Awareness of Incontinence in Ethnic Communities
# Table of contents

Acknowledgements ................................................................. 2  
Executive summary .............................................................. 3  
Introduction ........................................................................... 5  
Project background ............................................................... 6  
Aims and objectives ............................................................. 6  
Deliverables ........................................................................... 6  
Literature review ................................................................... 7  
Methodology ........................................................................... 11  
Findings ................................................................................. 15  
Discussion .............................................................................. 19  
Recommendations ................................................................. 22  
References ............................................................................. 23  
Appendix A – Focus group schedule and information sheet .... 25  
Appendix B – Table: Data analysis summary of key themes .... 27
Acknowledgements

We would like to thank the Ethnic Communities’ Council of Victoria (ECCV) and Monash University School of Nursing & Midwifery, Clayton staff for their collaboration on the project.

ECCV kindly hosted the project advisory group meetings and provided additional support and advice throughout the project. Monash University provided significant expertise in conducting data analysis of the research and co-writing the final report.

We greatly appreciate the assistance of representatives from organisations that formed the project advisory group. They provided invaluable input and assistance with the recruitment of participants from the different ethnic communities. We acknowledge their genuine concern and desire to address incontinence problems for their community members and clients.

Advisory group members:

• Australian Greek Welfare Society
• Australian Multicultural Community Services (formerly Australian Polish Community Services)
• Australian Turkish Community Services
• Australian Vietnamese Womens Association
• Baptcare
• CELAS
• Centre for Cultural Diversity in Ageing
• Chinese Community Social Services Centre Inc.
• Co. As. It. (Italian Assistance Association)
• Continence Foundation of Australia
• Victorian Government Department of Health, Aged Care Branch
• Ethnic Communities’ Council of Victoria
• Macedonian Community Welfare Association of Victoria
• Royal District Nursing Service
• Russian Ethnic Council of Victoria
• Spectrum Migrant Resource Centre
• Victorian Arabic Social Services
• Western Continence Service, Western Health

Finally we would like to acknowledge and thank the Victorian Government Department of Health, Aged Care Branch and the Lord Mayor’s Charitable Foundation for their funding support to undertake this project.
Executive summary

The Victorian Continence Resource Centre (VCRC) undertook this project to explore the awareness of people from different ethnic communities in relation to the prevention, treatment and management of incontinence.

The findings and recommendations in this report will provide aged, community and health organisations (ethno-specific and mainstream) with practical advice to help raise awareness of incontinence prevention, causes, treatments and management among ethnically diverse communities.

The project was a collaboration between the Ethnic Communities’ Council of Victoria (ECCV) and other multicultural, ethno-specific, health and aged services represented on the project advisory group.

Through funding obtained in 2009 and 2010 from the Lord Mayor’s Charitable Foundation and the Victorian Government Department of Health, Aged Care Branch, ten ethnic communities were selected and approached to participate. The ethnic communities were Arabic speaking, Chinese, Italian, Greek, Macedonian, Polish, Russian, Spanish speaking, Turkish and Vietnamese.

Methodology

Focus groups were planned and conducted in the selected ethnic communities following identification of potential issues from a review of research literature on ethnicity and incontinence. VCRC liaised with ECCV and ethno-specific organisations in planning the focus groups, recruiting appropriate participants and convening the focus groups. Participants included older men and women, and middle aged women. The latter group were included because of the earlier life stage prevalence of incontinence among women compared to men. Incontinence problems were not implied through participation. Instead, the discussions held were general discussions to gauge knowledge and understanding of the issue in general. Twenty focus groups were conducted with a total of 218 participants (167 female and 51 male). Translated information about the focus groups and questioning were given to participants prior to and at the commencement of each discussion. The translations were prepared using accredited translators then a cultural and linguistic review was conducted by the ethno-specific services to ensure appropriateness of content and meaning. Interpreters and bi-lingual workers were involved in conducting each of the focus groups in the preferred language of the participants. Verbal consent was obtained at the commencement of the discussions and consent was also given to audio record the sessions for completion of note taking. Following the focus groups, notes were transcribed and collated and analysed in collaboration with staff of Monash University, School of Nursing and Midwifery. Patterns of response were coded and grouped into themes and sub-themes.

Findings

Key findings aligned with three themes: knowledge and awareness, quality of life impacts and management of incontinence.

- Knowledge of incontinence (particularly causes and treatments) was found to be low across all groups. A belief that incontinence is an inevitable part of ageing was common. Knowledge was impacted by the fact that in some languages there is not a term to describe ‘incontinence’ or otherwise the translated term often has a negative or detrimental meaning.

- Limitations to participation in social activities was reported as a common impact on people’s day to day lives.

- Amongst Muslim men and women, incontinence could lead to religious restriction.

- Cultural and religious influences were expressed in relation to preferences for information in their preferred language; and preference for a doctor who spoke their language.

- Gender preferences were also noted, particularly among women from some groups about speaking only to female family and friends rather than husbands, sons and male interpreters. Some women also expressed a gender preference to see a female doctor.
• Communication and language barriers were perceived to limit people's access to information and support services. Participants expressed a desire to receive more verbal and written information in their preferred language about incontinence causes and treatments, including pelvic floor muscle exercises. A range of multi-media formats such as ethno-specific publications and radio programs were also suggested.

Recommendations

The following recommendations are made in relation to the project findings:

1. Provide ongoing community education and information on incontinence in the preferred language of ethnic communities.

2. Use appropriate translation guidelines in the review and development of translated health information about incontinence. Bi-lingual information resources should be developed which include both English and the translated language in the same document.

3. A common glossary of incontinence-related terms be developed and translated into different languages. This will overcome the difficulties with interpreting and translating incontinence terms in some languages.

4. Develop or review existing translated health information (state and national) about incontinence for people from ethnic communities with low English proficiency to be consistent with these findings and recommendations.

5. Develop or adapt key messages to inform ethnic communities to improve awareness of incontinence. This should be aimed at changing perceptions that incontinence is not an inevitable part of ageing but is preventable and treatable. Improve understanding of pelvic floor muscles, including where the muscles are located, their role in prevention and treatment of incontinence and instruction on how to do pelvic floor muscle exercises.

6. Consider multiple formats for disseminating information including targeting ethno-specific publications and radio programs.

7. A summary information resource for health, community and aged services be developed, incorporating the findings and recommendations.

8. Deliver ongoing professional development opportunities to staff and volunteers to enhance knowledge, skills and confidence in supporting clients with incontinence. The training should include: identification of those at risk of developing incontinence, strategies to promote continence and manage incontinence.

9. Through staff training increase capacity of services providing exercise programs to ethnic communities to incorporate pelvic floor muscle exercises.

10. Acknowledge individual cultural and religious preferences and beliefs, particularly concerning gender relationships and language preferences.

11. Continence services improve data collection and reporting relating to service usage by people from different ethnic communities.
Introduction

Incontinence is a common health issue that affects people across the life span. It is an issue that individuals find difficult to raise with health professionals.

It is not easy for an adult to say ‘I wet myself’. Thus incontinence continues to be a taboo subject because of a complex of emotions it causes the person such as embarrassment, shame, and anxiety. Incontinence is the loss of bladder or bowel control. Urinary incontinence is defined as: the complaint of any involuntary leakage of urine (Abrams et al 2002). Faecal incontinence (bowel) is the involuntary loss of liquid or solid stool that is a social or hygienic problem (Norton et al 2005). A need for frequent toileting, a feeling of urgency and/or constipation can also be associated with incontinence.

The prevalence of incontinence in Australia is estimated at 1 in 4 or 24% of the population experience urinary incontinence (females 38% and males 10%). Up to 3% of individuals experience faecal incontinence (females 4% and males 2%) (AIHW 2006). Whilst incontinence is not a life threatening illness, the condition can have significant impacts on a person’s quality of life and lead to social isolation and depression.

There are high levels of under-reporting of incontinence due to a stigma associated with the condition and lack of discussion or acceptance of the issue as a common problem. Embarrassment and shame are also strong factors, along with a perception that incontinence is a normal part of ageing (Pearson et al 2002). Under reporting is common due to people not considering the incontinence a big enough issue (Dugan et al 2001).

Limited information about perceptions of incontinence among ethnic communities is known. Research in the UK suggests that among ethnic minority groups incontinence symptoms are commonly normalised as part of ageing or as a consequence of childbirth. Help seeking behaviour is also hindered due to feelings of embarrassment and lack of available information in culturally sensitive formats (Doshani et al 2007).

This report describes a research project conducted in Melbourne, Australia, that aimed to explore the experience of different ethnic community members about incontinence. Further, it aimed to support health, ageing and community organisations to meet the continence needs of people from ethnic communities.
Project background

In 2009 the VCRC approached several funding bodies in order to undertake the project.

Despite a growing ageing population, the centre recognised a lack of requests for information from ethnic communities related to incontinence. Findings from a pilot project addressing continence issues among Home and Community Care clients highlighted a need for further information and education about incontinence for people from non-English speaking backgrounds (HDG Consulting 2009).

Funding was obtained from the Lord Mayor’s Charitable Foundation and the Victorian Government Department of Health, Aged Care Branch in 2009 and 2010. Throughout 2010 and 2011, the VCRC worked in collaboration with various organisations and ethnic communities. A project advisory group guided implementation of the project. Following data collection through focus groups conducted, independent data analysis and reporting was performed in collaboration with Monash University, School of Nursing and Midwifery in 2011.

Aims and objectives

The overall goal of this project is to raise awareness of incontinence issues among ethnic communities in Victoria. Improved understanding of the cultural and social influences around incontinence in ethnic communities will assist service providers to provide more culturally appropriate and targeted care.

The project aimed to:

• identify continence perceptions, needs and issues among specific ethnic communities
• increase awareness of incontinence within a cultural context in specific ethnic communities and among community and health organisations

Deliverables

The intended outcomes of the project were to:

1. Identify culturally appropriate strategies to work with people from ethnic communities for continence promotion and awareness raising
2. Provide information resources to health, aged and community organisations to assist them in supporting and meeting the continence needs of people from ethnic communities
A review of the published research literature was conducted to identify links between the prevalence of incontinence and ethnicity and to explore general attitudes and awareness of people from various ethnicities to incontinence.

Furthermore, the review aimed to explore health and social care beliefs and practices in ethnic communities which may impact on health behaviours, self management and health seeking behaviour relevant to the prevention and management of incontinence.

Search strategy

Electronic databases including CINAHL, MEDLINE, PsycINFO, ASSIA, PubMed, Medscape, JBI ConNect, Google and others were searched using search terms including ‘ethnic’ and ‘incontinence’, ‘ethnicity’, ‘culture’, ‘urinary incontinence’ and ‘access’. A PubMed search in December 2009 using ‘ethnic AND incontinence’ listed 76 articles. Other articles were identified using snowballing techniques from key articles reviewed. Research articles from English publications were included and commentary articles were excluded.

Search results

A number of studies were located which focused on specific ethnic population groups or provided comparisons between different ethnic groups. Most articles located referred to overseas studies, highlighting a lack of research in Australia in this area. Studies tended to focus on prevalence of urinary incontinence, particularly among women. Those studies that included examination of other themes other than prevalence rates were included. Common themes that were the subject of these often qualitative studies included psycho-social or quality of life impacts, knowledge and perceptions, health seeking behaviour and treatment preferences. This report has been structured around discussion of these themes.

Limitations

Few studies located were population based. Comparability of results and quantitative data from studies is often not appropriate due to different definitions used for incontinence, small sample sizes and different sampling methods used.

Key themes

Prevalence and risk factors

There is a lack of available and reliable prevalence data related to incontinence among different ethnic groups. Few studies have been population based that compare prevalence and risk factors among different ethnic groups and among both men and women for different types of incontinence. Most of the studies reviewed focus on women and urinary incontinence (UI) in particular.

Two US studies reported ethnic differences in prevalence rates between Caucasians and minority groups for particular types of incontinence. These studies found that stress incontinence was highest among Caucasian women whilst urge UI symptoms were similar. Mixed incontinence was found to be highest among Afro-American women, followed by Hispanics then Caucasians. No significant racial/ethnic differences were found among men (Thom et al 2007; Tennstedt et al 2008).

A population based study in China of community dwelling women found 19% had urinary incontinence, lower than prevalence among Western women (Song et al 2005).

Some studies explore potential risk factors thought to be associated with UI among ethnic minority groups. The US BACH study found smoking status, alcohol use and physical activity level were not related to weekly incontinence indicator for men or women. However, waist circumference was found to be a risk factor for incontinence in women with risk increasing by 15% for every 10cm increase (higher still for Hispanic women 43%) (Tennstedt et al 2008).
A Chinese study found that age, vaginal delivery, parity, hypertension, constipation, alcohol consumption, episiotomy and higher body mass index are potential risk factors associated with stress incontinence. Urge incontinence was found to be associated with age, menopause, caesarean delivery, parity, constipation, foetal birth weight, episiotomy and higher body mass index (Song et al 2005).

Knowledge and perceptions

With regard to knowledge of the causes of incontinence most studies are fairly consistent in reporting that women from different ethnic groups feel that incontinence is a normal part of ageing and not a disease state.

Wilkinson (2001), in a qualitative study of Pakistani Muslim women found the women lacked understanding about their health problems and treatments in general.

Women’s uncertainty about the causes of UI and often self blame are reported by Komorowski & Chen (2006) among Chinese women. Similarly, Rizk et al (1999) describes women from the United Arab Emirates (UAE) feeling self blame from being overweight, not following advice of health professionals and not seeking help sooner.

In a Swedish study by Andersson (2009), Syrian women thought UI was due to the body becoming lax or weakened with increased age and after several childbirths. Sange et al (2008) found similar beliefs among South Asian (Indian and Pakistani) Muslim women in a UK study.

It is a common perception that UI is not seen as an illness and not serious enough to seek professional help. Among Chinese women in a study by Li et al (2007), this was often seen as wasting the doctor’s time.

Some ethnic groups perceive UI as a social or hygiene problem, as in the case of the Chinese (Li et al 2007). Whilst in the Middle East, incontinence is viewed as a neurological or senile disorder among women, rather than a gynaecologic condition caused by childbirth or menopause (Rizk et al 2006). One study in the UAE found 45% of women believed UI was caused by paralysis and/or neurological disorders. Women also perceived that UI was normal or untreatable (Rizk et al 1999). South Asian Indian women in a United Kingdom (UK) study by Doshani et al (2007) also described feeling that nothing could be done about UI and tended to accept it as part of ageing.

Kubik et al (2004) in a study from the United States of America (USA) found that socioeconomic status explained ethnic differences in knowledge of UI. Lack of awareness about the causes and treatments of UI can lead to poor understanding of the illness and may serve as a barrier to care seeking.

Quality of life impacts

Many of the studies reviewed describe impacts of UI on quality of life not dissimilar to those reported by western women.

Impacts reported in some studies in China included social problems such as limited participation in sport, sexual intercourse and social activities such as shopping and outings. Hygiene problems were also identified and associated with feelings of being dirty and having an offensive smell and soiled clothes (Li et al 2007; 2007a).

Similar restriction to activities due to embarrassment regarding odour and feeling unclean was reported by Chaliha et al (1999), of women from different religious faiths in the UK. This study explored the religious and cultural practices of ethnic minorities and affects on the experience of incontinence.

Chaliha also found that sexual restriction due to incontinence differed amongst individuals and seemed to be related to decreased libido due to feeling unclean rather than religious restriction.

Some Moroccan and Turkish Muslim women in Norway reported they did not feel shame as they believed the condition was created by Allah (Raboud 2006).

Negative affects are reported by Pakistani Muslim women who developed low self esteem evident in feelings of shame, dirtiness, embarrassment, self-blame and sinfulness due to religious restriction (Wilkinson 2001).

Religious restriction due to incontinence was found to be most marked among Jewish and Muslim women in the study by Chaliha et al (1999). This was related to the need for cleanliness when praying and attending places of worship. Some had modified prayer routines including voiding before prayer, restricting fluids and for some Muslim women altering the prayer position to the sitting rather than prostrate position.

In Jewish Law, the Torah states a person may not engage in prayer or the study of the Torah in the presence of excrement and Rabbis have extended this to include urine.
Islamic rules state that a person must be in a state of cleanliness (tahaarah) to perform certain acts of worship and for prayer to be valid. Ritual cleansing or ablution must be performed prior to prayer. This cleansing may include washing of the arms, face, feet, a complete bath or dry cleansing (with earth, sand or clean dust) in the absence of water. Defecation and urination nullify this cleansed state. Should any leakage occur, prayer should be delayed until the leakage ceases, as long as time remains for prayer. Body parts and clothes that are soiled should be washed prior to purification for prayer.

Muslim women reported feeling sinfulness arising from being unclean with UI. Worry about not being able to fulfil religious obligations led to fear and mental stress (Wilkinson et al 1999). Whilst prayer was regarded as an important factor in reducing mental stress, it was often difficult or impossible to practice which increased anxiety (Rizk et al 1999). For some women the act of ablution and prayer itself could lead to an incontinent episode (lying prostrate, sitting and standing many times in prayer). Furthermore Sange et al (2008) found that some Muslim women felt UI symptoms caused a barrier between them and Allah, believing it to be a form of punishment with a cure only possible through prayer.

Health seeking behaviour

Some variation exists between studies and ethnic groups in relation to help seeking behaviour for UI.

One study by Huang et al (2006) found no significant differences in the treatment seeking between Asians and Caucasians, with rates being low overall for both. A New Zealand study similarly found that failure to seek help occurred similarly across the ethnic groups studied (Maori, Pacific Islander and European) (Lara et al 1995). However a Chinese study reported 83% of women had sought help due to their quality of life or health being affected (Yu et al 2003).

A study in Europe comparing UI among women in France, Germany, Spain and the UK found that the two most predictive factors were common for all countries and included 1) willingness to take long term medication and 2) having spoken to others about UI (O’Donnell et al 2005).

One Chinese study reported fear as a major barrier to help seeking. Fear of not coping, fear of others finding out, fear of wasting resources and fear of the condition worsening (Li et al 2007).

A number of barriers are reported for women not seeking help. Among women from UAE, embarrassment to consult a doctor, particularly a male, was the most common reason for not seeking help (Rizk et al 1999). Women in the study also had low expectations of medical treatment and therefore chose to self-manage. Embarrassment, seeing the problem as a normal part of ageing and ignorance about available treatments was found among ethnic minority women from different religious faiths in another study (Chaliha et al 1999).

The same study found Muslim and Hindu women would firstly discuss such problems with close female family members, not male relatives. Jewish women would however discuss with their partners. All women would not discuss with anyone outside the family and felt that there was a taboo about discussion of incontinence in society (Chaliha et al 1999).

Communicating their problems and obtaining advice from female relatives or friends was also confirmed in a Swedish study of Syrian women. Older women described feeling shame and embarrassment and would never discuss UI in front of a man, including husbands, sons and male interpreters (Andersson 2009).

Most women would only disclose UI to female family and friends, with some never talking to males about women’s problems. Given this reluctance, access to healthcare can potentially be restricted should a female doctor or health professional not be available, and a male needs to be consulted or accompany a female family member to an appointment (Sange et al 2008).

Sange et al also found older Muslim women (35–70 years) did not attach as much importance to cultural influences as younger women did (21–34 years). The older women identified embarrassment as having greater influence over their behaviour than religion or culture stating that religion did not restrict seeking help. Most women did not consider UI to be a problem that would cause them to seek professional help and felt it would be a waste of the doctors time (Sange et al 2008).

On another note, one study found that women were less likely to consult a doctor if they did not accept surgery as a treatment option or were unwilling to take long term medication for UI. Therefore, it is important women are provided with more information about different treatment options for informed decision making (O’Donnell et al 2005).
Some Muslim women felt that their illness was from God, who is the only source of cure, and therefore believed a cure was only possible through prayer (Sange et al 2008).

**Treatment preferences**

Some studies identified different treatment preferences among different ethnic groups studied. Among Chinese women self management was preferred with women tailor making their own absorbent home made pads using toilet paper, towel and handkerchiefs (Li 2007; Komorowski et al 2006). In a study in UAE, some women also believed in self treatment, due to having low expectations of the benefit of medical management (Rizk 1999).

Self management including fluid restriction, wearing pads and not attending social gatherings was always considered prior to medical treatment. (Sange et al 2008).

Also among the Chinese was a preference for using traditional Chinese medicines including acupuncture and herbal medicines (plant or animal parts) to treat imbalances in the body (Li 2007; Komorowski et al 2006).

A preference for a doctor from the same ethnic group was also important. A study of UK Muslim women found that older women had chosen Asian GPs because of their ability to understand and communicate in their language and similar cultural background (Sange et al 2008).

Muslim women had a preference to see a female health professional, particularly if a physical examination was required. (Sange; Andersson 2009)

Often Muslim women would not tell a male GP about their UI due to fear of examination. Others preferred to tell a practice nurse, assuming they were female and had more time to spend with them in consultation than GPs (Sange 2008).

Younger participants in the study believed that examination by a male doctor was forbidden and religiously incorrect. Whilst the Quran does not dictate gender/client relationships of health professionals it is often a cultural practice adopted by some cultures. Unlike the younger women, older women felt that as care in the UK was free through the public system, unlike in their own country, they would have to see whoever they could (Sange et al 2008).

Jewish, Christian and Buddhist women, in comparison to Muslim women, had no preference for a female health professional. Some Hindu women preferred female doctors seemingly related to individual preferences and not religious rules (Sange et al 2008).

In summary, the key issues identified in the literature highlight a lack of knowledge about causes and treatments related to incontinence; negative impacts reported on quality of life; and some culturally and religiously based treatment preferences. These issues were explored further in the focus group discussions.
A qualitative research design was chosen as the best method for in-depth exploration of issues around incontinence that are shaped by various cultures.

This approach to project design allows researchers to describe, and then generate explanations for particular phenomena. Given the language barrier between the research team (who spoke English) and the targeted cultural and ethnic language groups, focus groups were facilitated by a bi-lingual worker where possible and an interpreter, with guidance from the attending project leader.

Focus group in-depth interviews are useful for investigating exploratory topics because the process allows multiple perspectives to be obtained from a small group of individuals (usually 6–10 people in a group), provided there is opportunity for each person to state their views. Focus group interviews have been applied to health research to give insights into understanding specific needs, and to identify strengths or weaknesses and needed improvement (Puchta & Potter 2004).

Target population – needs analysis

It is difficult to assess the incontinence care needs of different ethnic communities by examining current continence service usage data. The data obtained from a sample of metropolitan Melbourne and rural Victorian clinics was inconsistent and difficult to compare and not reliable enough to draw any firm conclusions in relation to service access.

Ethnic groups were selected for participation in the project based on an analysis of current and predicted Victorian population data. Australian Census data for overseas born, ageing and low English proficiency in Victoria was examined (Australian Bureau of Statistics 2006). Population projections in Victoria of speakers of languages other than English aged 65+ and in middle age were also reviewed (Howe 2006). Whilst there is a higher incidence of incontinence in aged persons, middle aged groups have been included as prevalence is higher among women in this age group. This group would perhaps benefit from early intervention (Hawthorne 2006). Proficiency in English was also considered as it is as an indicator of ease or difficulty with settlement and need for culturally appropriate services (Howe 2006). This resulted in selection of the following cultural groups that ranked highly across the indicators mentioned: Arabic speaking, Chinese, Italian, Greek, Macedonian, Polish, Russian, Spanish speaking, Turkish and Vietnamese.

Recruitment of participants

The project aimed to sample participants from the chosen ethnic communities in Melbourne. This was achieved through liaison with ethno-specific organisations to access social clubs and interest groups, or Home and Community Care planned activity groups associated with these organisations. The project leader liaised with the ECCV who provided contacts for the respective ethnic communities. The project leader made contact with the ethnic community organisations and invited participation in the project. Subsequent meetings or phone conversations followed to discuss the planning of the focus groups with the key workers associated with the groups. Information about the project and purpose of the focus groups including the question schedule were translated from English to each language through accredited translators. Key workers reviewed translations and made changes for cultural and linguistic appropriateness. Translated information was passed onto the community members and explained by the key workers to invite participation in the focus groups. Key workers often invited the whole group (as one) to participate.

It should be noted that the participants were invited to discuss continence or incontinence, though they did not have to be incontinent to participate. Incontinence was not implied and the study was promoted as a general discussion about issues around incontinence. The recruitment process is represented in diagram 1.
Practical difficulties encountered in recruitment/involvement of participants

The main barrier in recruitment was difficulty in recruiting men to participate in the discussions. Male interpreters and male bi-lingual workers led the discussions in the men’s groups where possible. Despite this, key workers reported that some male participants decided not to attend on the given day or there were limited number of men participating in groups anyway. Making contact with bi-lingual workers or community contacts for Arabic mens groups was particularly difficult. Another barrier faced was the lack of interpreter experience in interpreting content for this health issue, and for some, discomfort or confidence in discussing this topic with participants. A contributing factor was the difficulty with direct translation of incontinence terms for some languages (eg Vietnamese). The key workers were involved in reviewing the translated information and identifying more culturally appropriate and sensitive terminology. This highlights the need for agreement about appropriate translated terms to be used to describe incontinence. One solution is to develop a glossary of incontinence terms for use in translation and interpreting. The project leader also endeavoured to overcome these difficulties through briefing interpreters prior to the session through the interpreter service, and specifically requesting interpreters with experience in interpreting health information.

Focus groups were organised via the key worker and the project leader relied upon this worker to explain the purpose of the discussion prior to the group. In some instances it was apparent that participants expected to receive education and information from the project leader on the topic rather than to be asked questions in a focus group discussion. This suggested a misunderstanding in briefing of the groups prior to the sessions. Information about the purpose of the discussion was, however, explained verbally at the commencement of each focus group and was also provided in writing in both English and the relevant language translation. This information included reference to participants providing consent and the option of withdrawing consent by leaving the discussion at any point. Key workers for each group also signed a consent form on behalf of their group. Consent to audio record the discussion was verbally requested and obtained at the commencement of each session.

Ethical considerations

The VCRC and its legal entity, the Continence Foundation of Australia, Victorian Branch does not have an independent ethics committee. Advice was sought from a project advisory group to ensure the processes and methodology in the project were culturally sensitive and appropriate. The advisory group comprised representatives of ethno-specific, multicultural and mainstream health and community organisations. Furthermore, the project team referred to guidelines developed by the Centre for Ethnicity and Health on how to conduct culturally appropriate focus groups (2010).
Conduct of focus groups

Focus groups were conducted at the usual meeting place of participants, such as a community hall or centre. The time taken was between one hour and one hour and 30 minutes. The project leader attended each session. Where possible, each session was gender specific applying to both participants and interpreters/bi-lingual workers. A focus group interview schedule was developed around the key themes based upon those identified in the literature review. Thirteen questions were developed (shown in Appendix A). These were provided to interpreters and participants in both English and a translated version. However, focus group discussions were iterative with prompts and probing questions being asked where necessary to follow up a line of discussion.

Audio recordings were made of the focus groups with verbal consent of participants. Interpreted responses to questions were recorded in writing by the project leader. Notes were transcribed by the project leader and confirmed using the audio recordings. Each groups’ narrative record was notated by age and gender of participants and subsequently, their ideas and responses were collated into clusters around these demographs being either young women, older women, older men, or a mixed gender group. The transcribed records were then analysed through NVivo data analysis computer software.

Data analysis of focus groups

Five focus group note files (25%) were analysed phrase by phrase using NVivo computer software. Open coding was applied (using the terminology of the narratives to cluster similar views) to identify a pattern of response based on each of the 13 focus group questions. This resulted in 61 themes being identified. In a second stage, the identified sub-themes were used as an organising template to group further participant responses for each of the remaining 15 focus groups (Crabtree et al 1999).

New sub-themes were added at each stage. These results were tabulated using agreement as a stratifier (yes = applicable; no = not applicable to that ethnic group), giving a matrix of result elements by ethnic language group. A summary of common group responses are provided in appendix B. The commonality of responses across groups was explored by two researchers to extract the key findings. To add to the rigour of the study, the initial qualitative analysis that relies on interpretation of data was conducted by a researcher who was independent of the research team.

Description of focus groups

Twenty focus group discussions were held. There were 218 participants (51 male and 167 female) who represented 10 ethnic groups. Most groups included participants aged 65+ years, five groups included middle aged women. The younger women were included as the prevalence of incontinence is higher among this group.

A summary of ethnicity and gender of the focus group participants is provided in table 1. Due to the sensitivity of the topic, gender-specific focus groups were arranged where appropriate. There were five focus groups conducted with male participants.
Table 1. Focus groups participants – ethnicity and gender

<table>
<thead>
<tr>
<th>Ethnic Group</th>
<th>Number of participants</th>
<th>Total per ethnic group</th>
<th>Female</th>
<th>Male</th>
</tr>
</thead>
<tbody>
<tr>
<td>Arabic speaking</td>
<td>group 1 15 10</td>
<td>25</td>
<td>25</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chinese</td>
<td>group 1 7 5</td>
<td>20</td>
<td>9</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>group 2 8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>group 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greek</td>
<td>group 1 13</td>
<td>13</td>
<td>13</td>
<td>–</td>
</tr>
<tr>
<td>Italian</td>
<td>group 1 14 13</td>
<td>27</td>
<td>13</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Polish</td>
<td>group 1 12 5</td>
<td>17</td>
<td>17</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vietnamese</td>
<td>group 1 7 12 9</td>
<td>28</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>group 2 18</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>group 3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Macedonian</td>
<td>group 1 8 18</td>
<td>26</td>
<td>26</td>
<td>–</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Russian</td>
<td>group 1 20 6</td>
<td>26</td>
<td>16</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spanish speaking</td>
<td>group 1 14</td>
<td>14</td>
<td>14</td>
<td>–</td>
</tr>
<tr>
<td>Turkish</td>
<td>group 1 9 13</td>
<td>22</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td></td>
<td>218</td>
<td>167</td>
<td>51</td>
</tr>
</tbody>
</table>

Note: Arabic speaking included participants of Christian and Muslim faiths from mainly Middle Eastern countries of birth.
Findings

This section presents a summary of key findings from examination of the focus group narratives to give an insight into the perceptions of the participants by ethnic group.

Where extracts from focus groups are given, these were selected as being representative of a groups’ perspective although they are not actual quotations due to the notation of participant’s responses in English via an interpreter.

Low level of knowledge and understanding of incontinence

Overall, participants’ knowledge about incontinence was low. Half the groups (Russian, Turkish, Polish and Italian) reported that they did not know of the causes of incontinence. There were also multiple explanations given for causes of incontinence. The most common responses shared across most groups were:

- a belief it is due to ageing and occurs in older age
- it is due to the birthing process, or
- it’s due to weak muscles (unsure which muscle – bladder muscle or ‘down there’ indicating pelvic area).

Others reported they thought it to be a kidney problem (Greek and Turkish), or caused by eating the wrong foods in pregnancy (Vietnamese). There was a disconnect between knowledge of incontinence (involuntary loss of urine) and urinary frequency; often they mentioned kidney function and focused their comments on experiences of a need for frequent urination – rather than relating incontinence to loss of bladder control. Importantly, many believed that incontinence is unavoidable in old age. Table 2 provides a summary of responses concerning perceptions of incontinence.

There was also a low level of knowledge of incontinence treatments, with participants in around half the groups (Greek, Russian, Macedonian, Turkish, Polish and Vietnamese) reporting they did not know of treatments. As was stated, the groups were composed of various individuals with some who were known to have the problem of incontinence, and others who did not, so various levels of awareness were not unexpected. Fluid restriction was mentioned by several participants as a treatment but is incorrect, as this may exacerbate a problem (also mentioned as preventing incontinence). There were some beliefs in traditional foods, or animal or herbal medicines amongst Arabic, Chinese and Vietnamese groups however they were not commonly agreed or practiced. Around one-third of groups mentioned exercise as a treatment although many were unsure of which type of exercise – some referring to a ‘breathing exercise’ rather than specific pelvic floor muscle exercises.

Impact on quality of life

Many participants viewed incontinence as impacting negatively on an individual’s quality of life although overall, perceptions were mixed. While half the groups voiced this issue (stating this would limit social outings), the other half disagreed. Many thought a person could be prepared, managing with absorbent incontinence pads and also access to toilets. There was a view however that planning frequent access to a toilet was difficult.

- It’s like a burden on the mind – worrying about the toilet when they go out.
  – Chinese older woman

- [I] don’t feel comfortable if I have to go out.
  – Macedonian older woman

- Holidays and travel are affected – like staying overnight, or at a friend’s place.
  – Chinese men and women

- I don’t let it weigh on me – I take my pads and precautions and continue on with my activities.
  – Italian older woman

Wearing of incontinence pads or ‘nappies’ as some participants referred to them, were regarded as burdensome, but there was thought to be no choice in this as other treatment options were not known. For example:

- I have to change pads all the time.
  – Greek older woman
My father had it recently … and he just wore pads … but it didn’t really affect his daily life.
– Russian younger woman

A negative impact on some cultural or religious traditions in everyday life for a person with incontinence was apparent in the discussions. For Muslims, the condition might limit their ability to perform prayer or visit a mosque for prayer due to being ‘unclean’ and not being fit for prayer.

It affects prayer time – cannot go to group prayers so would pray at home.
– Younger Arabic woman

Methods of praying would be affected … in my religion one has to be cleansed and be clean and concentrate … in terms of concentrating the problem of incontinence would be quite difficult … you would have to cleanse yourself again and again.
– Turkish older man

There were some references to this issue and a need for repeated washing before praying among Macedonian, Turkish and Arabic participants.

In terms of anxiety about incontinence and the effect on everyday life if they had this condition, participants were asked how concerned they would be. Nearly all agreed they would be concerned or very concerned with suggestions this would lead them to seek help. However, there were some views in the Chinese groups that they may just live with the condition.
Management of incontinence

In discussions, participants were asked about barriers to communication in the form of accessing information, support and services including help-seeking behaviour and treatment preferences. Nearly all participants suggested they were comfortable in talking about incontinence with others because it was a ‘normal’ thing. However some Arabic older women and Spanish speaking women and Chinese volunteers would be shy and others might be embarrassed.

A lot of people feel shy to talk about this. Before, people used not to talk at all because it was a taboo subject.
– Arabic older woman

Because it’s some sort of sickness its embarrassing.
– Chinese older men and women

If you have this issue you need to see a GP first; this is not incurable, no need to be embarrassed.
– Chinese older man

Gender differences were apparent when talking about the topic as some women preferred to speak with females rather than males. This was referred to by Macedonian younger women, Arabic older women and Chinese volunteers (men and women) to seek out their children or female friends. Chinese participants suggested that females in general are more open and would speak with female friends, while males were more private.

All groups agreed they were likely to speak with their doctor about their medical condition with a preference in some groups (Chinese, Vietnamese, and Arabic-speaking) for a doctor who spoke their own language and/or who understood their culture. Some Arabic, Chinese and Vietnamese women expressed a preference for a female doctor.

How can services be improved?

As it is uncertain how many of the participants had been diagnosed with incontinence and required or had utilised services for incontinence, the value of responses about service improvement is limited. Participants could not respond appropriately to this question when they were not aware of services available eg Continence Clinics or the National Continence Helpline.

However, when asked about what treatments would be acceptable most participants agreed that incontinence pads may be necessary but wearing of pads was thought to be burdensome (Greek, Russian, Macedonian, Polish, Arabic and Chinese). Some participants were not aware of the difference between continence pads and sanitary pads used by women or even nappies for children. Some people hoped for medications as treatment, or even surgery. Some participants (Italians) also made comment they were happy with health services in Australia compared with back home.

How can ethnic communities be better informed?

Participants were asked what other information they would like to access and about the best way of informing their community. Responses indicated that they would like to know about causes of incontinence and therapies and services that are available, with some asking for relevant exercise information.

Why does it occur, is it because of the bladder, kidneys, or other things, who knows?
– Polish older women

What different treatments and services are available?
– Italian older women

How to do the exercise … where are the classes to learn how to do them?
– Russian older men and women

Clinics should make available qualified interpreters and also publicise this service.
– Italian older men

A variety of strategies for disseminating information were mentioned. Multiple media sources were suggested: Ethnic language radio, TV, newspaper, brochures, as well as healthcare professionals providing written and verbal advice. Nearly every mention of this related to receiving information in their preferred language. Talks and presentations to clubs and groups were thought valuable. Although there was a strong preference for both written materials and spoken word to be delivered in their preferred language, several suggested they would ask friends or children to read written materials that were in English.
[We need] easier access to information in our own language, one could read then know, and then you could go to the doctor with it.
– Polish older woman

Through the [social] clubs – talks on this topic, many members don’t know about it.
– Italian older women

Listening to the radio…some listen and some don’t.
– Macedonian older women

Maybe at the GP and maybe have posters.
– Turkish older women

[SBS] Vietnamese radio has program in morning and evening.
– Vietnamese younger women

[We need] pamphlets in Russian.
– Russian younger women

Brochures in our language.
– Polish older women

There was no mention of the Internet as a possible resource or source of information for these participant groups – rather, spoken or written information was more accessible.

The overall responses suggest that most participants would be interested to know more about the condition of incontinence and would appreciate improved access to culturally appropriate written and multimedia (TV, radio) information.
Incontinence is a common health issue but the majority of people do not seek help (Kinchen et al 2003, Pearson et al 2002).

Common themes in the literature for this lack of help seeking include: shame and embarrassment, normalisation as part of getting old, having a baby, being a woman, and not considering it a big enough problem (Kinchen et al 2003, Pearson et al 2002, Horrocks et al 2004, Hagglund et al 2007). The findings in this project mirror the perceptions in the broader population suggested in the literature.

The limited knowledge and understanding of the causes and treatments of incontinence among ethnic communities can serve as a barrier in itself to seeking help. Differences in socioeconomic status have been found to explain ethnic differences in knowledge of incontinence (Kubik et al 2004). Their findings also suggest a limited concept or understanding of prevention which can be linked to poor health literacy.

Whilst detailed social and demographic information of participants was not obtained, the majority of participants were overseas born and aged 65 years and older. Available community profiles for the ethnic groups targeted in this project suggest many participants would have lower levels of education (Fronditha Care 2010, Migrant Information Centre Eastern Melbourne 2009 & 2010, Victorian Multicultural Commission 2008).

It was anticipated that the project findings would identify more marked associations around incontinence and cultural and religious beliefs and practices. The findings suggest some common themes experienced across all population groups. Shame, embarrassment and restriction of social activities were negative effects identified by some participants across the ethnic groups that are similar to the broader population. Key differences that were significant amongst some of the ethnic groups relate to religious practice and treatment preferences.

Negative impacts associated with incontinence were most concerning for Muslim men and women who reported that incontinence potentially limited their religious practice. In particular, incontinence caused worry and frustration in relation to carrying out prayer rituals. This is in keeping with the literature that details Muslim women feeling sinful from being unclean with incontinence and that worry about not being able to fulfil religious obligations led to fear and mental stress (Wilkinson et al 1999).

Specific cultural and religious beliefs were found to relate to some views on the management of incontinence, and in particular treatment preferences. The literature describes how Chinese people may have a preference for using traditional medicine. Some herbal or home remedies were named after prompting by some focus group participants. However, there was little consensus around these. Among the Chinese and Vietnamese groups, some participants (although not all), reported they were likely to practice traditional medicine or a combination of this and western approaches.

Gender preference was identified by Muslim women for female health professionals. The literature suggests this is due to embarrassment and fear of examination by a male doctor (Rizk et al 1999). Some participants from the Arabic, Chinese and Vietnamese groups also expressed a preference for female health professionals. But this was not true for all participants of these groups. It was difficult to determine any gender preference for GPs by men in the focus groups due to the low number of men participating.

Consulting a doctor from the same ethnic group was a more common preference reported by men and women in the focus groups. This is due to their ability to understand and communicate in the person’s preferred language.

Some focus group participants including Greek, Arabic and Chinese participants reported they would self-manage rather than seek professional help. The common self management strategies include fluid restriction, wearing continence pads and restricting social activities. These findings are in keeping with the literature (Li 2007; Komorowski et al 2006; Sange et al 2008). Some participants also mentioned medication and surgery as acceptable treatments. This finding is in contrast to the literature which describes low expectations of or lack of acceptance of medical treatments (Rizk et al 1999).
For many ethnic groups, incontinence is not a topic discussed outside the family and is often considered a taboo subject to discuss in public society (Chaliha et al 1999). Whilst some women in the focus groups suggested they would only discuss the issue with other women and never with males including, husbands, sons and male interpreters, other women mentioned they would talk to their partners. There were differences by ethnic group about which family members, friends or relatives they would openly speak with. Most did however suggest they would speak with their doctor.

Communication and language barriers are significant for many non-English speaking born people with limited English language skills. This represents an added burden with regard to access to information and support services. Such barriers are more amenable to change than barriers posed by culturally based attitudes and behaviours. Strategies that would improve communication about the prevention, treatment and management of incontinence would go a long way to improving knowledge and understanding of incontinence in ethnic communities. Furthermore, it is important people are provided with information about different treatment options for informed decision making and consideration is made of gender/client relationships with professionals to reduce barriers to accessing care.

Implications for service delivery

The project highlights key themes which illustrate the experience and impact of incontinence on people from different ethnic backgrounds. These have implications for the prevention, treatment and management of incontinence among culturally and linguistically diverse groups.

We found a lack of useful knowledge about the causes of incontinence and available treatments among community members. Many participants had a poor understanding of the causes and treatments that limit their ability to make informed decisions. Given this, services and staff working with people from ethnic communities (particularly ageing clients), should adopt a more pro-active approach to identifying and supporting those with the condition. More broadly, there is a role for services to inform and educate clients to improve awareness, knowledge and skills for preventing and managing continence problems. This would involve in the first instance up skilling staff and volunteers working with people from ethnic communities on these issues.

There are barriers to understanding caused by language. The terms ‘incontinence’ or ‘continence’ are often used interchangeably in the field of continence prevention, treatment and management. However, these terms may not have a direct translation in some languages. Negative connotations can also be associated with use of the terms in some languages. Anecdotally, some people reported they had never heard of this health issue or had never before heard the terms in their own language. The development of a set of common terms and agreed translations for each language would encourage greater consistency in use of appropriate incontinence terminology. The use of these terms would go some way towards improving awareness and reducing possible stigma. Organisations should be encouraged to refer to these common translated terms when using or instructing interpreters and developing translated materials.

Key messages should focus on:

- incontinence affects people of all ages and from all cultural backgrounds
- the condition is preventable and not an inevitable part of ageing
- treatments are available and the majority of people are cured.

Awareness raising and education within ethnic communities should include these key messages that challenge common misperceptions held. Staff and volunteers within health and community organisations that provide services to ethnic communities are vital in changing perceptions about incontinence and reinforcing key messages.

Services and staff play an important role in improving the quality of life for their clients. They need to increase their awareness of the negative impact incontinence has on people’s day to day lives. Restriction of social activities is a common self management strategy, which may lead to social isolation and depression (Continence Foundation of Australia 2008).

Other possible impacts of incontinence on day to day life include:

- sleep disturbance
- frequent need for a toilet which can cause anxiety and be burdensome
- anxiety or fear associated with worry about having a toileting accident, having the problem discovered, inconveniencing others and perhaps being a burden or wasting resources (e.g. GP time, money with purchasing continence pads)
• embarrassment if others were to find out
• limitation on intimate and sexual relationships
• financial cost associated with purchase of absorbent products, cleaning and washing, replacing soiled bedding and furniture
• added carer burden.

(AIHW 2006)
The imperative for services is to actively promote strategies for individuals to adopt that better manages their incontinence.

Limitations
Incontinence is a sensitive subject. Participant responses may have been limited to socially acceptable answers given the nature of focus group discussions. Responses were also not direct quotations but provided through an interpreter which could potentially introduce bias and inaccuracy. The small sample size also poses limitations of the representativeness and transferability of the findings. A strength of the design was however, the data analysis performed by an independent researcher.

Conclusion
Cultural considerations are essential but should not be overstated at the risk of stereotyping. It is important to appreciate that individuals have different preferences and needs. Health and community workers need to practice person-centred care through individualised needs identification. Specifically, this means identifying particular preferences concerning same gender clinician and interpreter and preferred language.

This project highlights that the provision of information about incontinence has not been adequate to ethnic communities. The way forward is to ensure knowledge and language is not a barrier for individuals to make informed decisions. Education and information about how to prevent incontinence and its management options must be provided in formats that people with low English proficiency can access and understand.
Recommendations

The following recommendations are made in relation to the project findings:

1. Provide ongoing community education and information on incontinence in the preferred language of ethnic communities.

2. Use appropriate translation guidelines in the review and development of translated health information about incontinence. Bi-lingual information resources should be developed which include both English and the translated language in the same document.

3. A common glossary of incontinence-related terms be developed and translated into different languages. This will overcome the difficulties with interpreting and translating incontinence terms in some languages.

4. Develop or review existing translated health information (state and national) about incontinence for people from ethnic communities with low English proficiency to be consistent with these findings and recommendations.

5. Develop or adapt key messages to inform ethnic communities to improve awareness of incontinence. This should be aimed at changing perceptions that incontinence is not an inevitable part of ageing but is preventable and treatable. Improve understanding of pelvic floor muscles, including where the muscles are located, their role in prevention and treatment of incontinence and instruction on how to do pelvic floor muscle exercises.

6. Consider multiple formats for disseminating information including targeting ethno-specific publications and radio programs.

7. A summary information resource for health, community and aged services be developed, incorporating the findings and recommendations.

8. Deliver ongoing professional development opportunities to staff and volunteers to enhance knowledge, skills and confidence in supporting clients with incontinence. The training should include: identification of those at risk of developing incontinence, strategies to promote continence and manage incontinence.

9. Through staff training increase capacity of services providing exercise programs to ethnic communities to incorporate pelvic floor muscle exercises.

10. Acknowledge individual cultural and religious preferences and beliefs, particularly concerning gender relationships and language preferences.

11. Continence services improve data collection and reporting relating to service usage by people from different ethnic communities.
References


Migrant Information Centre Eastern Melbourne (2009 and 2010) Home and Personal Care Kit, Cultural & Religious Profiles to Assist in Providing Culturally Sensitive Care and Effective Communication


24 Awareness of Incontinence in Ethnic Communities
Appendix A

Focus group schedule and information sheet

Questions for discussion

1. How comfortable do you feel to talk about this topic?
2. What do you believe causes incontinence?
3. Can you think of cultural beliefs or practices that may help prevent incontinence?
4. What cultural or religious traditions are affected by incontinence?
5. Who do people talk to about this health problem?
6. When should people seek help from a health professional for this problem?
7. How concerned should people be if they were incontinent?
8. How can being incontinent affect people day to day?
9. How can incontinence be treated or managed?
10. What treatments do you think people in your community would try and accept?
11. What more information would you like about incontinence to increase awareness in your community?
12. How could this information be provided to your community?
13. What can be done to improve the services provided for managing incontinence problems?
Continence in Ethnic Communities Project

*Information about the discussion group*

Hello and welcome.

The purpose of this discussion is to hear your views about incontinence (bladder and bowel control problems).

The term incontinence refers to problems with the control of your bladder and bowel.

The questions will be about what you know about incontinence, its causes, and treatments. Your cultural beliefs and attitudes about incontinence will also be considered.

You will not be asked if you have ever experienced incontinence. However, if you feel comfortable, you may share a personal experience relating to yourself, a family member or friend.

The information we receive will help us to improve awareness of incontinence in your community. It will also help us to provide better access to information and services.

There will be no more than 10-12 participants in the discussion group.

The discussion will be led by a facilitator who speaks your language. An interpreter may be present to interpret what you say into English for note taking.

Your consent is given by participating in the group. You are free to withdraw from the discussion at any time.

The discussion will be audio recorded for the purpose of reviewing and completing notes. Upon completion of the transcription notes, the audio recordings will be destroyed, for privacy reasons.

Information will be anonymous and participant names will not be used for any comments you make during the discussion.

Feedback about outcomes of the project will be provided to participants through your community organisation or group at the completion of the project.

For any queries concerning the discussion group please contact the project officer, Deborah Manning, at the Victorian Continence Resource Centre, on ph: 9816 8266.

We thankyou and appreciate your participation.
Appendix B

Full list of focus group responses/themes with commonly agreed items in bold

<table>
<thead>
<tr>
<th>MAIN QUESTION ASKED</th>
<th>IDENTIFIED RESPONSE THEME/S</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Comfort in talking about incontinence</td>
<td>Shy, Normal/comfortable, Embarrassing Taboo, Uncertain</td>
</tr>
<tr>
<td></td>
<td>Gender divide, Relieves great burden discussing</td>
</tr>
<tr>
<td>2. Cause of incontinence</td>
<td>Delaying urination, Too frequent of urination</td>
</tr>
<tr>
<td></td>
<td><strong>Pressure on bladder</strong>, Weak bladder, Bladder prolapse, Weak muscles</td>
</tr>
<tr>
<td></td>
<td>Physiological, Prostate problem, Kidney problem, Illnesses</td>
</tr>
<tr>
<td></td>
<td>Illnesses</td>
</tr>
<tr>
<td></td>
<td>Prostate problem</td>
</tr>
<tr>
<td></td>
<td><strong>Birthing</strong></td>
</tr>
<tr>
<td></td>
<td>Other beliefs, Eating wrong foods in pregnancy, Stress in mind, Lifting, Punishment of gods</td>
</tr>
<tr>
<td></td>
<td><strong>Getting older</strong></td>
</tr>
<tr>
<td></td>
<td>Dehydration/over-hydration, Constipation</td>
</tr>
<tr>
<td></td>
<td>No idea</td>
</tr>
<tr>
<td>3. Prevention</td>
<td>Diet or foods</td>
</tr>
<tr>
<td></td>
<td><strong>No known cultural preventative</strong></td>
</tr>
<tr>
<td></td>
<td>Fluid restriction, Drinking more water</td>
</tr>
<tr>
<td></td>
<td>Pelvic exercise, Exercising your body</td>
</tr>
<tr>
<td>4. Affect on cultural-religious traditions</td>
<td>No effect</td>
</tr>
<tr>
<td></td>
<td><strong>Limit social interactions</strong>, Get depressed</td>
</tr>
<tr>
<td></td>
<td>Religious restriction, Unclean belief, Limit mosque visits</td>
</tr>
<tr>
<td>5. People you talk to about it</td>
<td>Doctor, Doctor preferences</td>
</tr>
<tr>
<td></td>
<td>Friend</td>
</tr>
<tr>
<td></td>
<td>Husband, Wife, Mother, Elder/family, Children</td>
</tr>
<tr>
<td></td>
<td>Daughters/granddaughter, Females</td>
</tr>
<tr>
<td></td>
<td>No-one, Find information yourself</td>
</tr>
<tr>
<td></td>
<td>Chemist</td>
</tr>
<tr>
<td>6. When do you seek health professional help</td>
<td><strong>When symptomatic</strong> (straight away)</td>
</tr>
<tr>
<td></td>
<td>When symptoms persist</td>
</tr>
<tr>
<td></td>
<td>Self-manage</td>
</tr>
<tr>
<td></td>
<td>Don’t know/no answer given</td>
</tr>
<tr>
<td>7. Degree of concern if incontinent</td>
<td>Concerned, Very concerned, More concerned if severe</td>
</tr>
<tr>
<td></td>
<td>Just live with it</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
</tr>
<tr>
<td>8. Daily effect on individual</td>
<td>Toilet access difficult/burden, Frequent toileting embarrassing, Public toilet access is good</td>
</tr>
<tr>
<td></td>
<td><strong>Wearing of nappies burdensome</strong></td>
</tr>
<tr>
<td></td>
<td>Conscious of the smell</td>
</tr>
<tr>
<td></td>
<td><strong>Limits going out</strong>, Not an issue because go out equipped</td>
</tr>
<tr>
<td></td>
<td>Restrict fluid intake/refuse drinks</td>
</tr>
<tr>
<td></td>
<td>Washing/changing frequently, Repeated washing before praying</td>
</tr>
<tr>
<td></td>
<td>Interrupts sleep</td>
</tr>
<tr>
<td>MAIN QUESTION ASKED</td>
<td>IDENTIFIED RESPONSE THEME/S</td>
</tr>
<tr>
<td>---------------------</td>
<td>-----------------------------</td>
</tr>
<tr>
<td>9. Treatment or management knowledge</td>
<td>Animal or herbal medicines</td>
</tr>
<tr>
<td></td>
<td>Fluid restriction beliefs, Drink more fluids</td>
</tr>
<tr>
<td></td>
<td>Don't know</td>
</tr>
<tr>
<td></td>
<td>Food beliefs, Coffee/tea, Good diet</td>
</tr>
<tr>
<td></td>
<td>Teaching/education</td>
</tr>
<tr>
<td></td>
<td>Medical treatment, Bladder surgery/surgery, Medication – tablets, patches</td>
</tr>
<tr>
<td></td>
<td>Exercise</td>
</tr>
<tr>
<td></td>
<td>Massage/acupuncture</td>
</tr>
<tr>
<td></td>
<td>Meditation/de-stress</td>
</tr>
<tr>
<td></td>
<td>Regular elimination</td>
</tr>
<tr>
<td>10. Acceptable treatments</td>
<td>Use incontinence pads</td>
</tr>
<tr>
<td></td>
<td>Medicines</td>
</tr>
<tr>
<td></td>
<td>Surgery</td>
</tr>
<tr>
<td></td>
<td>Attend Continence clinic</td>
</tr>
<tr>
<td></td>
<td>Doctor advice</td>
</tr>
<tr>
<td></td>
<td>Don't know</td>
</tr>
<tr>
<td></td>
<td>Exercises</td>
</tr>
<tr>
<td></td>
<td>Hope for cure</td>
</tr>
<tr>
<td>11. What more information would you like to increase community awareness</td>
<td>Information about therapies</td>
</tr>
<tr>
<td></td>
<td>Information about causes</td>
</tr>
<tr>
<td></td>
<td>Information about prevention</td>
</tr>
<tr>
<td></td>
<td>Food and health</td>
</tr>
<tr>
<td></td>
<td>Brochures in own language</td>
</tr>
<tr>
<td></td>
<td>What services are available</td>
</tr>
<tr>
<td></td>
<td>What are the pads</td>
</tr>
<tr>
<td></td>
<td>Knowledgeable doctor is enough</td>
</tr>
<tr>
<td></td>
<td>What natural treatments there are not medicines, Details of exercises</td>
</tr>
<tr>
<td></td>
<td>Don't know/no answer</td>
</tr>
<tr>
<td>12. How can community be informed of treatments</td>
<td>By experiencers (those who have condition)</td>
</tr>
<tr>
<td></td>
<td>By media</td>
</tr>
<tr>
<td></td>
<td>Q&amp;A session on SBS</td>
</tr>
<tr>
<td></td>
<td>By more information</td>
</tr>
<tr>
<td></td>
<td>Group discussion/talks</td>
</tr>
<tr>
<td></td>
<td>Club meeting (nationalities)</td>
</tr>
<tr>
<td></td>
<td>Case presentation</td>
</tr>
<tr>
<td></td>
<td>From doctors</td>
</tr>
<tr>
<td></td>
<td>From hospital</td>
</tr>
<tr>
<td></td>
<td>From community health services</td>
</tr>
<tr>
<td></td>
<td>Telephone information line</td>
</tr>
<tr>
<td></td>
<td>Community radio (in own language)</td>
</tr>
<tr>
<td></td>
<td>Newspaper – own language</td>
</tr>
</tbody>
</table>
12. How can community be informed of treatments (continued)

<table>
<thead>
<tr>
<th>MAIN QUESTION ASKED</th>
<th>IDENTIFIED RESPONSE THEME/S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community TV (own language),</td>
<td>Brochures (own language), Brochures from government</td>
</tr>
<tr>
<td>Brochures (own language), Brochures</td>
<td>Posters, Posters at GP</td>
</tr>
<tr>
<td>from government</td>
<td></td>
</tr>
</tbody>
</table>

13. How services can be improved

<table>
<thead>
<tr>
<th>MAIN QUESTION ASKED</th>
<th>IDENTIFIED RESPONSE THEME/S</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community radio information</td>
<td></td>
</tr>
<tr>
<td>Group information sessions</td>
<td></td>
</tr>
<tr>
<td>Talks</td>
<td></td>
</tr>
<tr>
<td>Demonstrate exercises</td>
<td></td>
</tr>
<tr>
<td>Brochures (own language)</td>
<td></td>
</tr>
<tr>
<td>GP Practice nurse with interpreter</td>
<td></td>
</tr>
<tr>
<td>Health Services with interpreter</td>
<td></td>
</tr>
<tr>
<td>Specialist clinics with interpreter</td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
</tr>
<tr>
<td>Not aware of Helpline or continence</td>
<td></td>
</tr>
<tr>
<td>clinics</td>
<td></td>
</tr>
</tbody>
</table>