



A Focus Group Study of Consumer Priorities for Pain Management Resources in NSW Final Report

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Executive Summary

In 2012, the NSW Ministry of Health allocated funds to the Agency of Clinical Innovation (ACI) to develop educational resources specifically for use in the primary care sector. Three priority projects were identified and endorsed through the ACI Pain Network: the development of a GP toolkit, the development of a series of online paediatric pain modules for clinicians and consumers, and the development of consumer pain resources. Chronic Pain Australia was commissioned to conduct a needs analysis as the first phase of the consumer pain resources project. While there are numerous consumer pain-related resources available, there has been little research on what the key areas of need as identified by the consumer are. This report outlines the process and results of the needs analysis, and makes recommendations for priority content areas and presentation formats for the proposed consumer materials.

Focus groups were used to collect data. Five focus groups were held in January 2013 in urban, regional and rural locations in NSW. This was to ensure the perspectives of people living in different geographic locales were taken into consideration. Fifty-three people participated, with groups comprising between three and sixteen people. Content analysis of the focus groups was conducted. The results of the analysis are presented in the report in four sections, including where people have obtained pain-related information, identified information needs, formats in which people would like to be able to obtain pain-related information, and how and where they would like to be able to access this information.

It was clear from the focus group discussions that the information needs of people with chronic pain vary depending on a number of individual and contextual factors, including the duration and type of pain. In addition, there is variation in presentation and access preferences between individual consumers. It is therefore not realistic to aim for a pain educational resource that will meet the needs of all consumers. The recommendations outlined in this report are considered a starting point for the development of comprehensive consumer pain management resources in NSW. In addition, it is important to continue the involvement of people living with pain in the design and evaluation of future resources. Of further note is the significant proportion of focus group participants, mostly in the regional and rural groups, who did not have access to and/or use the internet to obtain pain-related information. While the internet is increasingly used to provide and obtain health-related information, it is clear from the results of this study that limiting consumer resources to an internet-based format would result in these resources remaining inaccessible to a large proportion of the population living with pain.

With the above points in mind, the following recommendations are made:

Content areas

1. Information that explains the pain experience and helps people understand why they are experiencing ongoing pain and validates the reality of their pain experience. This explanation should not be confined to the neuroplasticity model.
2. Treatment and management options, including risks, side-effects and, where available, the evidence base.
3. Comprehensive pain coping skills, aligned with the biopsychosocial or “whole person” model of pain management.
4. Experiences and perspectives of other people living with chronic pain.
5. National and local resource directories.
6. Information for partners and children to help them understand chronic pain.
7. Information on communication and managing relationships, including health professional, personal and social relationships.

Presentation formats

- A comprehensive website that presents the seven content areas using appropriate text and audiovisual techniques. The site should have the capacity for user tailoring of content, depending on the pain condition. Information should also be layered, with the capacity for users to obtain progressively detailed information on topics, depending on their level of interest and understanding. Wherever possible, website content should be downloadable and/or printable.
- In recognition of the significant proportion of people with pain who do not use or have access to the internet, a ‘hard copy’ resource kit, including printed and DVD materials, that reflects the content of the website should be developed and made available via health professionals and other community access points such as libraries.
- Printed fact sheets on the topics contained within the website, particularly with regard to the understanding pain, treatment and management options, pain coping skills and information for families content areas, be developed and made available in appropriate access points within the community.

1. Background and introduction

The impact of chronic pain on the Australian community is well documented.¹⁻³ Chronic pain is a complex condition, usually requiring a multimodal and multidisciplinary approach to treatment and management. In recent years there has been an increasing focus on consumer participation and collaboration in the planning, design, delivery and evaluation of health services, and in Australia this has recently become more formalised in the National Safety and Quality Health Service Standard 2: Partnering with Consumers.⁴ The importance of involving consumers in health resource and service development has also been recognised in the chronic pain context. Goal 2 of the Australian National Pain Strategy (NPS)³ highlights the importance of collaborating with people living with chronic pain to achieve the goal of knowledgeable, empowered and supported consumers. One aspect of this is to improve the availability of education and information materials for consumers and their families. Emerging evidence that involvement of consumers in the development of health information resources improves the relevance and accessibility of material⁵ suggests that consultation with people living with chronic pain is an important first step in resource development.

The NSW Pain Management Plan 2012-2016⁶ proposed model of care includes at its foundation a population health approach, incorporating information, education, self help and patient-led support groups. In 2012, funds were allocated to develop educational resources specifically for use in the primary care sector. Three priority areas were identified and endorsed through the NSW Agency for Clinical Innovation (ACI) Pain Network: the development of a GP toolkit, the development of a series of online paediatric pain modules for clinicians and consumers, and the development of consumer pain resources.

This report deals specifically with the needs analysis conducted to inform the development of consumer pain resources. This process was initiated in recognition that involving consumers in developing materials would encourage a patient-centred approach and help ensure end users' needs are met.⁷ Data was collected via five focus groups held over a one-week period in January 2013. The remaining sections of this report outline the study results, briefly discusses these findings, and concludes with recommendations for content areas and presentation formats for the proposed consumer materials.

2. Aims and Objectives

The aim of this project was to explore the information needs of people with chronic pain in NSW and preferred methods of presenting and accessing this information, to inform the development of consumer pain management resources. To meet this aim, the objectives of the project were to:

- Conduct five consumer focus groups across metropolitan, regional and rural NSW.
- Perform content analysis of collected data.
- Provide a report of collated content analysis and detailing suitable content and format for priority consumer resources.

3. Method

A focus group questioning route (see Appendix A) was developed, guided by the process outlined by Krueger and Casey.⁸ The Project Consultant developed a draft question route which was circulated to the ACI Pain Management Network Manager, ACI Pain Project Officer, a Chronic Pain Australia representative and the Pain Project Educational Consultant for comment. The question route was refined following feedback on the draft.

Five focus groups were held over one week in five different locations in NSW – Lismore, Armidale, Newcastle, Sydney and Dubbo. These locations were selected to ensure the perspectives of people living in urban, regional and rural locations were represented. People living with pain with a variety of levels of experience and efficacy in sourcing information to help them manage their pain were specifically targeted. The focus groups were advertised via relevant organisations and local print and radio media. A total of 53 people participated, with each group comprising between three and sixteen people (see Table 1). Demographic information and written informed consent was provided by all participants before focus groups began. All focus groups were digitally recorded, with participants' permission, and transcribed verbatim into computer-readable files. Focus group transcript analysis was guided by qualitative content analysis procedures⁹, with QSR NVivo 9 software used for data management.

The results of the analysis are presented in four sections:

- Sources of chronic pain information
- Identified information needs
- Information presentation format preferences
- Information access point preferences

Representative quotes from de-identified focus group participants are used to illustrate the findings throughout.

4. Results

4.1 Sources of chronic pain information

Participants were asked where they had previously obtained information about chronic pain. A wide variety of information sources were discussed. Health care practitioners that were specifically mentioned included GPs, physiotherapists, pharmacists, a pain educator, a pain specialist, an exercise physiologist, a rheumatologist and a psychologist. Pain clinics were identified by some as a source of information, but these participants thought the information obtained while doing these programs should have been provided much earlier in their pain journey. Some participants also identified a lack of follow-up resources and support following pain clinic programs, as explained by a female participant:

I've been to a chronic pain specialist and I got to the end of his help, and that was it. He sent me to a pain management inpatient thing in hospital, and I did that for two weeks, which was very – I think it was good. I think a lot of the things I'd already come across myself and I understood that they were things that would benefit chronic pain. But after that, yeah, he sort of, suggested that that would be...he just finished up with that and said, "That's it". As in, there was nowhere else to go.

Other people living with pain were identified as a valuable source of information by many participants. One participant described this as “not just information from a formal source, but it's what we all find helpful and how we personally cope”. Information from others living with pain was viewed as a trustworthy and experiential source of information regarding different treatment and coping strategies, as well as having the added benefit of providing support, empathy and validation of the pain experience. One female participant said the “biggest thing” she had got out of a residential pain management program was the contacts she made with other patients, “I'm still in contact with those people. I don't remember a lot of what we did in the course, but I'm still in contact with the people. And that's the most important thing I got out of that course, was the contact and the support and the ongoing connection with those people”.

The internet was identified as a source of information by some participants in all five focus groups. Caution is required in interpreting this result, however, as over 45% (n = 24) of

participants had not used the internet at all to obtain pain-related information. Reasons cited for this included lack of access, not being able to afford an internet connection, and lack of understanding of how to use the internet. Those who had used the internet also identified difficulties in using this medium, including navigation issues in terms of knowing what information to look for, the volume and trustworthiness of the information available, not being able to find information specific to their condition, lack of Australian content, and difficulties in sitting at a computer for any length of time due to pain-related issues. In addition, many participants said they preferred to be given information in a one-on-one situation by a health care professional or peers, with the internet seen as a good follow-up, rather than a primary source of information, for example, “I think it’s one-on-one, getting that information, is much better because then you learn the strategies and you get the full attention of the person. Afterwards accessing the internet was good and reading information but that first understanding from someone was very helpful.”

Printed materials, particularly books, were identified as an information source by participants in all focus groups. However, some found books to be difficult to understand and/or concentrate on when in pain. For example, in one focus group a few participants commented that they had found a particular book on pain management helpful. Another participant, however, had difficulties with it, “I’ve tried to read it, I can’t read it. I think it’s great for clinicians, it’s too heavy for people, I can’t concentrate all the way through it. There was so much data in there and it’s really hard to get through the whole book”. Other sources of information included public seminars, newspaper magazine articles and television programs.

Overall, participants nominated a disparate range of information sources on chronic pain. There was general dissatisfaction with the amount and quality of information available, as well as the timing of information provision. Many participants spoke of being unable to get any information in the early stages of their pain journey, and having to individually gather and synthesise information collected from different sources over time.

4.2 Identified information needs

Participants were asked to identify the sort of information they had found useful in their journey with pain, and/or information they would have liked to have access to at this point of time or earlier in their pain experience. It was apparent from discussions during the focus groups that participants’ information needs varied, depending on a number of variables, including the duration of their pain; the presence or absence of a personally relevant diagnosis to explain pain; and whether pain was due to an identified chronic disease, for example, rheumatoid

arthritis, or was of an unspecified nature. While it is not possible to identify a 'one size fits all' approach to information provision, the following categories of information were identified by analysis of the focus group transcripts.

- **Understanding pain**

An interest in understanding more about why they had pain was expressed by participants in all focus groups. Many participants, particularly those who had attended a pain clinic, talked of the benefit of learning about concepts they variously described as “neuroplasticity”, “rewiring the brain” and “sensitization of the central nervous system”, in helping them understand why they had ongoing pain. This was particularly the case when a reason for pain had not been identified through available diagnostic tests. For example, one woman said, “I didn’t even know I had chronic pain until I went to the pain clinic. That’s no lie. I didn’t even know anything about it...So now I know I’ve got chronic pain, I am not a physio junkie anymore, because that’s what I was”. In addition to pain clinics, a few participants said they had learned about these concepts by reading books.

Overall, participants believed it was helpful to have pain explained in this way. Some talked of not being able to move forward in searching for ways to manage their pain until they had obtained this understanding. However, other participants indicated that, while they had heard of these concepts, they did not understand them. This suggests more work is required to identify effective ways to communicate this message to people with pain. In addition, comments from some participants who had chronic diseases, such as Rheumatoid Arthritis, and/or co-morbidities, highlight a need for caution in limiting the explanation of pain to the neuroplasticity model.

- **Pain Treatment and Management Strategies**

Participants in all focus groups expressed interest in receiving information about medications, interventional treatments such as surgery, physiotherapy and chiropractic, and non-pharmacological pain management strategies. Many participants said that medical professionals, in particular General Practitioners (GPs), limited their advice on pain management to the prescription of medications, as reflected in this comment from a male participant:

Like, my GP, don't get me wrong, was very good at trying to manage my pain but the way he was managing it was, obviously, with drugs. So you use all sorts of different drugs and

whatever. Finally, I fell over and walked into his surgery one day and I was just bloody falling apart. So finally I get to go in and see him, he says, "Okay, you've got some depression here," so he sends me to a psychiatrist. The psychiatrist, luckily enough, knows about a pain management clinic – he was the one that organised me to go to the pain management clinic. And what I've really found all the way along is that the drugs, you can take every drug in the world but it doesn't stop chronic pain.

A desire for improved information about medications was a frequently identified gap in current treatment information provision. Participants wanted more information about the medications they were prescribed, particularly in terms of dosage, side effects, possible drug interactions, and the impact on their body and general health of using medications long-term, for example, "It's very hard to know whether what's prescribed is going to be good for you in the end. I'm on pain patches and they keep increasing them, so I'm a bit concerned about becoming addicted or not being able to get off them. And they're not working very well anyway". Examples of unexpected side effects included being hospitalised for hemorrhoid removal due to medication-induced constipation and loss of teeth following long-term opioid use. Most participants did not think they were being given sufficient information about medications by their medical practitioners, although there were a few exceptions. Some participants identified pharmacists as a good source of medication information, for example, "I was on two tablets that the doctor had put me on and it was a young girl in the chemist who said, 'Do you know this one wipes this out?' And I thought, well why didn't the doctor tell me that?" Many participants considered it important to have prescriptions filled at only one pharmacy so the pharmacist would become familiar with an individual's condition and medications. Participants' experiences of pharmacists varied however, highlighting the importance of individual relationships in supportive pain management.

Consumer Medication Information sheets dispensed by pharmacists were considered useful information sources, although some found these too long, the language overly complex and the print too small. One suggestion was to put the most important information, such as dosage, side effects and contraindications, in dot points at the beginning of the leaflet, followed by the more detailed information.

Participants were also interested in more information about non-pharmacological pain treatments or management strategies. Overall, participants seem to have experienced trouble obtaining this sort of information. Participants spoke of coming to the end of available treatment options and being told by health care professionals that they would just have to "learn to live

with it”, but many struggled with how to go about this without more direction and support. As one female participant said: “It’s one thing to manage or to hand out tablets or to fix the pain, but it’s ongoing, so therefore it’s really a lifestyle change. And people have to learn to live with this chronic problem that they have. And there’s very little support in the community for that”.

Although participants didn’t always articulate what a more comprehensive approach might encompass, comments such as “how to manage my pain and how to manage my life”, “more information on how to be able to deal with pain”, “what do you do daily to cope, to make a life for yourself” and “probably more the psychological side of things” indicated that participants were looking for the type of information that is often discussed under the biopsychosocial approach to pain management.¹ Specific examples of what participants had found helpful or would like more information about included: exercises, pacing, acceptance, sleep difficulties, pain management counselling, TENS machines, diet, acupuncture, chiropractic, surgical options, distraction, Cognitive Behaviour Therapy, relaxation, massage and meditation. Most participants who had attended multidisciplinary pain clinics indicated that the comprehensive approach and strategies offered by these clinics should be more available within the community and provided at an earlier stage of an individual’s pain journey. One participant summarised this when he said: “I’d just like to see some of those basic pain management skills, simplified and put out there, things like pacing and gentle exercise, meditation, things like that. Simple, easy to consume messages”.

▪ **How others cope and live with pain**

Many participants expressed an interest in hearing other people’s experiences of living with pain, and the treatments and strategies others had found useful. This experiential knowledge obtained from peers was considered by some to be as important as information obtained from more “formal” sources. Participants were not suggesting an uncritical acceptance of advice provided by other people living with pain. Rather, this “lived experience” information would be evaluated depending on individual context and previous experience. This was expressed by one woman who said, “I also probably found it most useful talking to other people with pain and how they’re coping and what their strategies are. And then picking and choosing”. As noted above, an identified additional benefit of learning from others’ experiences was support and validation of the chronic pain experience. Some participants described living with chronic pain in terms such as “isolating” and “frightening”, and access to others’ stories was considered valuable in terms of realising that they were not alone in their experience.

▪ **Communicating with Health Care Providers**

One of the most frequently discussed issues in the focus groups was difficulty in communicating with health care professionals, particularly doctors. Comments from participants suggested these issues included doctors having limited time in consultations, being given little or no information and/or conflicting information from different health professionals, and not being listened to or not being believed by doctors. One woman expressed this when she said:

I've just really been appalled by the lack of information and the lack of assistance in even finding information, getting any kind of diagnosis, doctors scratching their heads, et cetera. .You know, people think you're making it up...So it's really that information, initially, from the medical people that you're dealing with and that's a real stonewall.

Some participants expressed a desire to create partnerships with health professionals, rather than a binary expert/patient relationship. While addressing systemic issues such as these is beyond the scope of this project, it does point to the potential benefit of providing information about strategies for communicating with doctors, the types of questions to ask, and what one participant described as “assertiveness training” to assist people to advocate for themselves in the health care encounter.

▪ **Information for family and friends**

Many participants spoke of the impact of pain on their families, particularly partners and young children. For some participants, lack of understanding from family members compounded the distress of living with pain, for example, “I’d be walking up into the supermarket on a slope and he’d think, well, why isn’t she keeping up with me? What’s she doing? He thought I was lazy because I wanted him to park as close to the place as possible”.

Others expressed concern about the distress their pain was causing their partner, and/or the impact it might be having on their children, as expressed by one man when talking about his young son, “He comes up to me every single morning and says, ‘Dad, do you want a hand up?’ I don’t know what psychological effect it’s doing to him, but...a four year old that walks up to his Dad and says, ‘Dad, are you ok this morning?’”. Participants were therefore interested in not only information about pain for themselves, but also for their family and other significant people in their lives, to help them understand why their family member may be in pain, what they may be experiencing, and perhaps to help them cope with the distress they may also be experiencing from watching a loved one living with pain. Another potential area of need may be

information about how to manage family member relationships from the point of view of the person in pain.

- **What's available, where to go and who to see**

Common to all focus groups was an interest in having access to information about who and where they can go to obtain help in managing their pain, particularly resources available in the local area. Participants were interested in different kinds of resources, including different health care disciplines that provide pain management or treatment services, condition-specific services, local support groups, and individual local health care providers, such as doctors, psychologists or psychiatrists, who had knowledge of and an interest in treating people with chronic pain. Typical was this comment from a male participant:

I think from an information point of view, I would love to know, in certain areas, which doctors are current on chronic pain, which GPs actually go out of their way to stay involved in the chronic pain community...I mean, I've kind of got one now. He's not really [a doctor who specialises in] chronic pain but, you know, I know they're around. But where are they? That would be a great point to start with.

Participants were also interested in information about government programs that may be of assistance, for example, the Commonwealth Enhanced Primary Care initiative.

- **Hope**

Participants were interested in information that provided a hopeful message. Many spoke of being told by health professionals that they would have to “learn to live with it”, and this was considered a very unhelpful message in the absence of any follow up information or support on how to do this. The meaning of what would constitute hopeful information requires further exploration. However, comments from focus group participants suggest that elements would include the “understanding pain” type of information discussed above, positive stories of others’ experiences, and information about current research and other activities focused on helping people manage and also reduce pain. For example, one man spoke of his experience with a pain educator, emphasising the need for a positive approach to information provision, “And positive, you know, there is hope, because I’d lost hope. I’d been a write off for quite a few years, and she [a pain educator] gave me a lot of hope and treatments and I just turned the corner”. Another participant spoke of an interest in knowing about research and other efforts that were being done in the pain area,

Everybody agreed when we said hope was such a huge part of their own personal journey. And one of the things that I'll probably look for more than this basic information is looking for information that's advanced, that's into the future, to foster that hope, that there is actually things being done and that there are studies being done – you know what I mean?

4.3 Information presentation preferences

Participants were asked what formats should be used to present information about pain. The difficulty of developing a consumer information resource acceptable and useful to all consumers was most apparent during discussion of this topic. Suggested formats were varied and included a website; printed material of different kinds; video presentations, available on a website, in stand-alone DVD format or via web-based platforms such as YouTube; television programs, public seminars; group programs and personal communication from health professionals and others living with pain. These formats are discussed in more detail below, but are not in rank order.

- **One-to-one communication**

As discussed previously, many participants expressed a desire to obtain information about pain within a process of one-to-one communication with either knowledgeable and empathic health professionals or others living with pain. For some, having things explained on a one-to-one basis helped them understand, for example, “I like to have things explained to me because – so I can take it in a bit, but if I'm reading something on a screen, five seconds later, I've forgotten what I was reading”. Other methods of obtaining information, such as via a website or printed material, were seen as an adjunct to this interpersonal communication and associated supportive contact.

- **Text-based printed information**

Overall, participants were in favour of printed information that could be obtained from places such as GPs, pharmacies and other accessible community based venues. Most participants thought text-based information sheets, booklets or newsletters appropriate. Cited advantages of printed material included the capacity to read and understand information at their own pace and being able to refer back to the material over time, for example, during a pain flare up. In addition, people with chronic pain may often have difficulties with concentration, therefore the capacity to refer back to printed material was considered advantageous. This was expressed by

one participant when she said, “What I find though, when someone’s in pain, they don’t take it in. So if you can talk to them – or I like to talk to people about it, even if it’s sharing my story, but then have something to take it away and be able to refer back to it a bit later so I can read it again”.

People also raised health literacy issues, including use of simple language, attention to how the information is set out on the page, for example, use of dot points, the potential effect of font size and colour, and limiting the use of non-essential information such as figures and statistics.

During the focus groups, participants were shown two predominantly text-based information resources that, although featured on websites, were also either printable and/or available in hard copy form. Participants were asked to comment on the concept of predominantly text based written information. The first of example was the ‘Managing My Pain’ fact sheet available on the Chronic Pain Australia website (www.chronicpinaustralia.org.au). In terms of presentation, positive comments about this resource included the ease of printing and the use of links to other relevant sources of information. While most participants thought the information in the fact sheet was comprehensive and useful, particularly for those ‘new’ to chronic pain, suggested improvements included use of a larger font, use of simpler language, and attention to formatting issues such as breaking large chunks of text into smaller sections of information.

The second predominately text-based information resource was the Australian version of The Pain Toolkit (www.paintoolkit.org). This resource incorporates coloured cartoon-like illustrations with 12 pain management strategies. Again, participants were asked to comment on the concept of this form of pain information presentation. Participants’ views on the use of cartoon illustrations were mixed, with some commenting positively on these, such as “it’s cute”, while others found them off putting and would have preferred straight text, for example, “The cartoonish quality of it, mmm, you know, sort of says to me, I don’t know that I want to read this at all”. While some participants found the presentation and content simple, “like teaching you to suck eggs”, the predominant response to this resource was that it provided useful information for those in the early stages of living with chronic pain, and was presented in a user-friendly, clear and simple format. Some participants also considered this a good resource to give to family members to help them understand the chronic pain experience, for example, “That would be fantastic. Not only for the people suffering chronic pain, it’s also the families. To be able to give this to my partner – this is wonderful, because my partner finds it just as hard as I do at times”.

- **Website**

There was support for a website from participants who had internet access and were familiar with obtaining information in this way. Some participants said they had obtained more useful information from the internet than from health professionals, and/or found the internet a very useful source of health information, as explained by one male participant:

The Internet is fantastic, as far as I'm concerned. I mean, there are people that say that there's a lot of junk on there, and sure there's a lot of junk on there but you've got to choose what you want to look at. It's a little bit like going into a library, you're not going to look at every book or you're not going to really go to the R rated section if you don't want to, you go to the sections you're after.

Other participants who had used the internet voiced some concerns from their experience, such as finding conflicting or confusing information, and being able to judge which information was trustworthy. There was some support for a website that provided “vetted”, credible and as far as possible, evidence-based information. In addition, it was considered important to broadly promote such a website so that both health professionals and consumers became aware of it. For example, one participant spoke of the benefit of such a website being used as a referral point by health professionals:

If every GP, even if they've not got any particular interest in chronic pain, realise that at the point that your pain becomes chronic, that they could give you a reference to a reputable website, you know, preferably a government one or a university one or a medical science research type one and at least tell you that that exists, that you might go there and profitably look at it, you know?

However, as 45% of the sample had never used the internet to obtain pain-related information, it is clear that limiting the development of consumer pain management resources to an internet-based format could result in these resources remaining inaccessible to a large proportion of the population living with pain. Participants also considered it important that any written information on a website should be in a format that is easily printable, for the reasons outlined in the discussion concerning printed material above.

During the focus groups, participants were shown an example of a US-based website (PainACTION – www.painaction.com) and asked to comment on the concept of this kind of website. PainACTION is a comprehensive website presenting information on pain sub-groups in varied media. There is capacity for user interaction and tailoring of information. Focus group participant responses to this website concept were mixed. Some participants liked the different pain subgroups, the variety of information available, and the capacity of the website to generate electronic monthly newsletters to registered users, tailored to their selected interest areas. Negative comments included a dislike of being required to register for a website, a need for Australian content, issues of credibility due to what was seen as the commercialised presentation of the website, dislike of “pop up” surveys, and the time and effort required to sift through the large amount of information available to identify personally relevant content.

▪ Videos

Views on the use of video formats to convey pain-related information were again mixed. A few participants found watching videos more engaging than reading text, and could reduce feelings of isolation. Other participants commented that they did not click on videos to watch them when these were included on a website as they were not interested in obtaining information using this medium. During the focus groups, participants were shown two different video presentation methods. The first was a relaxation video from a Scottish website that featured an individual talking about relaxation as a pain management strategy (www.painassociation.com). Participants were asked to comment on the format of the presentation, rather than the content. Participants’ comments suggested that the quality of the video production, including physical and verbal attributes of the presenter and the background, was an important consideration with regards to whether participants were prepared to watch the presentation and consider the information provided.

The second form of video presentation was a short animation titled ‘Understanding Pain: What to do about it in less than five minutes’

(www.youtube.com/watch?v=4b8oB757DKc). Overall, participant comments regarding this format were very positive. Comments included that the format was engaging, simple, effective and helped make the content easy to understand. Exceptions included one participant who had epilepsy and did not feel comfortable watching the fast moving animated format. Other exceptions centred more on the content of the video, in terms of the content being simplistic, suggesting that all chronic pain could be resolved by following the five-step approach outlined in the video. A few other participants felt that while the information contained in the animation may

be applicable to some forms of chronic pain, it was not necessarily appropriate for all chronic pain states, for example, in the presence of a progressive chronic disease, and that this should be stated in the video.

- **DVD and CD formats**

There was some discussion in the focus groups about the benefits of providing pain-related information in DVD or CD format. For some participants this was considered preferable to web-based information as it was accessible to those who did not use the internet and could also be used in contexts separate to a computer.

4.4 Information access point preferences

Participants were asked where they would like to be able to obtain pain-related information, in terms of appropriate access points. Participant responses can be grouped into four broad categories, discussed below.

- **Individual access points**

Participants expressed interest in obtaining information from their GPs, other health professionals and others living with chronic pain. In all focus groups there was considerable discussion concerning dissatisfaction and disappointment about the apparent lack of knowledge and understanding about chronic pain exhibited by health professionals, with particular emphasis given to experiences with GPs. In addition, many participants thought the generally short GP consultation time inhibited any meaningful discussion concerning their chronic pain situation. While the training and practice of health care professionals is beyond the scope of this study, the frequency with which this issue was raised and the strength of feeling expressed by participants across all focus groups needs to be noted.

Participants described their GP in terms such as being “the first port of call” and the health professional they relied on for information, advice and referral to other health services. As such, there was a desire that GPs should not only be well informed about chronic pain issues but should also have access to appropriate information resources that they could give to patients with ongoing pain. Suggested resources included fact sheets, referral to an appropriate website, and some form of chronic pain information kit. Positive responses to the Australian version of The Pain Toolkit in some of the focus groups suggest that a resource of this kind may be useful, for example, “[The GP] gives it to you – you’ve got something to walk home with, 20 years ago I had nothing to go home with”. Some participants suggested that it would be helpful for a GP to

work through something like The Pain Toolkit with patients with chronic pain within the consultation process, as expressed by this female participant, “I thought this would be a great tool to have with your GP when all the first stuff starts happening and you and your GP work with this”.

Participants suggested other health professionals as appropriate access points for pain-related information, including psychologists, nurses and pharmacists. Pharmacists were considered by some to be in a good position to distribute pain information as they were in contact with people at the point of distribution of pain medications. Some participants also expressed a desire for some kind of knowledgeable health care worker located within the community who could distribute information and guidance to people living with ongoing pain.

Many participants identified others living with chronic pain as a good information access point, particularly in terms of lived experience with different treatments and management strategies. Participants were looking for not only what one person described as “formal information” but also experiential information about how to live and cope with pain on a daily basis. Talking with others who understood the experience of living with pain was also considered valuable from a support and validation perspective.

▪ **Physical location access points**

Many participants were interested in being able to access pain-related information within their local community, what one person described as “local points of contact”. Suggested examples included doctor’s surgeries, pharmacies, libraries, community health centres, neighbourhood centres, public information seminars, support groups, other local service providers and in the waiting areas of GPs, imaging clinics and hospitals. There were mixed views on the format of the information that should be made available in these venues. For example, many participants suggested that something like the ‘Understanding Pain: What to do about it in less than five minutes’ video, discussed above, could be shown on television screens in pharmacies and health-related waiting rooms. Other participants suggested information sheets and pamphlets could be publicly displayed in various venues, although there was also discussion about the “hit and miss” potential of this strategy, in terms of whether organisations would in fact display them and/or people would pick them up to read. Libraries were considered by some to be a good repository for more comprehensive information resources and for something like The Pain Toolkit, which people could borrow to take home and consider at their leisure.

While participants considered the distribution of information in these local points of contact to be important, they also considered an important adjunct to this was the capacity to interact with knowledgeable people, whether health professionals or others living with pain, to provide support and guidance in the chronic pain journey. This was considered particularly important in the early stages of the chronic pain experience.

- **Information and Communications Technology access points**

In this report, Information and Communications Technology access points encompass internet-based resources such as websites and social media, and Smartphone applications. Issues concerning the use of the internet as a source of information have been discussed earlier in this report. These included limited access and use of the internet for health-related information by a significant proportion of focus group participants, navigation and trustworthiness issues, lack of Australian content and difficulties in using computers due to pain-related issues. As discussed previously, views concerning using a website to disseminate pain-related information were mixed. Some participants already using and familiar with internet technology were supportive of the idea, while others, particularly those with little or no experience of the internet, were not. Issues relating to the hosting of a website may also be significant. This was described by one participant as a website having a “credible frontage”. Again, views concerning this were mixed. For example, some participants favoured a government or university hosted site, with issues such as credibility and trustworthiness being cited. Other participants were not comfortable with the concept of a government-sponsored website, citing, for example, concerns due to previous experiences with government services and the quality and content of previously accessed government sites. A preference for a website to be hosted by a non-government organisation that specialised in pain issues was suggested by some.

There was limited discussion within the focus groups about the use of social media such as Facebook and Twitter. A few participants commented on advantages of using Facebook in terms of capacity for user interactivity, daily updating of new and relevant information, and linkage to a website. A few participants spoke of the value of online forums where they could communicate with others living with chronic pain. The use of Smartphone applications was mentioned by only one participant over the five focus groups.

- **‘Traditional’ media access points**

Traditional media access points included newspapers, radio and television. Local newspapers and radio were considered useful more in terms of advertising any local pain-related events, for

example, the focus groups or future information seminars, than providing pain-specific information. National newspapers, particularly 'lifestyle' type magazine supplements, were considered by a few participants to be a useful way to disseminate pain-related information to the broader public. A few participants thought television could also be used to promote broader public understanding of chronic pain, for example, by broadcasting the 'Understanding Pain: What to do about it in less than five minutes' video as an advertisement or public service announcement. Pain-related television programs were also suggested by a few participants.

5. Conclusion

This report has presented the outcomes of a focus group study on the information needs and information presentation and access preferences of a sample of people living with chronic pain in NSW. The results have been presented in four key areas: sources of chronic pain information, identified information needs, information format preferences and information access point preferences.

Participants nominated a disparate range of information sources on chronic pain. This perhaps reflects the lack of a functional care pathway, as identified in the 2012 Report of the NSW Pain Management Taskforce⁷, which has also been noted in other studies concerning chronic pain management.¹⁰⁻¹² While consideration of care pathways is beyond the scope of this report, provision of information that explains pain processes, pain medicines and pain treatment and management strategies would contribute to the capacity of consumers to make informed decisions about their health care. In addition, focus group participants consistently expressed a need to have information about pain-related health and support services, particularly in their local areas. This need for localised service information was also identified by Conway and Higgins¹ in their literature review of models of care for pain management in NSW.

Overall, it can be concluded that the development of a website providing information identified by the needs analysis had provisional support from focus group participants who had access to and experience in using the internet to obtain information. Advantages of what one participant described as a "one stop shop" website included access to credible Australian content, reduction in the amount of searching, evaluating and synthesizing of information across numerous websites of varying quality that participants currently engage in, and provision of a referral point, for both patients and health professionals, as a source of trustworthy information on chronic pain. The diversity of conditions that can cause chronic pain and differing levels of interest and literacy of potential users also suggest that consideration of issues such as capacity

for user tailoring of content and “layering” of progressively more detailed information should be considered. A website of this kind would benefit from the involvement of both consumers and health professionals in its development and would require appropriate marketing in order for it to become a known and trusted information point. Participants supporting a website also emphasised that one-to-one contact with what one participant described as “a human being who gives a damn” remained a desired way to obtain pain-related information and ongoing support.

The significant proportion of focus group participants who did not have internet access or use it to obtain health information indicates that effective and equitable information provision requires the development of hard copy resources that as much as practicable mirror those provided on a website. Such resources could be made available via the information access points discussed in section 4.4, including GPs and other health professionals, pharmacies, libraries, community health centres, support groups and other community-based services. In addition, the capacity for information on the website to be easily printed in an accessible format would provide health professionals with a resource to share with their patients. Support for existing resources such as the Australian version of The Pain Toolkit and the ‘Understanding Pain: What to do about it in less than five minutes’ video suggest that these resources could also be made more widely available via the access points discussed in section 4.4. Less positive feedback on and responses to the ‘Understanding Pain’ video, for example, the applicability of the information for people with degenerative conditions and the implication that all chronic pain can be managed by following the steps shown in the video, need to be considered. There are implications for further development of these and similar resources in light of these to ensure resources are optimized to address the range of causes of pain and to reduce potential stigma and invalidation of people’s experiences.

Participants identified a variety of information needs, including information to help them understand pain, treatment and management strategies, how others cope and live with pain, communicating with health professionals, information for family and friends and resource directories. This reflects the need for evidence-based information outlined in the Report of the NSW Pain Management Taskforce⁷, but incorporates additional categories of lay or experience-based information, communication issues, and information tailored to help family members, including children, understand the pain a family member is experiencing.

Participants also identified a range of formats that they would like to receive information in, including one-to-one explanation, text-based printed information, web-based information, videos and DVD and CD formats. While the available budget will necessarily influence the scope of

consumer resource development, the results of this study suggest that a multi-media approach may be necessary to meet the presentation preferences of the diversity of people living with chronic pain.

Recommendations regarding the content and presentation of consumer pain management resources are outlined below. These are prefaced by the following considerations drawn from analysis of the focus group transcripts:

- The information needs of people with chronic pain vary depending on a number of individual and contextual factors, including the duration and type of pain.
- There is no one size fits all approach to the provision of pain information. Ideally, a range of presentation formats should be utilized.
- The recommendations are considered only a starting point for the development of comprehensive consumer pain management resources.
- Consistent with national and international best practice, development of resources should be done in ongoing partnership with people with chronic pain.

6. Recommendations

6.1 Content areas

1. Information that explains the pain experience and helps people understand why they are experiencing ongoing pain and validates the reality of their pain experience. This explanation should not be confined to the neuroplasticity model.
2. Treatment and management options, including risks, side-effects and, where available, the evidence base.
3. Comprehensive pain coping skills, aligned with the biopsychosocial or “whole person” model of pain management.
4. Experiences and perspectives of other people living with chronic pain.
5. National and local resource directories.
6. Information for partners and children to help them understand chronic pain.
7. Information on communication and managing relationships, including health professional, personal and social relationships.

6.2 Presentation formats

- A comprehensive website that presents the seven content areas using appropriate text and audiovisual techniques. The site should have the capacity for user tailoring of content,

depending on the pain condition. Information should also be layered, with the capacity for users to obtain progressively detailed information on topics, depending on their level of interest and understanding. Wherever possible, website content should be downloadable and/or printable.

- In recognition of the significant proportion of people with pain who do not use or have access to the internet, a 'hard copy' resource kit, including printed and DVD materials, that reflects the content of the website should be developed and made available via health professionals and other community access points such as libraries.
- Printed fact sheets on the topics contained within the website, particularly with regard to the understanding pain, treatment and management options, pain coping skills and information for families content areas, be developed and made available in appropriate access points within the community.

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Table 1: Participant characteristics (n = 53)

| Descriptor | N | % |
|---|---------------------|------|
| Mean age in years [SD] (range) | 60 [14.2] (26-88) | |
| Mean duration of pain – years [SD] (range) | 16 [12.9](.30 – 45) | |
| Gender – Female | 34 | 64.2 |
| Mean pain intensity - 0-10 scale ¹ [SD] (range) | 6.7 [1.8] (1-10) | |
| Mean pain coping – 0-10 scale ² | 6.5 [1.9] (3-10) | |
| Has used internet to obtain pain-related information – Yes | 29 | 54.7 |

¹ 0 = Low pain; 10 = High pain

² 0 = Not coping at all; 10 = Coping very well

Appendix A

Focus Group Question Route

Welcoming comments, housekeeping and facilitator introductions

Opening question

Tell us your first name and briefly why you've come along today – whatever you're comfortable telling us

Question 1: Everyone here has been on a journey of learning to live with chronic pain. As you've gone along your journey, what sort of information have you found:

- helpful
- unhelpful
- would you have liked to have had?

Question 2: How have you tried to get this information?

Question 3: What format do you think should be used to present information about pain?

Question 4: How would you like to be able to access this information?

Question 5: We'll now look at the examples of information that we sent out to you and you can tell us what you think about them.

- 'Managing My Pain' factsheet:
http://www.chronicpinaustralia.org.au/index.php?option=com_content&view=article&id=30&Itemid=232
- The Pain Toolkit (Aust version): <http://www.pain toolkit.org/assets/downloads/PTK-AUSTRALIA.pdf>
- 'Understanding Pain: What to do about it in less than five minutes' video:
<http://www.youtube.com/watch?v=4b8oB757DKc>
- Introduction to Relaxation video: <http://www.painassociation.com/videos/relaxation/>
- PainACTION website: <http://www.painaction.com/>

Question 6: Thinking back on everything we've discussed today, what would be the two most important things to you?

Question 8: Is there anything else that you came wanting to say that you didn't get a chance to say?