
<td>Comparison of 6 reusable bed pads (K2, Absorb plus 1593, Standard 221, Intera IN105, Kylie standard, Medipad 102)</td>
<td>Incontinent people in hospitals, nursing homes and community N=72</td>
<td>Multicentre crossover trial</td>
<td>Standard 221 and Kylie standard were rated best by consumers. Great variation between users in terms of acceptability, ease of washing, etc</td>
</tr>
<tr>
<td>174</td>
<td>Comparison of reusable Kylie bed pad (with &amp; without antimicrobial agent) to drawsheet</td>
<td>Geriatric hospital patients, severe faecal and urinary incontinence. N=32</td>
<td>Crossover study</td>
<td>Kylie bed pad more effective than drawsheet (more absorbent &amp; less nursing time, odour, skin erythema) No advantage in adding antimicrobial agent</td>
</tr>
</tbody>
</table>
Urinary collection devices

Apart from absorbent products, many people use urinary collection devices to manage their incontinence. These include urinary catheters of various types and penile sheaths, accessories such as drainage bags, connectors and tubes, urinals and commodes. Research evidence about the effectiveness of these collection devices is summarised below.

**Urinary catheters**

For many people, drainage of the bladder through a urinary catheter is an appropriate strategy for managing incontinence. Urethral and suprapubic catheters may be left insitu longterm, others may require only short term placement of the urinary catheter or intermittent catheterisation 180.

Very few research articles about the effectiveness of urinary catheters as a management strategy for incontinence were identified although ‘expert opinion’ papers abound. The research articles are summarised in Table 5. Two studies compared indwelling urethral catheters and bed pads for hospitalised patients, and results showed no difference in patient preference, equal incidence of bacteriuria, but conflicting cost estimates 181, 182. Interestingly, nurses favoured bed pads as they perceived the risk of urinary tract infection to be greater with catheters 181. Another study compared acceptability of internal urinary catheters with external penile sheaths 183. In that study patients found the urinary catheters to be less comfortable and more restricting, but nurses felt that they were easier to care for than penile sheaths 183. No research on effectiveness of suprapubic catheters was identified.

It is evident from this review that there is a paucity of quality information on which to base selection of urinary catheters, but a number of useful ‘expert opinion’ papers and texts have been published eg 6, 180, 184-187. The consensus seems to be that long term indwelling urinary catheterisation is indicated for intractable incontinence when other
non-invasive management strategies have failed, or for some types of urinary retention. Short term (less than 28 days) catheters may be used for temporary urine retention, perioperatively or for investigations. There is a trend for use of intermittent urethral catheters or suprapubic catheters for extended periods, rather than indwelling urethral catheters, to reduce complications such as urinary tract infection, mechanical trauma to the urethra and discomfort. Intermittent catheterisation may be a better option than indwelling urethral or suprapubic catheters for sexually active, more independent people, and may be associated with fewer complications like encrustations, blockages and infections. Intermittent catheterisation was best accepted by people who were able to catheterise themselves. Consideration of factors such as purpose of catheterisation, degree of patient involvement and carer support, latex allergy, gender, age and patient comfort are all necessary when choosing a catheter.

There has been limited research concerning the care of indwelling urinary catheters eg. Some guidelines on catheter care exist including a systematic review of care of short term indwelling catheters to prevent urinary tract infections.

Table 5 Summary of research about effectiveness of urinary catheters

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
<th>Outcome</th>
</tr>
</thead>
<tbody>
<tr>
<td>182</td>
<td>Indwelling catheter vs bed pads</td>
<td>elderly bedridden patients, dementia N=22</td>
<td>RCT</td>
<td>Indwelling catheter cheaper. No difference in bacteriuria.</td>
</tr>
<tr>
<td>181</td>
<td>Indwelling urethral catheter vs bed pads</td>
<td>elderly female patients N=78</td>
<td>prospective randomised clinical study</td>
<td>Catheters cost more than bed pads, take more nursing time. No difference in bacteriuria. No difference in patient preference. Nurses preferred bed pads (perceived lower infection risk)</td>
</tr>
<tr>
<td>183</td>
<td>Indwelling urethral catheter vs penile sheaths</td>
<td>N=104 older male patients N=99 nurses</td>
<td>Interview (patients) Survey (nurses)</td>
<td>Patients believed penile sheaths were more comfortable, less restrictive. Nurses agreed but believed penile sheaths fell off, leaked, required more nursing time.</td>
</tr>
</tbody>
</table>

Penile sheaths
Penile sheaths (also known as external male catheters, uridomes, condom catheters) are used by some incontinent men as an alternative to absorbent products or internal urinary catheters. They are a condom-like devices, usually made of thick latex, with or without adhesive to secure them to the penis, and with an opening at the tip to which a drainage
tube and bag can be attached. Penile sheaths are an acceptable means of managing moderate to severe urinary incontinence, particularly for men with limited mobility. Possible complications include dermatitis, latex allergy, urinary tract infection and necrosis.

There has been limited research on the efficacy of these devices, summarised in Table 6. The quality of these reports is low, but it appears that penile sheaths are well accepted compared to indwelling catheters. Comparisons of different penile sheaths are few, and researchers emphasise the importance of finding a product suitable to the individual consumer’s anatomy and lifestyle.

**Table 6 Summary of research on penile sheaths.**

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
<th>Outcome</th>
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<tr>
<td>183</td>
<td>Indwelling urethral catheter vs penile sheaths</td>
<td>N=104 older male patients; N=99 nurses</td>
<td>Interview (patients); Survey (nurses)</td>
<td>Patients believed penile sheaths were more comfortable, less restrictive. Nurses agreed but believed penile sheaths fell off, leaked, required more nursing time.</td>
</tr>
<tr>
<td>193, 195</td>
<td>Comparison of urinary sheath systems: Simpla Bubble U vs Conveen with Conveen leg bag vs Conveen with Seton S2 leg bag</td>
<td>elderly hospitalised males, severe incontinence; N=6</td>
<td>crossover study</td>
<td>No skin problems with any of these. Simpla Bubble U stayed in place longer than both Conveen systems. Leg bag and tubing components were probable confounders</td>
</tr>
<tr>
<td>194</td>
<td>Comparison of external catheters: Freedom vs hospital-constructed.</td>
<td>extended-care hospital patients; N=10</td>
<td>exploratory study</td>
<td>The Freedom catheter stayed on better (adhesive). Nurses preferred Freedom. Hospital-constructed device was useful for patients with friable skin &amp; low mobility.</td>
</tr>
<tr>
<td>196</td>
<td>Evaluation of penile sheaths: Easyflow</td>
<td>Experienced users of other penile sheaths; N=20</td>
<td>uncontrolled clinical evaluation</td>
<td>Most patients preferred Easyflow to previously used external catheters (easier to apply and remove, increased daytime dryness)</td>
</tr>
</tbody>
</table>
Evaluation of penile sheaths: VPI non-adhesive

Urology clinic patients N=14 uncontrolled clinical evaluation

Most patients found it effective

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
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</tr>
</thead>
<tbody>
<tr>
<td>208</td>
<td>Comparison of 10 urine drainage bags: (Bardic leg bag, Portex leg bag, Dover-Searle bed bag, Dover-Searle Portabag, Universal leg bag, Seton bed bag, Uri-leg bag, Meredith bed bag, Bardic bed bag, Seton Portabag)</td>
<td>Healthy medical and non-medical hospital staff N=47</td>
<td>Comparative laboratory study</td>
<td>Participants found the Dover-Searle bed bag easiest to empty (had a crocodile snap clip). Protect leg bag with bung was rated worst.</td>
</tr>
<tr>
<td>202</td>
<td>Comparison of 5 leg bags for penile sheath users (Conveen Contour, Conveen Security+, Incare, Bendi Bag, Incontiaid)</td>
<td>People with incontinence, in community N=34</td>
<td>multicentre clinical study, crossover</td>
<td>Coveen Contour rated best overall, most comfortable and discreet. Wheelchair users preferred the Bendi Bag design.</td>
</tr>
<tr>
<td>209</td>
<td>Comparison of 4 drainage bag systems (including taps and supports): Bard Uriplan, Simpla, Seton, Wallace</td>
<td>Community-dwelling incontinent people and their carers N=24</td>
<td>crossover study</td>
<td>Wallace system preferred overall. Many problems identified with most systems, eg stiff connectors, uncomfortable or inadequate supports, kinking tubes, valves that leak on emptying or need two hands.</td>
</tr>
<tr>
<td>205</td>
<td>Comparison of leg bag and catheter valve</td>
<td>Men with acute urinary retention. N=18</td>
<td>RCT, crossover</td>
<td>Most preferred the catheter valve to the leg bag (more discreet). Some had nocturnal frequency with the valve.</td>
</tr>
<tr>
<td>201</td>
<td>Evaluation of reusable drainage bag</td>
<td>Neurogenic bladder N=14</td>
<td>before and after study</td>
<td>No change in incidence of urinary tract infection attributable to reusable leg bag.</td>
</tr>
<tr>
<td>206, 207</td>
<td>Comparison of 7 catheter valves: Staubli (Metron Instruments), Uri-flo (Sims Portex), Medical valve (EMS), Bridge (Beambridge Medical), Bi-vent (DePuy Healthcare), Flip-flo (Bard) and Klick (Henley Medical)</td>
<td>Incontinent people N=46</td>
<td>multicentre study, within-participant comparisons</td>
<td>All rated performance of Staubli very highly, but most expensive. Most found Flip-flo and Uri-flo to be good. 56% rated the ‘Bi-vent’ valve as unacceptable</td>
</tr>
<tr>
<td>204</td>
<td>comparison of leg bag and 2 catheter valves: Uroflow (Simcare) and Flip-flo (Bard)</td>
<td>Incontinent people (neurogenic bladder, bladder outflow obstruction) N=28</td>
<td>RCT</td>
<td>no differences in quality of life, cost or adverse effects</td>
</tr>
</tbody>
</table>
comparison of 4 systems for fastening leg bags and conventional leg straps: Leg Bag Garment (Bard), Aquasleeve (DePuy), Shepheard Sporran System (EMS) and the Holster bag (Wallace)

Only Aquasleeve considered by consumers to be effective compared to conventional leg straps. Drawbacks of other systems were: difficulty of use, expense, poor fit and conspicuousness

Citation | Intervention | Participants | Type of study | Outcome |
---|---|---|---|---|
| | Experienced users of leg bags. N=52 | crossover study | Only Aquasleeve considered by consumers to be effective compared to conventional leg straps. Drawbacks of other systems were: difficulty of use, expense, poor fit and conspicuousness |

**Urinals and commodes**

Urinals (pans) and commodes are used to collect urine by many people with incontinence who do not wish to use absorbent products or catheters. Only one research article was identified which concerned effectiveness of urinals, and none about commodes. Table 8 summarises the results. Although all of 13 tested urinals were successful for some women, there was great variability in their suitability in different positions, with few suitable for use lying down, or for highly dependent women. Choice became more limited with increasing dependency.

A novel external urine collection device for women which adheres between the labia around the urethra has been developed and clinically evaluated, but no well designed clinical trials have been conducted to date.

**Table 8. Summary of research about effectiveness of urinals**

<table>
<thead>
<tr>
<th>Citation</th>
<th>Intervention</th>
<th>Participants</th>
<th>Type of study</th>
<th>Outcome</th>
</tr>
</thead>
</table>
### Other continence products

No research on faecal collecting devices was identified although several articles describing such devices were found in the nursing literature \(^{10, 212, 213}\). No research on penile clamps or anal plugs was identified. Research literature about associated products such as waterproof furniture protection, odour control products, special skin care or hygiene products was also not identified.

A systematic review of over 60 trials of various treatment for childhood enuresis found that the use of enuresis alarms was 13 times more effective than no treatment in helping children achieve 14 consecutive dry nights and that enuresis alarms had a more sustained effect than treatment with drugs (imipramine or desmopressin) \(^{214}\). Only one comparative study of enuresis alarms was identified \(^{215}\).

### Limitations

This systematic review summarised the research evidence about effectiveness of continence aids and appliances, and research on related consumer issues. Although the review was systematically conducted according to a protocol which specified methods for finding, appraising and summarising the literature, there are some limitations, mostly

<table>
<thead>
<tr>
<th>210</th>
<th>comparison of 13 urinals</th>
<th>community-dwelling women N=36</th>
<th>multicentre clinical evaluation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Femicep (Sims Portex), Bridge Saddle Pan (Beambridge Medical), Female Urinal (Henley Medical), Petal Female Urinal (Warwick Sasco), Spil Pruf (Aremco), Bridge Urinal (Beambridge Medical), Femupan (AJ Products), Bedpan female with red Subaseal stopper (Henley Medical), Bridge Hand Pan (Beambridge Medical), St Peter’s Boat (Henley Medical), Bridge Urinal with handle (Beambridge Medical), Female Chair Urinal (Aremco) and Cygnet Female Urinal (Warwick Sasco)</td>
<td>All urinals successful for some women. Only Petal assessed by more than 31% of consumers as good in all positions. Most were only useful when sitting on edge of bed, standing or crouching. Less suitable urinals available for more dependent women.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>211</td>
<td>Evaluation of female urine collection device</td>
<td>descriptive clinical trial</td>
<td></td>
</tr>
</tbody>
</table>

No research on faecal collecting devices was identified although several articles describing such devices were found in the nursing literature \(^{10, 212, 213}\). No research on penile clamps or anal plugs was identified. Research literature about associated products such as waterproof furniture protection, odour control products, special skin care or hygiene products was also not identified.

A systematic review of over 60 trials of various treatment for childhood enuresis found that the use of enuresis alarms was 13 times more effective than no treatment in helping children achieve 14 consecutive dry nights and that enuresis alarms had a more sustained effect than treatment with drugs (imipramine or desmopressin) \(^{214}\). Only one comparative study of enuresis alarms was identified \(^{215}\).
relating to the scope, quality, currency and integration of the evidence.

- International standards for some continence products are being developed but most of the literature on effectiveness of products did not refer to them.

- Measures of effectiveness varied widely between studies, so that comparison and integration of results of similar studies was difficult.

- Many research articles did not include sufficient detail to adequately assess the study design or rework the results. No attempt at contacting authors for raw data was made due to time constraints.

- There was very little research on consumer needs and contexts, although ‘expert opinion’, anecdotal and discussion papers on these issues were common. This review has focussed on research evidence, citing ‘expert opinion’ papers for background and context only.

- Qualitative methods are often appropriate for exploring consumer issues, but internationally agreed methods for systematically reviewing and collating such evidence are still being developed. This review summarised the research evidence and survey data pertaining to consumer views in a narrative form only, and not as tables, as the issues, methods and outcomes were so variable.

- It is evident that there is a variety of factors which influence efficacy of a product for an individual consumer. Therefore this review cannot provide guidelines for the ‘average consumer’, but rather summarises the evidence about advantages and disadvantages of products and highlights issues to be considered by individual consumers, their carers and health professionals when selecting products.

- The range of continence products is constantly changing and therefore many of the research articles pertain to products which have been modified or discontinued. Furthermore, the availability, cost, brand name and manufacturers of products globally vary over time and place.

### Conclusion

This systematic review has highlighted the paucity of high quality research into the effectiveness of continence products or the needs and contexts of consumers. However, product evaluation which is meaningful to consumers does not fit the conventional criteria for high quality research since it involves subjective rating of multiple outcomes in uncontrolled contexts of daily living. In recent years there has been a trend for more of these clinical evaluations to determine those features of products which consumers should consider when selecting continence products.

A recurrent theme in the literature is the need for individual assessment to find products to suit the particular needs of each consumer. It is evident that people with incontinence, their carers and health professionals lack knowledge about the condition and treatment options. Selection of continence aids and appliances is difficult in the absence of comprehensive information. The Consumer Guide and Information being developed in this project will inform consumer choice.

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41. Fedorkow D. (1997) Hormone replacement therapy did not reduce the number of


57. The Simon Foundation Finding an incontinence product.

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63. Reprint #2. Finding an incontinence product to suit your needs. The Informer, a quarterly publication of the Simon Foundation.


http://www.continenceworldwide.org/articles/canada.htm
Nursing Times, 96, 20.
123. (2000) (Final Draft) ISO/FDIS 16021 Urine absorbing aids - basic principles for evaluation of single-use adult-incontinence-absorbing aids from the perspective of users and caregivers.


REVIEW OF GREY LITERATURE ON CONTINENCE PRODUCTS

Authors: Sandra Dunn, Inge Kowanko, Jan Paterson, Rae Winter, Rosalie Donhardt

Introduction

There are many sources of information about continence products apart from those from the scientific and healthcare literature. These include consumer information from special interest groups and a variety of documents from manufacturers, suppliers and distributors of continence products. This type of information is commonly known as grey literature. As grey literature is generally more accessible to consumers than the scientific literature, it may influence consumer choice of product. Grey literature about continence products was reviewed in terms of its content and format to determine what information is provided and how useful it might be in aiding product selection. This section of the report summarises the methods and results of the review of grey literature. A systematic review of the scientific literature on effectiveness of continence products and related consumer needs was also conducted as part of this project and is reported elsewhere.

Methods

An incidental sample of relevant grey literature available within the time and financial constraints of this project was gathered. Continence organisations in Australia and elsewhere were identified from personal contacts of the investigators, internet searches and secondary referrals. These organisations were contacted and product directories and other relevant consumer information were requested or purchased. Documents from manufacturers, suppliers and distributors of continence products were obtained from the Independent Living Centre (SA). The most recent documents available from each source were selected. They included consumer guides, directories, websites, consumer information leaflets, factsheets, product catalogues, brochures on specific products and advertisements. Only documents which addressed continence management with products were included in this review.

These documents were subject to a content analysis\(^1\). Content analysis entails quantifying narrative data according to themes developed by the researcher. In this case, each item of literature was treated as a unit of analysis, and themes were issues considered important to consumers derived from preliminary findings from interviews with consumers and from the scientific literature review. There were 24 themes grouped under the following headings: design, general continence information, product information, selection of products. A computer spreadsheet was developed as a template to facilitate data collection and analysis (Appendix 4). Each item of grey literature was examined, and the presence, absence or non-applicability of information addressing each theme was noted on the spreadsheet. Percentage frequencies were calculated.

Results

Over 100 items of ‘grey’ literature were reviewed. These are listed below in References. Information from consumer organisations and from industry was analysed separately, and the results are summarised in Tables 1 and 2, respectively.

Grey literature from consumer groups

Most of the consumer organisations were not-for-profit organisations such as the Continence Foundation of Australia and similar groups internationally which primarily cater for the lay public, and to a more limited extent to health professionals specialising in continence. A range of consumer information relevant to continence products was obtained from these organisations, published as leaflets, books, newsletters and websites. Some consumer groups produced directories of continence products. Table 1 summarises the results of the content analysis of grey literature from consumer organisations.

All the documents from consumer groups had a user-friendly design with simple language and layout. Over 60% included images, but a small minority used humour. About half included brief but general information about incontinence, its aetiology and prognosis, the various treatment options, and management with continence aids and appliances. Most referred the reader to specialist practitioners for assessment and advice, and many of these organisations gave local telephone advice numbers.

About half the documents from consumer organisations were product directories, meant to inform consumers about the range of products, or factsheets about particular product categories (eg reusable bedpads). The appearance, composition, function, method of use and care of the products were adequately described in most of these documents. However, many of them did not appear to be helpful in assisting consumers to select the optimal product for their needs, because only about one third indicated suitability for different severities and types of incontinence, gender, body size, manual dexterity and the like. Very few provided information about aesthetics and comfort of the product during use, and the capacity of absorbent products was rarely quantified. Only a third of these documents included contact details of suppliers of products, and an indication of price was given in only one.
Table 1. Content analysis of grey literature relevant to continence products from consumer groups.

Percentage frequencies of presence (% yes), absence (% no) or non-applicability (n/a) of information on each theme from 40 items.

<table>
<thead>
<tr>
<th>Themes</th>
<th>% yes</th>
<th>% no</th>
<th>% n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>simple language?</td>
<td>98</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>simple layout?</td>
<td>100</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>humour?</td>
<td>18</td>
<td>82</td>
<td>0</td>
</tr>
<tr>
<td>includes images?</td>
<td>68</td>
<td>32</td>
<td>0</td>
</tr>
<tr>
<td><strong>General continence information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence defined and described?</td>
<td>48</td>
<td>45</td>
<td>7</td>
</tr>
<tr>
<td>Treatment options discussed?</td>
<td>45</td>
<td>48</td>
<td>7</td>
</tr>
<tr>
<td>Professional assessment recommended?</td>
<td>58</td>
<td>40</td>
<td>2</td>
</tr>
<tr>
<td>Referral details for assessment and support given?</td>
<td>83</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>Management options with products described?</td>
<td>45</td>
<td>53</td>
<td>2</td>
</tr>
<tr>
<td><strong>Product information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composition, appearance described?</td>
<td>53</td>
<td>2</td>
<td>45</td>
</tr>
<tr>
<td>Function explained?</td>
<td>50</td>
<td>5</td>
<td>45</td>
</tr>
<tr>
<td>capacity given (where appropriate)?</td>
<td>13</td>
<td>35</td>
<td>53</td>
</tr>
<tr>
<td>Method of use/application described?</td>
<td>50</td>
<td>5</td>
<td>45</td>
</tr>
<tr>
<td>Aesthetics, comfort addressed?</td>
<td>24</td>
<td>31</td>
<td>45</td>
</tr>
<tr>
<td>Care, laundry, disposal described?</td>
<td>42</td>
<td>13</td>
<td>45</td>
</tr>
<tr>
<td>Supplier/distributor details included?</td>
<td>37</td>
<td>14</td>
<td>49</td>
</tr>
<tr>
<td>Cost information included?</td>
<td>5</td>
<td>45</td>
<td>50</td>
</tr>
<tr>
<td>Ordering information included?</td>
<td>28</td>
<td>22</td>
<td>50</td>
</tr>
<tr>
<td><strong>Selection of products</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence type (faecal/urinary/both)?</td>
<td>38</td>
<td>18</td>
<td>44</td>
</tr>
<tr>
<td>Severity?</td>
<td>38</td>
<td>18</td>
<td>44</td>
</tr>
<tr>
<td>Gender?</td>
<td>39</td>
<td>22</td>
<td>39</td>
</tr>
<tr>
<td>Age?</td>
<td>21</td>
<td>33</td>
<td>46</td>
</tr>
<tr>
<td>size of person?</td>
<td>29</td>
<td>32</td>
<td>39</td>
</tr>
<tr>
<td>Mobility/dexterity/dependency/etc?</td>
<td>22</td>
<td>39</td>
<td>39</td>
</tr>
</tbody>
</table>
**Grey literature from industry**

Documents from manufacturers, suppliers and distributors of continence products included catalogues, brochures, advertising leaflets and websites. Their target audience appeared to vary from informed users of continence products to specialist health professionals to purchasing officers of healthcare institutions. Table 2 summarises the results of the content analysis of these documents.

Most of the grey literature items from industry were of simple design, easily read and understood, and almost all included images of the products. Compared to the documents from consumer groups, there was less information about incontinence in general, in keeping with a more informed audience. Documents from the continence industry mostly included details of product composition, function, application and appearance, and as expected from advertising material, claimed high degrees of comfort and effectiveness, rarely supported by research evidence. Most indicated whether the product was suitable for urinary, faecal or both types of incontinence, and detailed the sizes available. However, capacity of absorbent products, suitability for different severities of incontinence, and issues of manual dexterity were rarely addressed. Only about a quarter of the documents included information about care, laundry and disposal of products. Although nearly all documents from industry included contact details for the product suppliers, prices were generally absent.
Table 2. Content analysis of grey literature relevant to continence products from industry.

Percentage frequencies of presence (% yes), absence (% no) or non-applicability (n/a) of information on each theme from 67 items.

<table>
<thead>
<tr>
<th>Themes</th>
<th>% yes</th>
<th>% no</th>
<th>% n/a</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Design</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple language?</td>
<td>87</td>
<td>13</td>
<td>0</td>
</tr>
<tr>
<td>Simple layout?</td>
<td>91</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>Humour?</td>
<td>6</td>
<td>94</td>
<td>0</td>
</tr>
<tr>
<td>Includes images?</td>
<td>90</td>
<td>10</td>
<td>0</td>
</tr>
<tr>
<td><strong>General continence information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence defined and described?</td>
<td>4</td>
<td>93</td>
<td>3</td>
</tr>
<tr>
<td>Treatment options discussed?</td>
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<tr>
<td>Professional assessment recommended?</td>
<td>6</td>
<td>93</td>
<td>1</td>
</tr>
<tr>
<td>Referral details given?</td>
<td>4</td>
<td>94</td>
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</tr>
<tr>
<td>Management options with products described?</td>
<td>3</td>
<td>96</td>
<td>1</td>
</tr>
<tr>
<td><strong>Product information</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Composition, appearance described?</td>
<td>94</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>Function explained?</td>
<td>86</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Capacity given (where appropriate)?</td>
<td>41</td>
<td>23</td>
<td>36</td>
</tr>
<tr>
<td>Method of use/application described?</td>
<td>85</td>
<td>14</td>
<td>2</td>
</tr>
<tr>
<td>Aesthetics, comfort addressed?</td>
<td>86</td>
<td>12</td>
<td>2</td>
</tr>
<tr>
<td>Care, laundry, disposal described?</td>
<td>24</td>
<td>74</td>
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<td>Supplier/distributor details included?</td>
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<tr>
<td>Cost information included?</td>
<td>5</td>
<td>94</td>
<td>2</td>
</tr>
<tr>
<td>Ordering information included?</td>
<td>89</td>
<td>9</td>
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</tr>
<tr>
<td><strong>Selection of products</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Incontinence type (faecal/urinary/both)?</td>
<td>68</td>
<td>27</td>
<td>5</td>
</tr>
<tr>
<td>Severity?</td>
<td>25</td>
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<tr>
<td>Gender?</td>
<td>51</td>
<td>40</td>
<td>9</td>
</tr>
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<td>Age?</td>
<td>9</td>
<td>84</td>
<td>7</td>
</tr>
<tr>
<td>Size of person?</td>
<td>64</td>
<td>28</td>
<td>7</td>
</tr>
<tr>
<td>Mobility/dexterity/dependency/etc?</td>
<td>9</td>
<td>84</td>
<td>7</td>
</tr>
</tbody>
</table>
Discussion

This review of grey literature on continence products is not meant to be exhaustive, as only an incidental sample of documents was analysed. However, documents were derived from a wide variety of sources, both nationally and internationally, and are likely to be indicative of the range of the available grey literature. A simple content analysis was chosen to analyse these documents, as this method was considered appropriate for rapidly determining their scope and nature.

It became apparent that the grey literature could be divided into two categories based on their origin: consumer organisations and industry. Their purposes and target audiences differed, and hence the tone and content also differed. Literature from consumer groups mostly sought to inform consumers about incontinence, stressed the need for professional advice and gave limited but unbiased information about products. In contrast, literature from industry sources assumed a more informed audience and promoted particular brands of product.

It is likely that consumers searching for general information about incontinence can obtain it from documents from consumer organisations, at least to the point where informed questions could be asked of a health professional. Choosing what category of product might be suitable (eg pads or catheters) would be difficult on the basis of any of this grey literature, and it is not surprising that consumers are referred to professionals for individual assessment and advice. However, many consumers know what category of product they need, but want to select a product from within that category that meets their particular requirements (eg what type of absorbent bodyworn pad). The results of this review suggest that existing information from consumer groups and industry rarely facilitates such selection of products, since key issues of concern to consumers, such as price, absorbent capacity, and comfort are rarely included.

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The continence foundation (UK). The misbehaving bladder.
The continence foundation (UK). The well behaved bladder.
The continence foundation (UK). The well behaved bowel.
The continence foundation (UK). Adult bedwetting.
The continence foundation (UK). Problems with continence: answering your questions.
The continence foundation (UK). Expecting a baby?
The continence foundation (UK). The confused incontinent person at home. Factsheet no 1.
The continence foundation (UK). Washable pads and pants. Factsheet no 3.
The continence foundation (UK). Advice for relatives of people in residential or nursing homes. Factsheet no 5.
The continence foundation (UK). Bladder control after a prostate operation. Factsheet no 6.
Swedish Handicap Institute. http://www.hi.se/inko
DHSS. Video: Aids and appliances used for the management of incontinence 1987
The Canadian Continence Foundation. Is urine leakage keeping you from sex? laughing? golf? socializing?
Future environmental services. Hos-toma.
Coloplast. Go in to bat without pads.
Coloplast. Conveen easicath.
Coloplast. Conveen anal plug.
Coloplast. Conveen security+ urine bag 500ml.
Coloplast. Conveen drip collector.
Coloplast. Conveen urisheaths.
Coloplast. Conveen security+ urisheaths.
Coloplast. Continence management is skin deep. Cleanse, treat, protect. Want to know how?
Sancella. Tena fix is now available in XXLarge.
Sancella. New supershields by Tena.
Sancella. Tena Fix cotton special designed to hold fast and last.
Sancella. Why do you need a link nurse?
Sancella. Weak bladder, fortunately it's manageable.
Sancella. Tena direct.
Sancella. New Tena Pants make TLC even easier.
Sancella. Family guide to continence care.
Sancella. Tena comfort gives your clients the TLC they deserve.
Sancella. Tena comfort application guide, Tena slip application guide.
Sancella. The TLC you've come to expect with a TLZ that's brand new.
Sancella. TLC for residents, nurses and aged care facilities.
Bard. Uriplan leg bags.
Kimberly-Clark Healthcare. Choose the right protection.
Convatec. Convatec price list.
Convatec. FlexiSeal faecal collector.
Convatec. Conquest male continence system.
Convatec. ProSys Leg Bag.
Convatec. ProSys Urihesive system NL.
Convatec. ProSys self-adhering male external catheter.
Convatec. Features of the accuseal cath.
Convatec. ProSys Bedside drainage bag.
Convatec. Introducing convacare barrier wipes and adhesive remover.
Urocare. Health care products.
Mentor. Mentor Urology.
Urocare. Male urinal top kit.
Mentor. Freedom cath, active cath.
Mentor. Clear advantage silicone self adhering male external catheter.
Rochester medical. "Pop on" self adhering male external catheters.
Overview of the Australian market

There are about 48 companies in Australia in the business of manufacturing, supplying or distributing continence products nationally. Absorbent products (eg disposable and reusable pads, pants and underpads) account for the largest sector of the market. Other continence products include urinary drainage and collection devices (eg catheters, leg bags, urinals) and other equipment (eg faecal collectors, skin care products).

The Australian market is dominated by eleven major companies that supply the bulk of disposable and/or reusable absorbent continence products nationally. All these major companies import products, and only three manufacture some of their continence products in Australia. Of the remaining smaller companies that supply continence products nationally, approximately twelve manufacture some or all of their products in Australia.

Some disposable absorbent products are distributed through retail outlets like supermarkets and pharmacies, and although the range of products available is limited, anecdotal evidence suggests that a large proportion of community-dwelling consumers obtain their products through these retail outlets. The two largest suppliers of continence products in Australia distribute their goods through pharmacies exclusively. Two other national companies offer consumers a toll free telephone ordering and home delivery system, and one of these also accepts internet orders. Companies also supply products through public assistance schemes (eg CAAS, MASS, etc), medical and rehabilitation equipment suppliers, and buying groups (eg Tradewest).

International perspective

Since the majority of continence products sold in Australia are manufactured overseas, international market trends are likely to impact on the domestic market. The small amount of readily available information about international trends in the continence product market is summarised below and related where possible to the Australian situation.

Research in the USA has shown that the market for absorbent continence products is expanding with increasing longevity and activity in old age, improved health awareness and advancing medical technologies\(^1,2\). The trend for company mergers and acquisitions has led to fewer but larger companies offering complete product ranges to their clients\(^1\). Changing consumer values, such as a desire for environmentally friendly products, better comfort and lower cost, are predicted to drive innovation in the industry\(^2\). The income of the absorbent continence product industry in the USA was $2.6 billion US in 1999 and is forecast to reach $5.6 billion by 2006\(^1\).

Recent market research in 12 countries from North America, Europe and the Asia-Pacific region demonstrated an association between consumption of one brand of pads for light-moderate urinary loss with gross domestic product\(^3\), suggesting that richer countries spend more on continence products than poorer countries. However, there was no such association when consumption of pads for severe incontinence was assessed\(^3\), possibly reflecting standards of healthcare and early intervention. The amount of government subsidy for continence products varies considerably between countries\(^4,5\) and also impacts on consumption\(^3\).

Ideally, all products should comply with meaningful, internationally recognised manufacturing standards, to ensure that consumers get products which perform as they
are intended and to facilitate comparison between products. However, the fact that most continence products are imported has implications for quality standards. It is evident from the review of the research literature that there are almost no internationally recognised standards for products. Furthermore, the few standards that exist are based on laboratory measurements which have little relevance to actual performance during use. An obvious example is the urine holding capacity of absorbent pads which is often given as total capacity but which is more usefully measured as working capacity. Data is currently being collected from industry on their quality assurance regimens, and will be summarised in the Final Report.

Another factor which could affect the market is professional endorsement. In the UK, the Association for Continence Advice has endorsed certain continence products that meet their criteria and whose manufacturers sponsor the Association financially, but ramifications for the market have not been explored. This strategy has been considered by the Continence Foundation of Australia as a way of raising revenue. The Heart Foundation in Australia uses a similar strategy with their well known ‘tick’ endorsement on certain brands of food.

Research on the European urological catheter market suggests that intermittent catheter usage will increase, perhaps at the expense of Foley catheters, as community and home-based healthcare expands. New infection control mechanisms are likely to be the focus for research and development of urinary catheters, and price competition between companies is likely to be a major driver of the European catheter market in future.

Supply and demand for continence products in Australia

*Introduction*

There is very little literature addressing supply and demand for continence products in Australia. The available literature is limited in scope, based on outdated or invalid information and provides an inadequate view of the state of play in regard to Australian demand for continence products. This Consultancy Team therefore derived a multipronged approach for estimating the Australian supply and demand for continence products. Consumers, industry, health care professionals and health economists were involved in developing and implementing the chosen strategy. Supply and demand for continence products across Australia has been estimated based on the following assumptions:

- The major consumers of continence products in Australia are the retail sector (e.g. pharmacies, department stores, supermarkets), public assistance schemes (e.g. CAAS, ILEP, TIME), and the health care sector (i.e. aged care facilities and public and private hospitals);
- Although variations in demand, purchasing patterns, auditing practices etc may occur between states and institutions, overall demand can be estimated from representative figures obtained from a variety of government and non-government sources;
- Demand for continence products can be appropriately determined by $AUS expended for purchase of these products; and
- Products identified as ‘continence products’ for the purposes of this tender (i.e. catheters, penile sheaths, pads, pants, drainage bags etc) are used by consumers for the purpose of continence management only.

Based on these assumptions, demand for continence products across Australia was based on calculated demand from the three sectors: retail sector, public assistance schemes, and health care sector. Supply of continence products was to be estimated from sales data provided by industry through the survey (appendix 5), but insufficient data was obtained.
**Demand from the retail sector**

It is not practical to obtain estimates of demand from retail outlets or chains. The range and number of outlets is enormous and initial inquiries indicate that many do not have this information available. Companies were asked to assist by providing sales data, but most companies were unwilling to divulge commercial data, despite assurances of confidentiality.

**Demand from public assistance schemes**

In addition to Continence Aids Assistance Scheme (CAAS), a national scheme providing continence products for people aged 16 to 65 years with permanent incontinence due to disability and eligible for a disability support or Veterans Affairs pension, each state and territory administers a state-based aids and equipment scheme. Information for this report was obtained through speaking with one or more staff members in each scheme.

The public assistance schemes operating in the states and territories vary widely in eligibility criteria, scope, and benefits. Approximately 0.2 to 0.4% of each state’s population is served by the state schemes (NSW 0.2 – 0.3%; Qld 0.3%; Tas 0.4%; NT 0.2%; ACT, SA, WA and Vic N/A).

The demand estimates for continence products in the public assistance schemes were based on the following assumptions:

- Proportional representation of various groups within the larger Australian population e.g. incontinent persons, is consistent nationally; and
- The mean public assistance schemes’ expenditure per person related to continence products is consistent nationally.

Demand for continence products from public assistance schemes was estimated in the following manner:

- Annual expenditure for continence products (as defined by the individual scheme) was identified from the schemes’ records where possible (Qld, NSW, NT, ACT);
- The mean expenditure on continence products $/per person (pp) was estimated; and
- Annual expenditure on continence products for public assistance schemes was estimated based on actual expenditure or population.

This process yielded an estimated demand for continence products from public assistance schemes of $16.1 million Aus per annum (CAAS [incl. WA] $6.5mil; states and territories $9.6mil). The proportion of schemes’ total annual expenditure used for continence products varied between states and territories (Qld ~20%; NSW ~15-25%; NT 24%; ACT 10%; SA, WA, Vic, Tas N/A) and the expenditure per client also varied (NSW ~ $150 - $200/pp; Qld $225/pp; Tas $500/pp; NT $485/pp; ACT ~ $107/pp; CAAS $450/pp; SA, WA and Vic N/A: population weighted national mean $223/pp).

**Demand from the health care sector**

Demand was estimated separately for aged care facilities and public and private hospitals.

**Aged care facilities**

As of June 30 1999, there were 140,651 residential aged care places in Australia. Of those places, 61% (85,797) accommodated high care residents (Residential Classification Scale [RCS] 1-4 e.g. nursing homes) and 39% accommodated low care residents (RCS 5-8 e.g. hostel accommodation). Continence requirements for high care residents are funded by the aged care facility, however, depending on the public assistance scheme operating
in the state or territory (see below), low care residents may or may not receive financial support for their continence needs.

The estimated demand for continence products in aged care facilities was based on the following assumptions:

- Aged care facility expenditure on continence products does not depend on sector (i.e. public or private) or geographical location (rural, regional, or urban; state);
- All aged care facility demand for continence products arises from high care (RCS 1-4) rather than low care (RCS 5 – 8) facilities;
- All high care residents are incontinent; and
- Aged care expenditure on continence products is proportional to number of high care facility beds.

Demand for continence products from aged care facilities was estimated in the following manner:

- Annual expenditure on continence products was identified from the budget of representative high care aged care facilities (SA, WA and NSW);
- Annual expenditure per high care resident was determined; and
- Annual expenditure on continence products for all Australian aged care facilities was estimated based on number of high care beds.

This estimation showed an Australian aged care facility demand for continence products of $41.6 million per annum, approximately 20% of the annual aged care facilities’ expenditure for care products. Mean annual cost per high care resident was estimated at $485/pp.

Public and private hospitals

In 1998-99, 71% of all patient days were spent in public hospitals with the remainder in the private system. Although only 10% of Australian public hospitals have 201 or more patient beds, these 75 hospitals account for 53% of all available beds in the public health care system. Further, during 1998-99, $943.3 million (38%) was spent in the public system on consumable medical and surgical supplies from a total of $2,503.4 million expended on goods and services (drug supplies, medical and surgical supplies, food supplies, domestic services and repairs and maintenance).

The demand estimates for hospitals were based on the following assumptions:

- Hospital expenditure on continence products does not depend on sector (i.e. public or private) or geographical location (rural, regional, or urban; state);
- The number of hospital patient days is proportional to the number of available hospital beds; and
- Hospital expenditure on continence products is proportional to number of hospital patient days.

These assumptions were then compared to calculations based on another assumption:

- Hospital expenditure on continence products can be estimated from overall hospital expenditure on medical and surgical supplies.

Demand for continence products from public and private hospitals was estimated in the following manner:

- Continence products were identified from the stores purchasing list of a representative large metropolitan teaching hospital;
• Annual expenditure for these items was calculated and totaled to provide an annual expenditure on continence products;

• Annual expenditure on continence products for all large (> 201 beds) public hospitals (n = 75) was estimated;

• Annual expenditure on continence products for all public hospitals was estimated based on proportion of patient days; and

• Annual expenditure on continence products for all Australian hospitals was estimated based on proportion of patient days.

This estimation demonstrated a demand for continence products from all Australian public and private hospitals of $11.4 million per annum. This expenditure equates to 1.2% of the annual expenditure on medical and surgical supplies, and 0.08% of the annual recurrent expenditure, for Australian public hospitals (figures not available for private sector).

In an effort to validate this estimation, an alternative calculation from the same baseline was used:

• Annual expenditure for continence products as a proportion of medical and surgical supplies at a representative metropolitan teaching hospital was calculated;

• Annual hospital expenditure for medical and surgical supplies (including only consumable supplies and not equipment purchases) were calculated and compared to national hospital data (metropolitan hospital 36% of goods and services, national hospital data 38% of goods and services\(^9\)); and

• Annual national hospital expenditure for continence products were estimated based on proportion of goods and services expenditure.

This estimation yielded an estimated demand of $9.9 million per annum.

**Conclusion**

There are no clear cut mechanisms in place to enable tracking of supply and demand for continence products in Australia. Information obtained from literature, consumers and health professionals shows that many members of the community experiencing either occasional or intractable incontinence are unaware of continence management options and obtain continence products through retail outlets without any professional advice. It is not possible to estimate the demand for continence products from this retail sector although it may form the largest demand sector for continence products in Australia.

Although approximately 7 to 10% of the population may suffer from intractable incontinence\(^{10}\), and more than 80% of these people will be living outside health care facilities\(^{11}\), only an estimated 0.3% of the Australian population is assisted by any public assistance scheme. Public assistance schemes may provide 50% or less of the funding their clients require to manage their incontinence needs with a mean funding of $223/pp. Across Australia, the estimated demand for continence products through public assistance schemes is $16.1 million per annum. There are significant problems with equity and access to these schemes, and with supply and distribution of products through them\(^{12-14}\).

The demand for continence products within the Australian health care sector is significantly different between aged care facilities and hospitals. At a conservative estimate, in Australia 90% of high care aged care residents, and over 55% of all aged care residents, experience intractable incontinence. Approximately 20% of the annual aged care facilities’ expenditure for care products is spent on continence products. The estimated annual expenditure of $485/pp compares with public assistance expenditures of $223/pp. The estimated expenditure on continence products for Australian aged care facilities is $41.6 million per annum.
An estimated 42% of hospitalised patients experience incontinence, usually temporary and related to acute illness or injury\textsuperscript{13}. Continence products, for example bedpads and catheters, may be used for reasons other than incontinence e.g. protecting linen during invasive procedures or for diagnostic tests. Approximately 1.2% of the annual expenditure on medical and surgical supplies is spent on continence products. The estimated demand for continence products from Australian public and private hospitals is $11.4 million per annum.

Based on these estimates and assumptions, the estimated demand for continence products in Australia is $69.1 million per annum excluding the retail sector.

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LIAISON WITH INDUSTRY

Authors: Sandra Dunn, Rae Winter, Rosalie Donhardt, Jan Paterson, Inge Kowanko

Introduction

The cooperation of manufacturers, suppliers and distributors of continence products in Australia was crucial to the development of the Consumer Guide and Information on Continence Products, because the Research Team was reliant on them to provide detailed product information, distribution arrangements, and a range of supporting data.

Methods

All companies involved in the manufacture, supply or distribution of continence products in Australia were identified. Initially, the Research Team intended to obtain product and related information through interviews, and ethics approval was obtained from the Social and Behavioural Ethics Committee of the Flinders University (Appendix 1). All participants gave informed consent. Because so much information was sought, much of which would probably need to be specially accessed and collated, a survey form for companies was designed (Appendix 5). The survey was developed in consultation with the Reference Group, and survey questions were based on preliminary findings from consumer interviews. Other questions eg relating to sales and quality assurance were included because the Commonwealth had requested such information. Telephone interviews were planned to obtain follow-up information. Company representatives were given the option of discussing issues with one of the researchers if they felt uncomfortable with the survey.

Results

Participants

A total of 48 potentially relevant companies were identified nationally, and all were invited to take part in the project. Four were subsequently excluded because their products did not fit the criteria for the Guide, or because they were not directly involved in manufacturing or importing continence products. This left a total of 44 relevant companies, of which a total of 24 agreed to participate and returned completed survey forms and/or product documentation (response rate of 55%). Five companies declined involvement at this time. Numerous telephone calls to nonresponders and follow up interviews were needed to obtain such a high response rate. The number of calls made ranged from 10 to 20 per company. Participating companies are listed in Table 1.

Table 1. List of continence product companies included in the Guide

- Astra Tech
- Australian Pacific Paper Products Pty Ltd
- Bard Australia Pty Ltd
- Cello Paper Pty Ltd
- Coloplast Pty Ltd
- Comfort Care
- Confident Care Products
• Elanettes Staydry Products Pty Ltd
• Haines Medical Australia
• Paul Hartmann AG
• Hollister Inc Aust.
• Kimberly Clark Australia Pty Ltd
• Kuver Designs Pty Ltd
• Maersk Medical Pty Ltd
• Night’n’Day Comfort
• Mentor Medical Systems Pty Ltd
• Playgro Australia Pty Ltd
• Sancella Pty Ltd
• Sanicare Pty Ltd
• Sayco Pty Ltd
• SSL Australia Pty Ltd
• Tyco Healthcare Pty Ltd
• Vernon Carus Australia Pty Ltd
• Victoria Healthcare Products Pty Ltd

**Product information**

Detailed product information was entered into a relational electronic database (Microsoft Access). The database contains approximately 320 continence products, of which many are available in several sizes or variants. This database comprised the raw data for the Draft Guide. Details of suppliers and distributors in each state and territory were collated for insertion into the Draft Guide.

**Sales**

Other information was requested from industry also, in response to the Commonwealth’s tender brief, which sought an overview of supply and demand for continence products nationally. Therefore the survey form included specific questions about sales. The intention was to estimate national sales from the accumulated sales data obtained from individual companies. However, many companies chose not to divulge sales data, despite assurances of confidentiality, and that reports would not include individual company data. Only eight companies included sales figures in their survey returns (response rate of 18%). Therefore these sales figures were omitted from this report as the sample was too small and did not reflect the national situation.

**Quality assurance**

The Commonwealth had also requested some information about quality assurance regimens used by continence product industry, and therefore the survey included questions on this.
Of the companies that returned surveys, eleven mentioned that their products complied with international standards (ISO) and some also mentioned Australian standards. A further five companies described ‘in-house’ quality assurance processes. Most companies offered trained customer assistance over the phone, and some had email or internet contacts also. Again, the information supplied was insufficient to report formally.

Discussion

The Research Team acknowledges the assistance and goodwill of all participating industries. It has enabled the development of a Draft Consumer Guide which contains detailed product information from all the major companies and most of the smaller companies. Nevertheless, the short time frame for this project meant that some companies were left out of the Draft Guide because they did not provide information in time to be included. Although a great deal of effort was put into follow-up interviews, the priority was to obtain product information for the Draft Guide ahead of supporting information.

Also, it was evident that not all product information was available from industry, eg many companies were reluctant to give prices. No attempt was made to check the accuracy of the information provided, although anecdotally discrepancies exist, eg between quoted and actual dimensions of pads. Another important problem was the capacity of absorbent products. Although suppliers were asked for both working capacity and total capacity, many did not provide this information or did not specify the method of measurement.

The Research Team is confident that the continence product companies will eventually see the benefit of the Guide and will want to have their products included. The Guide represents a way of making their product known to a wider pool of consumers and health professionals. The fifteen companies who were not included in this Draft Guide had all expressed some interest, but filling out the survey form was not considered important compared to their other pressing business activities. Some of the five companies who chose not to be involved at this time did so for valid reasons, eg major changes in product range were in progress, and are likely to be interested in participating in future.
INTEGRATION OF RESEARCH FINDINGS

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The purpose of this section is to integrate and discuss the findings of the research conducted during this project in order to inform the development of the Draft Consumer Guide to Continence Products. The research findings were derived from:

- interviews and focus groups with incontinent people and carers
- interviews and focus groups with health professionals
- a survey and followup discussions with continence industry representatives
- a review of research and discussion papers in the professional healthcare literature
- a review of grey literature from consumer groups and industry
- a consideration of the market for continence products
- comments from the Reference Group and officers of the Commonwealth Department of Health and Aged Care.

It is evident that people new to the problem of incontinence want and need general information about the condition, options for treatment and management in the short and long term, and contacts for professional help and support. Product information is also needed to assist selection of an appropriate aid or appliance for individual consumers, both in the early stages and whenever circumstances, technological advances in products and/or the severity of incontinence change.

People who are incontinent and their carers want to achieve continence, but if that is not possible, social continence is the aim. The literature indicates that many people do not seek help for their incontinence, potentially compromising their quality of life through inappropriate management. Reasons include ignorance that help exists and embarrassment. Our interviews with incontinent people and carers show that this also occurs in the contemporary Australian context. Many of these people used absorbent products from the retail sector to contain their loss, without realising that there are many other treatment and management options which might provide a better solution for their problem.

The participants strongly expressed their need for information, telling of their frustration in the quest for information and problems in knowing what questions to ask and where to look for answers. Existing information was described as incomplete, scattered and difficult to access. Organisations such as the Continence Foundation of Australia and the National Continence Helpline have distributed consumer leaflets which partially address the need for introductory information about incontinence. However, it appears from the interviews and focus groups that this information may not be sufficient and/or readily available, particularly for people in country areas or from culturally and linguistically diverse groups. Comprehensive product information to aid product selection is even more difficult to find, as evidenced by the testimony of consumers and the review of grey literature. Some user-friendly guides to consumer products are available in other countries, such as that produced by the National Association for Continence in the USA, but none have all the features wanted by consumers (see below).

Some of the interviewed incontinent people and carers were disappointed by their local health professionals’ understanding of continence, yet relied on them for advice, not knowing where else to go. Few had been properly assessed by a health professional specialising in continence management. However, those who had seen continence nurse advisers were satisfied with their specialist advice. The research literature confirms that general health professionals’ knowledge and practice regarding incontinence is often
inadequate, a problem being addressed in some countries through training and appointment of specialist continence nurses. The generalist health professionals we interviewed mostly understood that incontinence assessment is complex, recognised their limited expertise about products and referred clients to specialists. On the other hand the continence nurse specialists we interviewed felt they had adequate knowledge about incontinence and products to manage it, and knew what was best for their clients.

Health professionals strongly advocated early assessment of incontinence by a specialist practitioner to ensure appropriate treatment and management, as noted in the interview findings and in the healthcare literature. This contrasts with the low incidence of assessment reported by the incontinent people and carers we interviewed. Taken together, our research suggests an underlying tension between health professionals and their clients with respect to decision making about management of incontinence. Health professionals were gatekeepers of knowledge, and promoted professional assessment and management decisions on their clients’ behalf. Conversely, incontinent people and their carers felt stigmatised and disempowered, had little confidence in health professionals (apart from continence nurse advisers), and wanted more information in order to manage the problem themselves or at least participate in management decisions.

The political and economic milieu influences the degree of responsibility individuals are expected to have for their own health care. There is a tradition of publicly funded health care in some European countries and the UK, which limits consumer choice and involvement in decision-making. Conversely, the US healthcare system has been privatised for a long time, and consumers are urged to ‘shop around’ for health professionals and products to suit their needs. In Australia there is a growing trend for privatisation and self-management of health care, shifting the onus of responsibility from providers to consumers. One effect of this trend may be to increase the quality of the health services and products in response to consumer demand, but another effect might be a further erosion of quality health care for disadvantaged groups. For many people, health care choices are limited by geography and financial resources, and therefore accessible comprehensive information will be valuable in sourcing appropriate products and assistance. Our interviews with incontinent people and carers uncovered a great deal of anger and hardship caused by the high costs associated with continence products, inequitable eligibility criteria for subsidy schemes, and limited choice and availability of products. The hope that the Guide will enable consumers to select the most appropriate product must be tempered by the reality of unaffordable products, and inconsistent or nonexistent supplies.

The market for continence products is large and growing and there is intense competition within the industry for market share. Manufacturers and suppliers that have the resources to advertise widely are likely to gain a larger portion of the market than smaller companies. According to health professionals that we interviewed, advertising material, catalogues and representatives of the continence product industry are major sources of information about products. Some manufacturers of continence products are even employing continence nurse advisers to work in healthcare institutions, presumably in return for purchase orders, a practice which effectively limits product selection within those institutions. Health professionals specialising in continence told us that they advised clients about products suitable for their particular needs on the basis of their professional experience and the feedback of other clients. Advertising brochures and information on packaging of products in retail outlets are also important sources of information for users of products. Our interviews and focus groups with incontinent people and their carers indicate that product selection is generally based on experimenting with available retail lines and/or recommendation.

The systematic review of the research literature on effectiveness of continence products highlighted the paucity of reliable evidence on which to base product choice. Research into product effectiveness is problematic as outcomes of interest to consumers are multiple and difficult to quantify. Also, products are constantly being improved and...
modified, and their availability fluctuates geographically and temporally. For all these reasons clinical trials of products are of limited value. Additionally, there are few recognised standards for quality of continence products, making it impossible to objectively compare similar products. Furthermore, integration of the research literature is difficult because the products, study participants, outcome measures and study designs differ widely. However, the literature consistently speaks of the need for individualised management strategies and product selection to suit each client’s particular needs and circumstances. This principle is universally agreed by health professionals and reflects the experience of users of continence products.

The literature review suggests that there are two major decisions to be made regarding management with continence products, each of which involves multiple considerations unique to each individual and their context of daily living. Firstly, incontinent people need to find a category of product that suits their needs. For example, an incontinent person may choose between absorbent bodyworn products, absorbent bed and chair pads, internal or external catheters and drainage equipment, and more. Professional assessment is recommended at this point. Factors to consider include gender, severity and type of incontinence, mobility, dexterity, cognitive ability, financial resources, degree of assistance and more.

Secondly, choices within each product category must be made. For example, if management with bodyworn absorbent products is the best option, decisions need to be made about whether to use disposable or reusable products, which style of product (briefs, adhesive pads, male pouch) and so on. The literature has highlighted the complexity of factors that need to be considered when selecting a product within a category, and they include cost-effectiveness, ability to care for or dispose of products, body size and shape, rate and frequency of loss, ease of application and changing, comfort and fit, aesthetics of the product (will the product show, leak or smell, and will others notice?) and availability. Many consumers opt for a combination of products, depending on their activities and priorities on any given day. For example, small cheap pads that leak occasionally may be acceptable at home, but a more absorbent product might be needed for social occasions. The people with incontinence, carers and health professionals that we interviewed all prioritised accessibility, cost, effectiveness and comfort when selecting or advising on products, and took account of individual needs.

As part of this research consumers were asked about their preferred content and format for the Guide. It was clear that incontinent people and their carers wanted brief leaflets containing introductory information that they could pick up in medical rooms, pharmacies, clubs, libraries and other public venues and peruse in privacy later. They wanted to know about diagnosis and prognosis, treatment and management options and where to go for further information, help and support. Health professionals mainly supported this idea, with the proviso that professional assessment be strongly promoted. Armed with such introductory information, consumers felt they would be able to approach health professionals and other sources of assistance with some insight.

A Guide containing detailed product information was welcomed by incontinent people, carers and health professionals. Users of products wanted to be able to see what was available and select products according to their individual requirements. Health professionals mostly wanted the Guide as a useful reference to support their practice. All consumers considered that the following information should ideally be included in the Guide: product purpose, suitability (for which type and severity of incontinence, gender, age), working capacity, composition (including allergy issues), dimensions, sizes, instructions for use (application, changing, care, laundry, disposal), cost, packaging options, supplier details and a quality rating. Most of this data is available from the continence industry, with two major exceptions. Firstly, as discussed above, the lack of standards and comparable studies means that a quality rating is impossible at present, although international research is underway to develop some meaningful standards that relate to user perceptions of effectiveness. Although the issue of cost was paramount to
the incontinent people and carers that we interviewed, prices were rarely included in
grey literature from industry or in existing product guides. Indeed, our survey of industry
highlighted that most companies were very reluctant to provide prices since they are
influenced by market factors such as wholesale or retail purchase, subsidised or not,
private or health institution purchase, bulk buying, mail order, country or city outlet.
DEVELOPMENT AND PILOT TESTING OF THE DRAFT GUIDE

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Introduction

The research consultancy team used an evidence based, consultative approach to developing the Draft Guide. The Guide is intended for consumers, defined here as people with incontinence, their carers and health professionals, and therefore the project was driven by their needs.

Research approach

The views of people with incontinence, their carers and health professionals were sought through interviews and focus groups. The industry perspective was explored by survey and informal discussions. Research and discussion papers from the health care literature were systematically reviewed and a content analysis of the grey literature (documents from consumer groups and industry) relevant to continence products was performed. The market for continence products was investigated, and estimates of national supply and demand for continence products were made. The integrated findings informed the development of the content and possible formats for the Draft Guide, and full reports appear elsewhere in this document. Detailed product information and product documents were collected from industry concurrently with the research activities. The Reference Group of key stakeholders advised the research team throughout the project.

Proposed content and formats of the Guide

It became apparent that consumers require both general introductory information about incontinence and detailed product information, in a number of different formats, including print and electronic versions.

The scope of the product information requested from industry for potential inclusion in the Draft Guide was developed from preliminary research. Industry was asked to provide the following data about each product (or range of related products, where applicable): name and code, a description of the product with a graphic, capacity and absorbency rate where appropriate, suitability for which type and severity of incontinence, suitability for which gender and age group, sizes, purpose and mode of action, how to use and apply the product, disposal and laundry, precautions for use, allergy issues, country of origin, cost, availability and ordering information. Information was entered into a computer database. Participating industries are listed elsewhere in this report. Fields were left blank if the suppliers did not provide information, eg prices were rarely given.

Midway through the project the consensus of the Research Team and Reference Group was that the Guide should eventually be made available in a number of different formats including:

1. A printed, full text version containing
   - an introductory section (briefly describing incontinence and the various treatments and therapies, need for individual professional assessment, management with continence products, selection and purchase of continence products),
• a large section of product information (divided into subsections based on product category, with detailed information about each product), and
• a final section with contact details of suppliers and distributors.

This full text version would be prepared in looseleaf format in a ring binder to enable easy replacement of pages as they are updated in future.

2. A series of brochures giving brief introductory information and suggesting suitable types of products for:
   • mild urine loss in females,
   • mild urine loss in males,
   • severe urine loss in females,
   • severe urine loss in males, and
   • faecal incontinence.

   It was envisaged that the brochures would be freely available and widely distributed. They would refer consumers to sources of help and professional assessment, and to the Guide for detailed product information. It was hoped that the brochures would be translated in the future.

3. Electronic versions of the whole Guide, including
   • a CD-ROM of the full text print version, and
   • an internet version accessible via the National Continence Management Strategy website.

   The Research team worked with a graphic designer/printer to develop samples of the print-based materials in several designs and layouts for pilot testing.

Pilot testing of draft samples of the Guide

Participants and methods

The draft samples sent for evaluation included a leaflet containing introductory information about mild incontinence in women, several pages of detailed product information (penile sheaths, absorbent pads) from the looseleaf binder full text version of the Draft Guide, and section divider pages. All materials were provided in several variants, in order to evaluate different amounts of information, several page layouts, with and without colour, background logos and icons. An evaluation form and explanatory letter was included in the package (Appendix 6).

These pilot test materials were posted to a purposive sample of over 60 interested people and stakeholders, comprising members of the Reference Group, participants from the interviews and focus groups conducted earlier in this project (people with incontinence, carers, health professionals), and others. The sample included people from culturally and linguistically diverse groups. These people were encouraged to seek the views of their peers and colleagues.

Results

A total of 32 written responses were received (53% response rate). The views of the Reference Group, which met in November and discussed the pilot materials, are also included in these results.
Almost all participants felt that the information was useful, easily understood and read. They stressed the importance of clear and simple text, suggesting large font, either black print on white background or white on blue, and removal of distracting background logos. There was some concern about jargon and unfamiliar terms, and the advice of a literacy expert was recommended. Illustration of the text with appropriate stand-alone icons was suggested.

A number of modifications to the text were suggested, such as:

- additions to and reformatting of the ‘where to go for help’ section on the back cover,
- inclusion of a date,
- adding that many people with incontinence can be successfully cured or treated and that therefore that professional assessment is encouraged,
- substituting ‘females’ for ‘women’ as these products are often suitable for girls,
- clearly defining mild incontinence in several ways (eg volume of loss in millilitres and cups, damp/wet/soaked clothing, light/medium/heavy),

None of the brochure options pilot tested were completely satisfactory. The brochure considered most attractive would have a plain blue cover similar to one of the options, but with white text. The Reference Group felt that the female icon should appear on the cover also, perhaps with the Commonwealth crest.

### Product information pages

Almost everyone believed that there was enough information to guide product choice, the text was easily read and the content easily understood. There were calls for large font and simple language. A comprehensive glossary of terms was considered essential.

There was overwhelming support for the inclusion of approximate prices since cost is a major factor for most consumers, although it was recognised that the guide would date quickly. Country of origin and product dimensions were considered useful, although questions were raised about the accuracy of such information. Similarly, indications of capacity and absorbency were popular, but required explanation and qualification (total capacity vs working capacity).

Participants wanted product codes. The Reference Group consensus was to include the code for the smallest pack size for each product and to indicate that other pack sizes are available, rather than giving the code for each variant, to save space in the Draft Guide.

No information was redundant, but some was generic to categories of products, and could be moved to the introductory section of the Draft Guide. Comments were made about ensuring the accuracy of information. Because the Research Team entered only information supplied by industry, a disclaimer will appear prominently in the Draft Guide.

The photographs were universally popular, but colour was not considered essential. Indeed several participated commented that the colours were disturbing, unrealistic and perhaps misleading (especially for products with colour-coded sizes). The consensus was that colour, although attractive, did not warrant the additional expense. The Reference Group’s view was to retain colour for the electronic versions, but to produce the print versions in black and white.
Opinions varied about the best way to arrange product information. Votes taken during the Reference Group meeting and written survey responses were collated, and the results are as follows. Twenty opted for a portrait layout with three or four rows, fifteen preferred a landscape layout with four columns, and fourteen preferred a portrait layout with four columns. Therefore the final version of the Draft Guide will be in portrait layout throughout, with product information arranged alphabetically by brand name in horizontal rows across the page. This layout avoids rotating the Guide between portrait and landscape during use, and is also more suited to looseleaf binding.

**Section and subsection divider pages**

Opinions varied widely. Many participants did not like any of the designs. They questioned the relevance of both the feather and whirlpool motifs, as well as the icons on these pages. Other participants expressed strong approval or disapproval for these designs. Collated votes taken from the written responses and Reference Group meeting were: feather and icons (5), whirlpool and icons (10), feather (4), whirlpool (4), icons (2), none of these (7). Extensive discussion by the Reference Group led to a fairly plain but striking compromise design in blue, white and yellow without any motifs or icons.

**Background Logos**

Most participants agreed that the background logos on both the brochure and the guide samples were irrelevant and distracting to the eye.

**Icons**

Icons were considered meaningful by almost all participants and there was very strong support for their inclusion. Icons facilitate searching for particular product attributes, such as reusability, or suitability for women, heavy incontinence, or faecal loss. However, participants commented that icons should be meaningful and universally recognised, and clearly defined in the Draft Guide. Several participants did not recognise the washing machine icon for reusable (washable) products, and so it was decided that this would be replaced by the wash-tub symbol often found on clothing labels. Similarly the well-known ‘hand dropping litter in a bin’ symbol would be used instead of the bin symbol initially suggested. A ‘U’ icon was also proposed to signify suitability for urinary incontinence, because a ‘B’ for bowel (faecal) incontinence was being used. Another concern was ambiguity of the drop symbol, defined in the pilot test package as absorbency. The intention was for the drop icon to signify capacity (volume), with more drops indicating larger capacity. This icon will be explained more clearly, and the distinctions drawn between capacity and absorption rate. Additionally, discrepancies between industry claims, usually based on laboratory measures of total capacity, and working capacity, which is more closely related to performance in use, will be highlighted. Only information supplied by industry will be included in the Draft Guide, and a disclaimer about its accuracy will appear prominently.

**Conclusion**

The Research Team in consultation with the Reference Group and informed by the pilot test results decided on the final format and content of the draft brochure and Draft Guide. Some compromises were necessary to accommodate the desire of consumers for complete information, gaps in information supplied by industry, and practical considerations.
It was decided that the Draft Consumer Guide to Continence Products would be prepared in two versions initially, a printed version and an electronic (CD-ROM) version. Additionally a series of leaflets giving brief introductory information was planned, but only one of these would be prepared at this point. Large font text and simple layman’s language would be used throughout, aiming for a year 6 literacy level. No background logos would be used to enhance visual clarity. These materials would all be dated so that consumers can judge the currency of the information.

Description of the Draft Consumer Guide to Continence Products

The full text printed version of the Draft Guide has been prepared in looseleaf format in a ring binder to enable easy replacement of pages as they are updated in future. It is divided into three main sections separated by visually striking but simple tabbed dividers.

The introductory section of the Draft Guide includes a brief description of incontinence and the various treatments and therapies, need for individual professional assessment, management with continence products, glossary, disclaimer, icon key, and information to assist consumers choosing between and within product categories. Generic information that consumers might want to consider when selecting within a product category is included the introductory section.

The middle section of the Draft Guide contains detailed product information (divided into subsections based on product category), arranged in alphabetical order of brand name. Portrait layout with products arranged in rows, rather than columns, is used. Information on each product includes a black and white photograph, brief description, composition, dimensions, instructions on use and care, approximate price, capacity, indications and contraindications, product code, available sizes and packaging options, country of origin and names of suppliers. Universally recognised icons are included to facilitate scanning of the guide for a product on the basis of major product or consumer characteristics.

The final section of the Draft Guide includes contact details of suppliers, manufacturers and distributors and an index.

An electronic (CD-ROM) version identical to the full text print version was also prepared in pdf format. The electronic version has the potential for developing sophisticated searching, easy updating, inclusion of videoclips, translation, and loading onto the internet with links to related sites.

To meet the strong desire of consumers for more information about incontinence and how to cope with it, a series of brochures giving brief introductory information and suggesting suitable types of products is also being considered. They are likely to contain abridged information from the first section of the guide, and will encourage consumers to access professional assistance and support services, and the complete Guide for further and more specific information relevant to individual needs and contexts. At this point a single brochure has been prepared on mild urine loss in females. Possible topics for further brochures might include mild urine loss in males, severe urine loss in females, severe urine loss in males, and faecal incontinence.

The Draft Guide and brochure accompany this report.
DEVELOPMENT OF RECOMMENDATIONS

Authors: Sandra Dunn, Inge Kowanko, Jan Paterson, Leigh Pretty, Rae Winter, Rosalie Donhardt

Research approach

Part of the Research Team’s brief was to develop recommendations for maintaining, marketing and distributing the Guide. In keeping with all other phases of this project, an evidence based, consultative approach was adopted. Research strategies included consulting with a range of people with incontinence, their carers and health professionals, liaising with industry, reviewing research literature and other documents, and working with a Reference Group of key stakeholders. Ideas about the Guide were derived from all the research activities throughout the project and further developed by the Research Team. Full reports on all phases of this project and their implications for the Guide appear elsewhere in this document. Most of the key suggestions about content and format have already been incorporated into the Draft Guide and brochure. However many other recommendations were beyond the scope of this project, and are listed below.

Recommendations

A variety of formats

It was agreed that the Guide should be made available in a variety of print and electronic versions, including brochures, full text printed copy in a ring binder, a searchable CD-ROM and on the internet. It was recommended that these materials be integrated such that they build upon each other, offering different levels of complexity and detail of information as required.

A series of brochures was proposed which provide brief general information, and refer the consumer to sources of help and support and to the Guide itself. There would be separate brochures aimed at males and females with different severities and types of incontinence, and other brochures on continence products. It was recommended that the pamphlets be translated into other languages, taking account of cultural sensitivities and linguistic ambiguities. One draft pamphlet ‘Mild urine loss in females’ was produced as part of this project.

It was recommended that the full text print version should provide general information about incontinence, assessment, treatments and management with products; comprehensive information about all available continence products; and contact details of suppliers and distributors. A looseleaf format was recommended to enable easy replacement of pages. A ring-bound full text printed draft of the ‘Consumer Guide to Continence Products’ was produced as part of this project.

It was suggested that the CD-ROM version should contain all the information in the print version, plus colour graphics, audio and videoclips and a variety of search strategies. As part of this project the electronic text and graphics files (pdf) of the full text Draft Guide and brochure were recorded onto CD-ROM.

It was recommended that the complete Guide be put on the internet, potentially enabling sophisticated search strategies, improved access and hyperlinks to related sites. It was also recommended that the research outputs of all the National Continence Management Strategy projects be integrated into a central consumer resource in both print and electronic forms. The central resource could include general information on assessment and treatment, directories of relevant professional services and other sources of support, information on products and suppliers (this Guide), and other research outputs (including
It was recognised that the Draft Guide prepared in this project is not complete. Therefore it was recommended that additions be made to the Draft Guide to include product categories (eg commodes, enuresis alarms and toilet modification devices) omitted from this version, and also products from suppliers who did not participate. Further suggestions for additions to the content included: a cross-referenced index, details of relevant national and international resources and organisations, a bibliography and references to research, and a handy hints section. It was recommended that the amended Guide be sent to participating suppliers for checking prior to publication.

The development of a variety of search strategies for the electronic versions was recommended to enable more or less detailed information to be retrieved according to individual need. Suggestions included pull down menus of keywords, more extensive use of icons in searching, and radio buttons to choose language and search styles. Links to the glossary and automatic suggestion of synonyms were also recommended.

It was recognised that the product information will age quickly, and therefore it was recommended that the Guide be continually updated. The internet version could offer immediate on-line access to the latest information through hyperlinks to suppliers and distributors. Annual revisions of the full text print and CD-ROM versions were recommended, facilitated by the inclusion of a mailing slip to request upgrades. Furthermore it was recommended that all materials be marked with the date on each page so that consumers would know how up-to-date the information was.

It was recommended that the Guide maintenance contract be outsourced to an organisation with specialised knowledge and skills relevant to continence products, professional advice and consumer assistance, database management, as well as strong links with the continence industry. It was recommended that the Independent Living Centre (SA) Inc, as a partner organisation in this project which developed the product database, and with all the necessary expertise and links, should be strongly considered for the role.

The prevailing view was that all versions of the Guide should be freely available at no charge. Options for funding the production were discussed, including advertising, payment by industry proportional to number of products included, and charging consumers for some or all versions of the Guide, but none of these options were considered acceptable. The consensus was that funding of the Guide and its maintenance should be a government responsibility, as part of its strategy for enabling people with disabilities to stay at home. There was, however, some support for a minimal charge for annual updates of the full text print version.

This Guide is meant for people who have incontinence, carers, health care professionals, and industry and therefore it was recommended that all marketing and evaluation should target this wide range of consumers. Furthermore, it was recommended that children with a chronic disability should not be overlooked, as it was perceived that the Draft Guide was aimed largely at adults.

It was agreed that the Guide be marketed and promoted widely in the public arena, eg pharmacies, groceries, libraries, health centres, yellow pages, community health services, and the National Continence Helpline. It was recommended that the brochures (translated where appropriate) be distributed widely in a range of public venues and community
centres for people to take away and read in privacy. Such venues would also have the full text printed version available for reference, as well as access to the CD-ROM version if computers are available. It was recommended that the web address for the internet version be widely publicised.

**Further research**

It was recognised that at present industry does not readily provide some information that consumers want. Therefore further research and development work by industry in collaboration with government bodies was recommended regarding: development and compliance with international standards, provision of relevant product information eg cost, quality assurance, allergenicity and packaging options; standardisation of icons used in packaging and catalogues. In particular, further product evaluation research involving consumers perceptions of performance in use are needed for better informed selection of products. Meaningful and consistent measures of the working capacity of absorbent products are urgently required.

It was recommended that the impact of the Guide be re-evaluated 12 months after release in terms of consumer use, acceptance and perceived usefulness.

There were difficulties in assessing the Australian market for continence products. Should the Commonwealth require further research on the market, creation of a central database for tracking supply and demand was recommended.

Consumers voiced many concerns about the public assistance schemes eg CAAS and the various state schemes, and an urgent review of these schemes, with respect to marketing, funding, product selection and consumer input, was recommended.
APPENDICES

Appendix 1. Ethics participant information sheet and consent forms (Focus Group Interviews)
Participant Sheet Information

FOCUS GROUP INTERVIEWS
Development of a consumer guide and information on continence products

You are invited to take part in a study designed to explore consumer needs, patterns of use and preferences in regard to continence products. At present, the choice of appropriate products for an individual with incontinence is influenced by the type of incontinence, individual needs, availability of resources. Without comprehensive and current information on the range of products available, informed choice is difficult. This study aims to develop a clear, concise, comprehensive and logical guide of continence products. It is designed to inform consumers of available products, how to access them and their appropriate use.

If you choose to participate, you will be asked to join in a focus group discussing areas such as:

- the types of continence products used by you or your relative,
- your usual sources of information regarding continence products or management,
- information you find most helpful in managing continence issues,
- your concerns regarding your current continence management or continence products, and
- any other information related to continence you care to discuss.

The interview will last approximately one to two hours, depending on the interest and responses of the group.

The benefit of your participation in this study is the opportunity to explore issues of concerns and learn more about continence products and management. The risks include loss of your time and the possibility you may experience some embarrassment during the group discussions. You are free to not participate in any part of the discussion or to leave at any time.

Your involvement in this study is entirely voluntary, and your non-participation will not affect your treatment or future involvement with any health care group in any way. Should you decide to withdraw from the study you may do this freely and without prejudice.
All records containing personal information will remain confidential and no information that could lead to your identification will be released. All interviews will be transcribed by people who are also required to keep your information confidential.

Should you require further details about the project, either before, during or after the study, you may contact Sandra Dunn on 08 8204 5543, fax 08 8204 5907 or e-mail <sandra.dunn@flinders.edu.au>.

This study has been reviewed by the Flinders Social and Behavioural Research Ethics Committee. Should you wish to discuss the project with someone not directly involved, in particular in relation to matters concerning policies, information about the conduct of the study or your rights as a participant, or should you wish to make a confidential complaint, you may contact the Secretary on 08 8201 3513, fax 08 8201 3756 or e-mail <lesley.wyndram@flinders.edu.au>.

IF YOU ARE INTERESTED IN PARTICIPATING IN THE FOCUS GROUP, PLEASE CONTACT:

Helen Murray                       Ph: 08 8201 3553
Administrative Assistant            Fax: 08 8201 3410
Flinders University School of Nursing E-mail: helen.murray@flinders.edu.au
Bedford Park SA 5042

*****************************************************************************

FOCUS GROUP CONTACT SHEET

I may be interested in participating in interviews for your study on continence products. Please contact me (please print clearly):

Name: _________________________________________________________
Phone: _________________________________________________________
Best times to call:
CONSENT TO PARTICIPATE IN RESEARCH
FOCUS GROUP INTERVIEWS

I, ____________________________, request and give consent to my involvement in the research project “Development of a consumer guide and information on continence products”. I acknowledge that the nature, purpose and contemplated effects of the research project, especially as far as they affect me have been fully explained to my satisfaction by __________________________ and my consent is given voluntarily.

I acknowledge that the details of the interview process have been explained to me, including indications of risks; any discomfort involved; and anticipation of the length of time which the interview will involve.

I have understood and am satisfied with the explanations I have been given.

I have been provided with a written information sheet.

I understand that my involvement in this research study may not be of any direct benefit to me and that I may withdraw my consent at any stage without affecting my rights or the responsibilities of the researchers in any respect.

I declare that I am over the age of 18 years.

Signature of research participant: _____________________________ Date: __________

Signature of witness: __________________________________________

Printed name of witness: __________________________________________

I, ___________________________, have described to _________________________ the research study and the nature and effects of the procedures involved. In my opinion he/she understands the explanation and has freely given his/her consent.

Signature: __________________________________________ Date: __________

Status in study: __________________________________________

114
Appendix 2: Systematic review search strategy for CINAHL database

#1 continen*
#2 incontinen*
#3 #1 or #2
#4 fecal or faecal
#5 urin*
#6 #4 or #5
#7 #3 and #6
#8 need* or prefer*
#9 client* or patient*
#10 #8 and #9
#11 #7 and #10
#12 continen* product*
#13 continen* aid*
#14 urin* catheter*
#15 rectal catheter*
#16 continen* pad*
#17 continen* pant*
#18 #12 or #13 or #14 or #15 or #16 or #17
#19 drainage bag*
#20 #18 or #19
#21 #20 and #11
## Appendix 3: Systematic review proforma

<table>
<thead>
<tr>
<th>RECORD NUMBER</th>
<th>AUTHOR</th>
<th>YEAR</th>
</tr>
</thead>
</table>

### 1. MAJOR FOCUS OF ARTICLE
- Product evaluation
- Consumer needs, assessment
- Continence management in general

### 2. TYPE OF ARTICLE
- Primary research
- Literature review
- Discussion or opinion paper
- Anecdote

### 3. METHODOLOGY

#### Quantitative
- RCT or quasi-experimental
- Descriptive survey
- Other

#### Qualitative
- Interviews
- Anecdote or Case study
- Other

### 4. DATA EXTRACTION

#### Consumer issues
- Needs
- Assessment
- Other

#### Product
- Disposable
- Reusable
- Wearable absorbent pads and pants
- Underlays, sheets
- Catheters and uridomes
- Drainage bags, taps, valves, connectors
- Skincare, hygiene, odour control
- Other

#### Consumer
- Incontinent people
- Carers
- Health professionals
- Number
- Degree of incontinence: mild / moderate / severe
- Aetiology of incontinence
- Gender: male / female
- Age
- Other

#### Measure of effectiveness
- Total capacity
- Working capacity
- Absorbance rate
- Consumer perceptions / satisfaction
- Other

#### Results summary
- ...
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### Appendix 4: Spreadsheet template for data collection from grey literature on continence products

| Source of grey literature | name of organisation   | type of organisation (eg manufacturer, consumer group, etc) | Country | Title | other citation details | format (eg book, leaflet, website, etc) | Distribution/access (eg free handout, members only, buy) | Design | simple language? | simple layout? | humour? | includes images? | General incontinence information | Incontinence defined and described? | Professional assessment recommended? | Referral details for assessment information and support given? | Management options with continence products described? | Product information | Composition, appearance described? | function explained (what it does)? | capacity given (where appropriate)? | Method of use/application described? | Aesthetics, comfort addressed (bulk, noise, allergy, etc)? | Care, laundry, disposal described? | Supplier/distributor details included? | Cost information included? | Ordering information included? | Selection of products enabled by | Incontinence type (faecal/urinary/both)? | severity (mild/mod/severe)? | Gender? | Age? | size of person? | Mobility/dexterity/dependency/etc? |
Appendix 5: Survey form for continence industry

General information about this company
The general information requested in this part of the survey may be included in the Consumer Guide for Continence Products. Please write information in the spaces provided or check the appropriate box(es).

<table>
<thead>
<tr>
<th>Name of Company</th>
<th>Name of Contact Person</th>
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<tr>
<th>Position</th>
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<th>Phones</th>
<th>Fax</th>
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<th>Email</th>
<th>Internet</th>
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</table>

Involvement of this company in continence products (tick one or more boxes)

- [ ] Research and development
- [ ] Manufacture
- [ ] Supply and distribution

Brands of continence products made or supplied by this company

Please list this company’s distributors in each state/territory, and their phone numbers.

This company manufactures or supplies the following types of continence products (tick one or more boxes)

- [ ] 1. Absorbent body-worn pads (disposable)
- [ ] 2. Absorbent body-worn pads (reusable)
- [ ] 3. Absorbent pants, pull-ups or all-in-ones (disposable)
- [ ] 4. Absorbent pants, pull-ups or all-in-ones (reusable)
- [ ] 5. Absorbent male pouches (disposable)
- [ ] 6. Absorbent male pouches (reusable)
- [ ] 7. Absorbent underpads for beds or chairs (disposable)
- [ ] 8. Absorbent underpads for beds or chairs (reusable)
- [ ] 9. Waterproof furniture protection
- [ ] 10. Urinary catheters (intermittent, short-term, long-term, or suprapubic)
- [ ] 11. Condom catheters (= uridomes, sheaths)
- [ ] 12. Urinary drainage bags (overnight or leg bag, sterile or non-sterile)
- [ ] 13. Drainage bag accessories (connectors, taps, or valves)
- [ ] 14. Urinals and/or pans
- [ ] 15. Commodes
- [ ] 16. Anal plugs
- [ ] 17. Faecal collectors
- [ ] 18. Odour control products
- [ ] 19. Skin care products
- [ ] 20. Enuresis alarms
- [ ] 21. Other
<table>
<thead>
<tr>
<th>Is a catalogue available? (tick a box)</th>
<th>Are brochures or leaflets for consumers available? (tick a box)</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ ] yes, enclosed</td>
<td>[ ] yes, enclosed</td>
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<tr>
<td>[ ] yes, see internet</td>
<td>[ ] yes, see internet</td>
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<td>[ ] yes, will post</td>
<td>[ ] yes, will post</td>
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<tr>
<td>[ ] yes, contact me</td>
<td>[ ] yes, contact me</td>
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<tr>
<td>[ ] no</td>
<td>[ ] no</td>
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<tr>
<th>Is advertising material available? (tick a box)</th>
<th>Are electronic picture files available? (tick a box)</th>
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<td>[ ] yes, enclosed</td>
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<td>[ ] yes, see internet</td>
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<td>[ ] yes, will post</td>
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<td>[ ] yes, contact me</td>
<td>[ ] yes, contact me</td>
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<tr>
<td>[ ] no</td>
<td>[ ] no</td>
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<thead>
<tr>
<th>Is an annual report available? (tick a box)</th>
<th>Are research/evaluation reports about this company’s continence products available? (tick a box)</th>
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<tbody>
<tr>
<td>[ ] yes, enclosed</td>
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<tr>
<td>[ ] yes, see internet</td>
<td>[ ] yes, see internet</td>
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<td>[ ] yes, will post</td>
<td>[ ] yes, will post</td>
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<tr>
<td>[ ] yes, contact me</td>
<td>[ ] yes, contact me</td>
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<tr>
<td>[ ] no</td>
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**Quality assurance regime**

*As part of this project the Commonwealth has asked for information about quality assurance regimes used by the continence product industry. Please provide as much information as you can.*

Does this company follow a quality assurance regime? (tick a box)

[ ] yes  [ ] no  [ ] not sure

If yes, please describe briefly the processes and outcome measures used in the quality assurance regime (attach additional pages if necessary)

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What systems and processes are in place to handle consumer enquiries about this company’s products?

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Supply and demand for continence products

As part of this project the Commonwealth has asked for an overview of supply and demand for continence products in Australia. Therefore we are asking each company for recent information about sales of continence products. The intention is to sum the sales from all companies nationally, breaking down the aggregated figures by product type and buyer category. The buyers have been categorised into retail sector (supermarkets, pharmacies, individual customers), health services (public and private hospitals and nursing homes and medical distributors) and subsidy schemes (eg CAAS, ILEP, MASS).

Actual sales by individual companies will be NOT be disclosed to the Commonwealth, other companies or individuals.

Is this company willing to provide recent sales data? *(tick a box)*
- [ ] yes, data entered below
- [ ] yes/maybe, contact me
- [ ] no

Please estimate this company’s Australian wholesale sales of the following types of continence products to the three buyer sectors during the most recent fiscal year for which data is available *(fiscal year dates………………………………)*.

<table>
<thead>
<tr>
<th>Product type</th>
<th>Retail</th>
<th>Health services</th>
<th>Subsidy schemes</th>
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</thead>
<tbody>
<tr>
<td>1. Absorbent body-worn pads (disposable)</td>
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<td></td>
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<tr>
<td>2. Absorbent body-worn pads (reusable)</td>
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<tr>
<td>3. Absorbent pants, pull-ups or all-in-ones (disposable)</td>
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<tr>
<td>4. Absorbent pants, pull-ups or all-in-ones (reusable)</td>
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<tr>
<td>5. Absorbent male pouches (disposable)</td>
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<td></td>
</tr>
<tr>
<td>6. Absorbent male pouches (reusable)</td>
<td></td>
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<tr>
<td>8. Absorbent underpads for beds or chairs (reusable)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Waterproof furniture protection</td>
<td></td>
<td></td>
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<tr>
<td>10. Urinary catheters (intermittent, short-term, long-term, or suprapubic)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>11. Condom catheters (= uridomes, sheaths)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Urinary drainage bags (overnight or leg bag, sterile or non-sterile)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. Drainage bag accessories (connectors, taps, or valves)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Urinals and / or pans</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. Commodes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. Anal plugs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. Faecal collectors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. Odour control products</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. Skin care products</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. Enuresis alarms</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. Other ………………………….</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Detailed product information**

Information from this part of the survey may be included in the Consumer Guide to Continence Products. Please provide as much information as you can so that this company’s products can be comprehensively described. Please use one page per product (different sizes of the same product may be entered on the same page). Please make additional copies of this page as required.

For each of the company’s continence products, please supply the following details (one product per page). Where information is common to a range of products, or available elsewhere (eg in a catalogue), simply make a note of that on the form.

<table>
<thead>
<tr>
<th>Product name and brand</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Product type (number from list on page 1)</td>
<td></td>
</tr>
<tr>
<td>Brief description of product (eg: what it is made of, what it looks like, fasteners, special features, properties)</td>
<td></td>
</tr>
<tr>
<td>Does this company use type or severity of incontinence to assist in the development and marketing of its continence products? (tick a box)</td>
<td>[ ] yes [ ] no</td>
</tr>
<tr>
<td>If yes, please specify urinary incontinence type (tick one or more boxes)</td>
<td>[ ] stress [ ] urge [ ] reflex [ ] overflow [ ] functional</td>
</tr>
<tr>
<td>urinary incontinence severity (tick one or more boxes)</td>
<td>[ ] mild [ ] moderate [ ] severe</td>
</tr>
<tr>
<td>faecal incontinence consistency (tick one or more boxes)</td>
<td>[ ] liquid [ ] solid</td>
</tr>
<tr>
<td>faecal incontinence amount (tick a box)</td>
<td>[ ] small amount [ ] large amount</td>
</tr>
<tr>
<td>Suitable for which consumers? gender (tick one or more boxes)</td>
<td>[ ] male [ ] female [ ] both</td>
</tr>
<tr>
<td>age (tick one or more boxes)</td>
<td>[ ] child [ ] adult [ ] both</td>
</tr>
<tr>
<td>Special instructions for care and laundry or disposal of product</td>
<td></td>
</tr>
<tr>
<td>Precautions for use, safety issues, allergenicity</td>
<td>[ ] retail sector (supermarkets, pharmacies, individual customers)</td>
</tr>
<tr>
<td>[ ] health services (hospitals, nursing homes, medical distributors)</td>
<td></td>
</tr>
<tr>
<td>[ ] subsidy schemes (eg CAAS, MASS)</td>
<td></td>
</tr>
<tr>
<td>[ ] other…………………………………………</td>
<td></td>
</tr>
<tr>
<td>Packaging options</td>
<td></td>
</tr>
<tr>
<td>Sizes</td>
<td></td>
</tr>
<tr>
<td>Dimension</td>
<td></td>
</tr>
<tr>
<td>Catalogue number (or suppliers code)</td>
<td></td>
</tr>
<tr>
<td>Capacity and method of measurement Total capacity (ml)</td>
<td></td>
</tr>
<tr>
<td>Functional (=working) capacity (ml)</td>
<td></td>
</tr>
<tr>
<td>Other…………………………</td>
<td></td>
</tr>
<tr>
<td>Wholesale cost in $Aus</td>
<td>Per item Per pack of ……</td>
</tr>
<tr>
<td>Per pack of …….</td>
<td></td>
</tr>
</tbody>
</table>

I am happy to have this product included in the Independent Living Centre Database. [ ] yes [ ] no (initials …………

Thankyou for completing this survey. Please return in the envelope provided to Mrs Helen Murray, School of Nursing, Flinders University, GPO Box 2100, Adelaide, 5001.
Appendix 6: Evaluation form for pilot testers.

**Brochure:**

Is the information useful?  yes [  ]  no [ ]  don’t know [ ]
Is the content easily understood?  yes [  ]  no [ ]  don’t know [ ]
Is the text easily read?  yes [  ]  no [ ]  don’t know [ ]

Comments and suggestions:

**Product guide:**

Is there enough information to guide product selection?  yes [  ]  no [ ]  don’t know [ ]

What information is missing:

Are product codes needed?  yes [  ]  no [ ]  don’t know [ ]
Are approximate prices needed?  yes [  ]  no [ ]  don’t know [ ]
Is the content easily understood?  yes [  ]  no [ ]  don’t know [ ]
Is the text easily read?  yes [  ]  no [ ]  don’t know [ ]
Is the country of origin needed?  yes [  ]  no [ ]  don’t know [ ]
Are product dimensions needed?  yes [  ]  no [ ]  don’t know [ ]

Which layout do you like? (tick one or more)
- 4 products per page, in columns, landscape format [  ]
- 4 products per page, in columns, portrait format [  ]
- 4 products per page, in rows, portrait format [  ]
- none of these [  ]

Should the photos be in colour?  yes [  ]  no [ ]  don’t know [ ]  doesn’t matter [  ]

Comments and suggestions:

**Section and subsection divider pages:**

Which designs do you like? (tick one or more)
- feather and icons [  ]
- whirlpool and icons [  ]
- feather [  ]
- whirlpool [  ]
- none of these [  ]

Comments and suggestions:

**Background logos:**

Which do you like? (tick one or more)
- feather [  ]
- whirlpool [  ]
- icons [  ]
- none [  ]

Comments and suggestions:

**Icons:**

Are they meaningful to you?  yes [  ]  no [ ]  don’t know [ ]
Should we use them?  yes [  ]  no [ ]  don’t know [ ]

Comments and suggestions:

Feel free to make further comments overleaf and on the drafts.

Please return this form and your drafts to Mrs Helen Murray, School of Nursing and Midwifery, Flinders University, GPO Box 2100, Adelaide in the enclosed reply-paid envelope by Friday 10 November 2000. Thankyou.