



ACI NSW Agency
for Clinical
Innovation

REPORT

Pain Management Network Multicultural report 2015



Executive Summary

The NSW pain plan 2012-2016 has been widely implemented. Service capacity has been significantly enhanced as a result, with waiting lists reduced by an average of 27 weeks across the state.

Services and resources have largely been designed to meet the needs of the general population, without specific consideration of the needs of the Culturally and Linguistically Diverse (CALD) communities. It has become evident, particularly for some areas of NSW where CALD populations are prevalent, that adaptation of existing materials and service models is necessary. Materials require translation and cultural adaptation in order to facilitate engagement with, and adoption of the self- management bio psychosocial approach advocated as best evidence for pain management.

The top four language groups were identified: Chinese, Arabic, Vietnamese and Greek. Ten consumer focus groups were then conducted in partnership with three Local Health Districts (LHDs): Sydney, Southwestern Sydney and Southeastern Sydney LHD

Emergent themes common to all groups were as follows:

- Culturally supported multidisciplinary care in the local community is necessary to facilitate engagement between people with chronic pain and the principles of pain management
- Community endorsement of the approach to pain management is necessary
- General practitioners require support in order to manage the specific CALD population with chronic pain
- Key messages regarding pain management need to be conveyed in simple and culturally modified language
- A community based pain programme delivered by local health workers would be useful
- CALD communities require supported access to information and specialist services at pain clinics

Key Differences between the four multicultural groups

- The stigma of pain is highly associated with cultural expectations
- The motivation to apply and maintain pain management strategies varies between cultural groups and is driven by different factors
- The desire to be healthy and well (and the behaviours that underpin that belief) vary in importance

The issues highlighted through this process illustrate key aspects of providing healthcare to people with chronic pain in Arabic speaking, Vietnamese, Chinese (Mandarin and Cantonese speaking) and Greek communities. Modifications to current practice should be undertaken to support the specific needs of these groups of people.

Analysis of Culturally and Linguistically Diverse (CALD) Focus Groups for ACI Chronic Pain Model of Care Patient Experience & Consumer Engagement (PEACE) Team & Pain Network

Background

The ACI Pain Management model of care identifies concerns regarding equity of access to specialist services for disadvantaged and minority groups. (See Appendix 1) The ACI Pain Management Network in conjunction with the Patient Experience and Consumer Engagement (PEACE) team and the Multicultural Health Managers in three targeted Local Health Districts (LHDs), organised focus groups for specific Culturally and Linguistically Diverse (CALD) communities in NSW. This included:

- Sydney LHD – Arabic, Vietnamese
- South Eastern Sydney LHD – Greek, Chinese (Mandarin & Cantonese)
- South Western Sydney LHD – Arabic, Vietnamese

The purpose of the focus groups was to explore the way in which the Arabic, Greek, Chinese and Vietnamese communities understand, manage and access services for chronic pain.

The outcomes will inform the development of culturally appropriate chronic pain resources and programmes across NSW, as part of developing the model of care for pain management

The methodology adopted for each focus group is outlined below:

- A verbal consent process at the beginning of each session with an opt-out option. This approach was taken to manage language difficulties with a written process for consent
- Consenting participants voluntarily providing their own experienced-based information about current knowledge of and access to chronic pain services in NSW
- Group dialogue was facilitated using set questions, which focused on the key evidenced based principles of chronic pain management
- Information shared during the focus groups was de-identified, scribed and recorded and scribed by ACI staff
- Each focus group had up to three observers (LHD/ACI staff) who participated in an adhoc fashion in the focus group discussion or facilitation
- Participants were sourced through existing locally-based multicultural community support groups
- Highly sensitive information relating to service delivery was relayed back to facilities as required via the local-facility key contact for investigation and appropriate management. Information detailing these issues has not been included in this report.

The experience-based information collected has been individually tabled for each multicultural group into two broad categories - *what is working well* (facilitating adoption of pain management strategies) and *what is not working well*; (inhibiting adoption of pain management strategies) with these categories further themed into Picker's 8 Dimensions of Care (see Appendix 2). The results below present the key themes that collectively emerged across each focus group along with selected illustrative quotes from participants.

It is important that the results contained in this report are considered in the context of the methodological limitations of each focus group.

These include

- Small numbers
- Lack of representation across all demographic contexts
- Variation in exposure to chronic pain
- Participants were already engaged with LHD activity, and cannot represent those who are not

1.0 Arabic Community Key Themes

45 Arabic community members from two Local Health Districts (LHDs) attended focus groups. The majority were women in their middle ages. The key themes commonly identified by the Arabic community across sites are highlighted below. Further detailed information including participant quotations is presented in Table 1.

1.1 Facilitating Experiences

The information below summarises the feedback from the participants in the focus groups about what they feel would enhance their ability to manage pain

- Group based learning in a familiar environment and learning from peers
- Understanding and structured support from the General Practitioner (GP)
- Lay leader to bring the community together to endorse new learnings
- Community acceptance and support for the principles of pain management
- Exercising together and using modes such as dance, aquatic exercise, walking group, Distraction and spiritual contemplation are useful strategies, whereas formal Cognitive Behaviour Therapy may prove difficult without context.

1.2 Inhibiting Experiences

The information below summarises the feedback from participants in the focus groups about what they feel limits their ability to manage pain

- Lack of GP knowledge and role in disseminating new information
- The lack of understanding about pain management
- Unfamiliar environments i.e. service delivered through Outpatient facilities
- Lack of transparency in accessing specialist care

Table 1: Arabic Community - What's Working Well

The following table highlights the detailed experiences described as “working well”.

PICKER	FACILITATING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> • Multicultural Workers role including NSW Multicultural Health Communication Service and the LHD Multicultural Health Services as a central point of communicating information • Language and gender specific community groups noting 	<p>'Well I listen to SBS radio'</p> <p>'We would like to spend more time learning about pain and how to manage it as a group'</p>

	<p>the motivators include friendship, food, religion and similar cultural or family roles; activities</p> <ul style="list-style-type: none"> • Ethnic radio and newspapers • Community gatherings such as festivals and church groups • Community venues such as the library and local schools • Investing the appropriate “time” in pain education • Facilitating role of the pharmacist in providing drug information. • Prepared to think about active self -management concepts 	<p>‘We go to the pharmacist for advice, but they usually provide advice about medications only’</p> <p>‘I am thinking differently about how I can learn to manage pain’</p>
Information & education	<ul style="list-style-type: none"> • Potential to see a way of managing pain using the self-management approach through vehicles and tools such as seminars, simple facts sheets. This potential is based on a “hunger” for information, but lack of knowledge on how to act on it. • Modified “Understanding Pain” educational video which stimulates visual learning and frames Evidence Based Practice • Information and education for self-management works when it is implemented at organised gatherings e.g. Cooking, arrange flowers then exercising in a group, swimming, dancing • When information is delivered by a legitimate person of authority and influence such as someone recommended by family/friends, a community member or trusted health professional such as an Arabic speaking GP or pharmacist • Supportive family members will assist the uptake and application of information 	<p>“ “Understanding pain” video communicates hope, pain control and is believable.”</p> <p>“The Arabic GP is the voice of authority”</p> <p>‘The video could be slowed down’</p>
Access to Care	<ul style="list-style-type: none"> • A structured approach is required to assist in accessing services and treatment that is in line with the values of the community; • Interpreter support will be required • GP support for specialist referral • Family support is critical • Financial outlay will prohibit participation 	<p>“It’s too expensive to go to swimming each week”</p> <p>‘Why won’t the GP refer me to a hospital specialist?’</p>

Table 2: Arabic Community - What’s Not Working Well

The following table highlights the detailed experiences described as ‘not working well’.

PICKER	INHIBITING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> • Reliance on high levels of literacy and health literacy; • Belief that pain is a “normal for age” cultural concept – that age could be 50; • Cultural norms around exercise, health management and self-management; • Not actively seeking self-management as a solution. 	<p>“Arabic speaking people tend to believe that pain is a normal part of ageing and to be expected. Many people over 50 will stop exercising believing it is for the young.”</p> <p>“I am looking to be fixed when I go to the doctor for pain”</p>

<p>Information & education</p>	<ul style="list-style-type: none"> • Too complex written information • Pivotal role of Arabic speaking GP • Information about specialist care options such as Chronic pain Clinic from GP • Lack of understanding of mechanisms of chronic pain • Stigma of pain impacts behaviour and actions to seek help • Formal psychological strategies e.g. relaxation and meditation are not well understood. The background and rationale will need to be taught/explained. Other strategies such as prayer/ music/spirituality are more commonly used and understood • Nothing offered beyond medications- this results in people seeking out local remedies e.g. chilli paste • Information is not translated using culturally appropriate concepts • Mixed messages about medications from health professionals • Locus of control sits with the GP/other (not the individual) – different extrinsic motivators will be required • Reliance on the internet as a source of reliable information 	<p>“GP’s do not understand pain”</p> <p>“Simple plain information is best”</p>
<p>Physical Comfort</p>	<ul style="list-style-type: none"> • Adhoc uncoordinated care impacts physical comfort and feeds negative no-change cycle; • Too much (uncoordinated) exercise • Medication (long-term, multiple medications, side-effects) • Gender roles frame the pain experience (especially with males accessing care in a later stage of pain) 	<p>“Use of medications creates unrealistic expectations of a cure”</p> <p>“The men try to be strong and don’t seek help for pain early- they do get angry though”</p>
<p>Access to Care</p>	<ul style="list-style-type: none"> • Tertiary services not culturally appropriate • Access and awareness of specialist care options such as Chronic pain Clinic • Financial outlay for healthcare including transport to and from appointments • Attending hospital based care 	

1.3 Summary findings from the Arabic speaking groups:

1. Group based education is required preferably in the community. The important elements include:
 - minimal financial outlay
 - emphasis on linking self- management and understanding of pain to improved quality of life
 - highlighting the social benefits of effective pain management including enjoyment of food and family
2. Formal psychological strategies, such as Cognitive behaviour therapy (CBT), are less well known and therefore less accessible to the community. Prayer and spiritual support are more acceptable and available

3. Promotion and endorsement of the materials by respected members of the community is essential
4. Current structures exist to promote and distribute educational support materials that are developed as a result of this project
5. Resources need to be provided to GPs
6. Internet resources can be considered including adaptation of the “Understanding Pain” video and other simple fact sheets specific to the topic areas
7. Simple messages are important due to literacy levels
8. Gender differences may mean reduced access for males

2.0 Vietnamese Community Key Themes

67 Vietnamese community members from two Local Health Districts (LHDs) attended focus groups. There was representation from middle aged and older people. The key themes commonly identified by the Vietnamese community across sites are highlighted below. Further detailed information including participant quotations is presented in Table 3.

2.1 Facilitating Experiences

The information below summarises the feedback from the participants in the focus groups about what they feel would enhance their ability to manage pain

- Holistic health care and self-management is culturally aligned
- Continuous group based learning in a familiar environment
- Understanding about pain and structured support from GP
- The presence of a lay leader to bring the community together to endorse new learnings

2.2 Inhibiting Experiences

The information below summarises the feedback from participants in the focus groups about what they feel limits their ability to manage pain

- GP knowledge and role in disseminating new information
- Suspicion of Western medicine (often viewed as poisons and toxins) results in combining eastern and western techniques for managing pain

Table 3: Vietnamese Community - What’s Working Well

The following table highlights the detailed experiences described as ‘working well’.

PICKER	FACILITATING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> • Multicultural Workers role including NSW Health Multicultural Communication Service • Open to new pain management concepts; • Pain toolkit concept and contents (self-management) are culturally acceptable e.g.: diet, exercise, holistic approach • Cultural motivators are food and exercise (Tai Chi; • Promotion should be via community centre, 	

	newspapers, flyers, facts sheet.	
Information & education	<ul style="list-style-type: none"> Information from lay community members "spiritual elders"; Vietnamese community centres, Vietnamese newspapers Use trusted sources/avenues to make change e.g.: the pharmacist is trusted Community and family engagement, support, validation of information – happy to learn from each other, recommendations of family/friends highly valued Locus of control is intrinsic (sits with the individual not others) therefore minimal extrinsic motivators are needed. It is noted that participants travelled from the eastern suburbs to the inner west to hear about pain management; Information needs to be staged over multiple topic specific sessions – change is viewed culturally as slow and continuous. 	"Sometimes the doctor tells me the exercises to do at home, but if it hurts too much I stop"
Physical Comfort	<ul style="list-style-type: none"> Seek active self-management as a solution; 	
Access to Care	<ul style="list-style-type: none"> Financial outlay is a significant consideration 	

Table 4: Vietnamese Community - What's Not Working Well

The following table highlights the detailed experiences described as 'not working well'.

PICKER	INHIBITING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> Mixed message from health care providers about how to approach treatment, care, and medication. 	
Information & education	<ul style="list-style-type: none"> Pivotal role of the GP is not working – Vietnamese GP is the voice of authority and needs to be targeted for additional education GPs may provide advice re exercise and diet but not in the context of pain and this means people are less likely to adhere to it Specialist roles in eastern versus western medicine are not the same e.g.: cupping = pain specialist Culturally appropriate translation of concepts such as "self-management" and "goals" will be important Temple offers education 	
Physical Comfort	<ul style="list-style-type: none"> Reliance on traditional remedies (e.g. cupping, herbs, acupuncture) on its own Mixing eastern and western medicine – cherry picking and combining medicines/treatments 	"When you have pain, you soak the part in hot water salt and vinegar"

	<p>from each approach to care</p> <ul style="list-style-type: none"> • Long term use of medicines • Cultural norms regarding what is normal for age (from GP) • Don't trust western medicine as it is "toxic" and "poison" e.g.: chemotherapy, pills 	
Access to Care	<ul style="list-style-type: none"> • Financial outlays for healthcare including transport • Access to specialist services including informed options for care • Adhoc uncoordinated care • Attending hospital based care 	

2.3 Summary findings from the Vietnamese speaking groups:

1. Current structures exist to promote materials
2. Group based education is familiar and currently accessed within existing structures
3. Access to care needs to impose limited financial outlay
4. Internet resources should be considered including adaptation of the "Understanding pain" video and other fact sheets
5. There is a need to provide resources and support to GPs
6. Promotion and endorsement by the community is essential – temple, community radio
7. Fact sheets will be helpful to support knowledge acquisition – the toolkit concept endorsed
8. Recognition of east/west approaches will be required
9. Health literacy levels support the development of more complex information

3.0 Chinese Community Key Themes

7 Chinese community members from one Local Health District (LHD) attended a focus group. The key themes commonly identified by the Chinese community are highlighted below. Further detailed information including participant quotations is included in Table 5.

3.1 Facilitating Experiences

The information below summarises the feedback from the participants in the focus groups about what they feel would enhance their ability to manage pain

- Group based community learning in language with peers
- Desire to keep active and healthy
- Ready understanding of the science of pain
- Active self-management concept is well understood

3.2 Inhibiting Experiences

The information below summarises the feedback from participants in the focus groups about what they feel limits their ability to manage pain

- GPs prescribing medications following very short consultations
- Limited access to appropriate information

Table 5: Chinese Community - What's Working Well

The following table highlights the detailed experiences described as 'working well'.

PICKER	FACILITATING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> Community messages distributed through Community SBS radio, 2AC private radio 2 large Chinese newspapers St George Migrant Centre Chinese Australian Service Society Family support is essential- often take family to appointments NSW Health Multicultural Communication site is helpful Use of computers is prevalent 	
Information & education	<ul style="list-style-type: none"> Fact sheets in Chinese would be helpful The u tube "Understanding pain" video would be helpful with voice over The family is an important source and endorser of information 	"Large font is best"
Physical Comfort	<p>Seek active self-management as a solution</p> <p>Exercise is an intrinsic part of health and well being</p>	"I have to walk to relieve my pain"
Access to Care	<p>Use physiotherapy and other exercise in the community</p> <p>Will seek out acupuncture massage and eastern medicine to support</p>	

Table 6: Chinese Community - What's Not Working Well

The following table highlights the detailed experiences described as 'not working well'.

PICKER	INHIBITING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> Need Chinese speaking staff and ready availability of interpreters 	"It is difficult to make appointments without interpreters"
Information & education	<ul style="list-style-type: none"> GP support for pain management is limited- short consults Family advice regarding toxic effects of Western medicine often conflicting Limited referral onto Specialist pain centres 	
Physical Comfort	<p>GPs are providing limited information about the context of diet and exercise</p>	
Access to Care	<p>Financial burden limits access to specialist services</p> <p>Cost of medications is prohibitive</p>	

3.3 Summary Findings from Chinese Speaking groups:

1. Current structures exist to promote materials
2. Group based education is familiar and currently accessed within existing structures
3. Access to care needs to impose limited financial outlay
4. Internet resources should be considered including adaptation of the “Understanding Pain” video and other fact sheets
5. There is a need to provide resources and support to GPs
6. Promotion and endorsement by the community is essential
7. Fact sheets will be helpful to support knowledge acquisition - toolkit concept endorsed
8. Recognition of east/west approaches will be required
9. Health literacy levels and willingness to learn support the development of more complex information
10. Physical exercise is valued

4.0 Greek Community Key Themes

26 Greek community members from two Local Health Districts (LHDs) attended focus groups. The key themes commonly identified by the Greek community across sites are highlighted below. Further detailed information including participant quotations is presented in Table 7.

4.1 Facilitating Experiences

The information below summarises the feedback from the participants in the focus groups about what they feel would enhance their ability to manage pain

- Group based learning in a familiar environment and learning from peers
- Understanding about pain and structured support from GP
- A lay leader to bring the community together to and endorse new learnings
- Exercising together- dance, aquatic exercise, walking group,

4.2 Inhibiting Experiences

The information below summarises the feedback from participants in the focus groups about what they feel limits their ability to manage pain

- Lack of GP knowledge and role in disseminating new information
- Having inadequate **information and understanding** about pain management
- Unfamiliar care environments e.g. outpatient based hospital care
- Lack of transparency in accessing specialist care
- Literacy levels may limit access to care

Table 7: Greek Community - What’s Working Well

The following table highlights the detailed experiences described as ‘working well’.

PICKER	FACILITATING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
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Communication	<ul style="list-style-type: none"> • Multicultural Workers role including NSW Health Multicultural Communication Service • Language and gender specific community groups noting the “cultural motivators” are friendship, food, church and similar cultural and family roles; activities • Peer supported attendance at sessions is important • Require simple messaging as literacy levels may be low • Ethnic radio and newspapers; • Community gatherings such as festivals and church groups; • Greek Welfare Centre • Investing the appropriate “time” in pain education • Prepared to think about active self - management concepts 	
Information & education	<ul style="list-style-type: none"> • Distraction and social connectivity are important facilitators 	“We need to make pain our friend” The more you think about pain, the worse it gets”
Physical Comfort	<ul style="list-style-type: none"> • Greek Meditation tapes – Mindfulness • Peer support is important • Social distraction is important 	“If you go out , everything gets better”
Access to Care	<ul style="list-style-type: none"> • Financial outlays for healthcare including transport; • Access to specialist services including informed options for care; • Adhoc uncoordinated care; • Attending hospital based care. 	

Table 8: Greek Community - What’s Not Working Well

The following table highlights the detailed experiences described as ‘not working well’.

PICKER	INHIBITING EXPERIENCE/TOOL/SERVICE	PARTICIPANT QUOTES
Communication	<ul style="list-style-type: none"> • Reliance on Doctor for information • Negative cycle of experience further inhibiting activity 	“The doctor will fix my pain”
Information & education	<ul style="list-style-type: none"> • Using passive strategies to manage pain 	
Physical Comfort	<ul style="list-style-type: none"> • Social isolation • Use of rest and local remedies to heal the problem • Combining medicine obtained from overseas pharmacies 	
Access to Care	<ul style="list-style-type: none"> • Financial outlays for healthcare including transport; • Access to specialist services including informed options for care; 	

	<ul style="list-style-type: none"> • Adhoc uncoordinated care; • Attending hospital based care. 	
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4.3 Summary Findings from Greek speaking groups:

1. Current structures exist to promote materials
2. Transport requirements, financial distress and literacy levels point to the need for free group based education in the community preferably with an emphasis on linking active self-management to improved quality of life
3. Understanding and incorporating the social benefits of effective pain management into pain education is important - food and family, and the need to address social isolation
4. Psychological strategies need to include prayer, and distraction, and develop understanding of the importance of social connectivity
5. There is very limited access to internet
6. Resources such as “Understanding pain” video and fact sheets would need to be promoted via community.
7. Mindfulness meditation tapes would be helpful
8. There is a need to provide resources and support to GPs
9. Promotion and endorsement by the community is essential
10. Simple messaging will be required
11. Recognised gender differences may mean reduced access for males

5.0 Key Similarities across the four multicultural groups

The common themes identified by all cultural groups achieved through asking the question “*what is the one thing in your opinion that would make the experience better?*” were as follows:

- Supported care (multidisciplinary coaching) in the local environment;
- Having an approach to pain management endorsed by the community;
- Supported access to specialist care

More specifically participants mentioned these items across all four cultural groups:

- There is a tendency to attend GPs of the specific cultural background and not challenge their views on management
- Simple messages regarding pain management strategies are necessary
- The u tube video “Understanding pain” received positive endorsement as a way of explaining pain, but needs slowing down
- A community based pain programme delivered by local health workers would be well regarded.

6.0 Key Differences between the four multicultural Communities

- The motivation to apply and maintain pain management strategies varies between cultural groups and is driven by different factors
- The desire to be healthy and well (and the behaviours that underpin that belief) vary
- The stigma of pain is highly associated with cultural expectations

7.0 Conclusion

The themes highlighted above illustrate key aspects of providing healthcare to people with chronic pain in Arabic speaking, Vietnamese, Chinese (Mandarin and Cantonese speaking) and Greek communities. The experiences of participants demonstrate the current challenges and opportunities to improve health care for this population. Capturing and interpreting these experiences will support service provision and improvement in the development of person-centred care approaches for people with chronic pain in NSW. Modifications to current practice should be undertaken to support the specific needs of these groups of people.

8.0 Recommended actions:

1. Disseminate report findings from consumer consultation to key stakeholders including LHD staff and multicultural workers and managers, ACI staff.
2. Explore opportunities to develop and deliver
 - community culturally appropriate pain management programmes in partnership with the multicultural health services and LHD pain clinics
 - Fact sheets in key areas
3. Identify GPs and other clinicians working with these communities to conduct needs analysis via focus group, webinar or individual consultation
4. Develop suite of questions for clinicians' consultation
5. Reduce speed of the "Understanding Pain" video and arrange translation into the 4 languages- host on pain website
6. Commence resource development/modification following consumer consultation
7. Establish communication plan to implement, promote and distribute the materials
8. Evaluate

Jenni .Johnson, Rosemary Dillon

Appendix 1

Objectives of the ACI Pain Management Model of Care for CALD Communities

1. Increased capacity to treat people with chronic pain in NSW in primary care or tertiary services

2. Increased capacity to understand and apply self-management approaches
3. Enable improvements in service delivery – where, how
4. Improve quality of life and productivity for people with chronic pain
5. Improve the triage and referral of patients with chronic pain

Appendix 2

Picker's 8 Dimensions of Care

1. Access to care
2. Respect for patient values, preferences and expressed need
3. Coordination and integration of care
4. Information, communication and education
5. Physical Comfort
6. Emotional support and alleviation of fear and anxiety
7. Involvement of family and friends
8. Transition and continuity