

**STAYING MOVING,
STAYING STRONG**



*Evaluating culturally adapted health information resources with
Aboriginal and Torres Strait Islander peoples living with arthritis*

Arthritis Australia Final Report

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Background and Scientific Objectives

Like many chronic conditions, the impact of arthritis is heightened in populations that experience a greater burden of disease due to health inequity.¹ Arthritis conditions including osteoarthritis, rheumatoid arthritis, systemic lupus erythematosus (lupus) and gout are highly prevalent among Aboriginal and Torres Strait Islander peoples (respectfully Aboriginal peoples herewith). The age-adjusted prevalence of arthritis conditions among Aboriginal peoples is 17% compared to 13% among non-Aboriginal peoples.² The burden of disease is also greater – for example, the burden of osteoarthritis among Aboriginal peoples is 31 Disability-Adjusted Life Years per-1000 people vs 22 per-1000 people for non-Aboriginal peoples.³ Arthritis is a multidimensional issue for Aboriginal peoples that significantly impacts all aspects of life including activities of daily living, caregiving, ability to engage in physical activities, adequate sleep, employment, family and social and cultural activities.⁴ Multidimensional impacts are often experienced within already complex health or life circumstances for Aboriginal peoples, which are associated with increased anxiety, depression and fear for the future.⁴ Despite the increased prevalence and burden of arthritis among Aboriginal peoples, access and utilisation of healthcare for arthritis by Aboriginal peoples is low. Aboriginal peoples with hip or knee osteoarthritis access primary care services and joint replacement at half the expected rate based on

incidence.^{3,5} Ineffective communication by health practitioners, experiences of racism and a lack of culturally secure musculoskeletal and health services currently act as barriers to care.⁴

Aboriginal peoples seeking care for arthritis also report receiving a lack of information about their condition⁴ and that health information provided is inadequate or presented in ways that are incongruent with Aboriginal peoples' beliefs and life experiences.^{6,7} The National Strategic Action Plan for Arthritis recommends providing health information resources to people with arthritis so that they can become active participants in the self-management of their symptoms.⁸ Information resources such as brochures, factsheets and websites can be stand-alone or provided within healthcare consultations and can act as powerful tools to empower patients and their families to have greater involvement in decisions about care and to engage in evidence-based self-management,^{9, 10} positively impacting health outcomes.¹¹ National consumer bodies (such as Arthritis Australia, MSK Australia) provide an extensive range of arthritis management resources that typically address beliefs and knowledge about arthritis and encourage patients to proactively self-manage their condition through evidence-based strategies such as pain management, staying active and engaging in physical activity.

Until recently there were no arthritis resources available that have been developed to meet the needs of Aboriginal people or involving input from Aboriginal peoples who experience arthritis. Aboriginal peoples need to be involved in the development of health resources, as governance of the process is likely to result in resources which are more meaningful and relevant to the social and cultural context of Aboriginal peoples. This may in turn, increase uptake of evidence-based recommendations made within the resources.¹² To address this healthcare gap, a multidisciplinary team of Aboriginal and non-Aboriginal clinicians, health service staff, and researchers from University of Melbourne and the Western Australia Centre for Rural Health were funded by the Commonwealth Government to conduct the Staying Moving, Staying Strong (SMSS) project¹³ to co-design and develop culturally secure arthritis information for Aboriginal peoples living with osteoarthritis, rheumatoid arthritis, lupus and gout. Informed by high-quality contemporary clinical practice guidelines¹⁴⁻¹⁶ community needs and preferences¹⁷ and co-designed with Aboriginal consumers, outputs from the SMSS project were four print brochures (Figure 1 and Figure 2), six community videos (Figure 3) that incorporate real stories from Aboriginal peoples who experience arthritis conditions and the Staying Strong with Arthritis website which acts as a platform for the resources: www.stayingstrongwitharthritis.org.au. The current project relates to the final, evaluation phase of the SMSS project.

The aim of this phase was to qualitatively evaluate the culturally secure arthritis health information resources that was co-designed with Aboriginal peoples during the SMSS project.

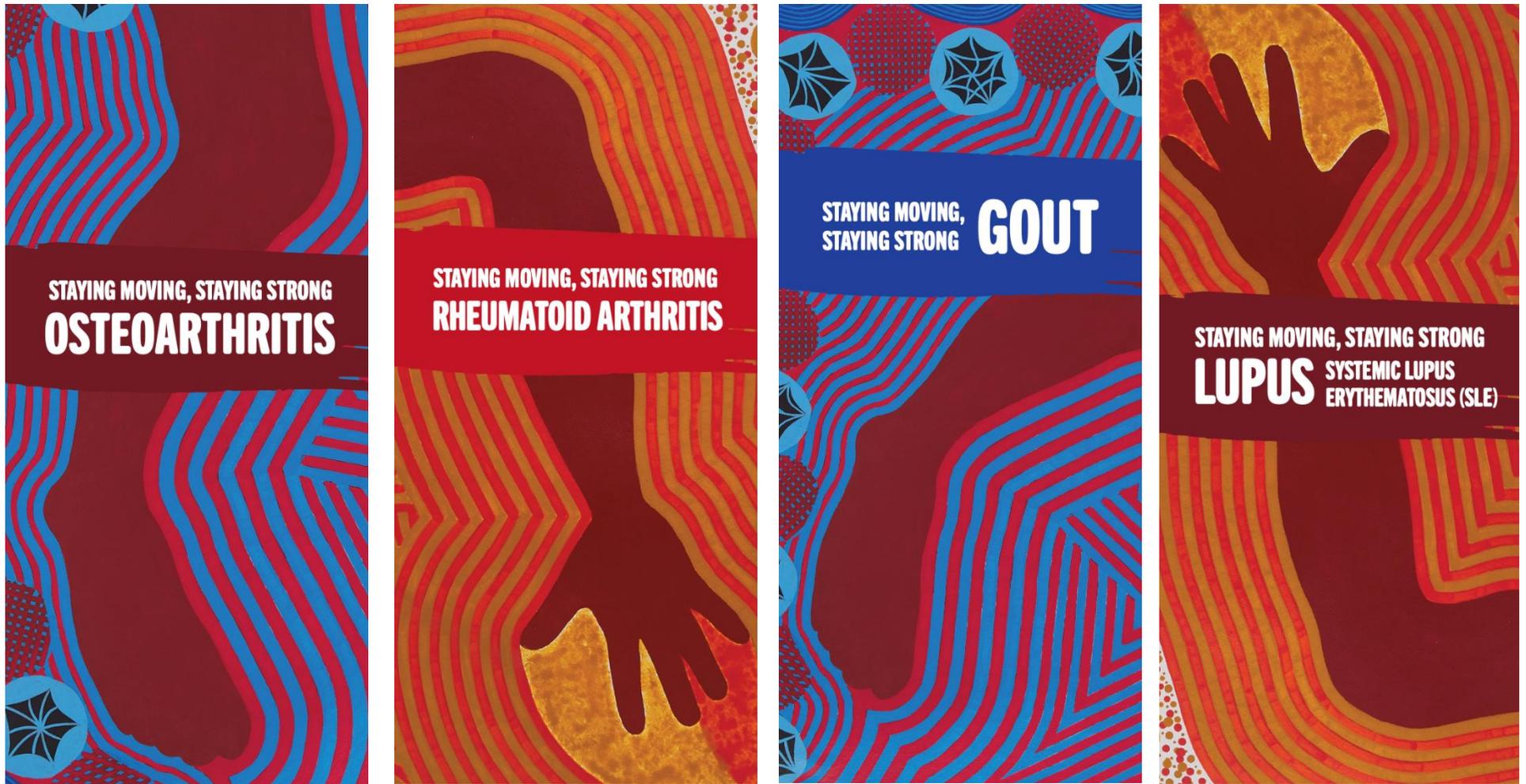


Figure 1: The SMSS brochures - Two Aboriginal artists were engaged to create artworks to be incorporated into the resources: Nicole Dickerson is a Yamatji artist based in Western Australia and Thomas 'Marksey' Marks, Wotjobaluk/Gunaikurnai artist based in Victoria).

WHAT IS OSTEOARTHRITIS?

- Osteoarthritis is when your joints, such as your knees, hips, back and hands are stiff and sore.
- This can happen for lots of reasons - weak muscles, not enough exercise or sleep, poor diet, smoking or stress.
- You're more likely to get osteoarthritis if it runs in the family, if you are overweight, or if you've had a big injury to the joint in the past.
- People can experience osteoarthritis at any age.
- It's often described as joint 'wear and tear'. But using your joints won't wear them away. Joints need to move to be healthy.

WHAT DOES OSTEOARTHRITIS FEEL LIKE?

- It's common to feel joint aches and pains. Joints can also be swollen or feel stiff.
- There can be good and bad days. Bad days (e.g. when joints are stiff and sore) are called 'flare ups'.
- Often joints feel more stiff and sore in the morning, before you get moving.
- Joint aches and pains can affect your body, mind and spirit.

Everyone with osteoarthritis has a different story.

"I notice I was just getting slower and slower and lots of aches and pains" — Aboriginal woman, aged 67.



HOW DO I KNOW IF I HAVE OSTEOARTHRITIS?

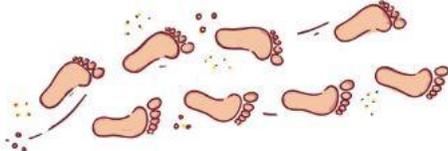
- If you feel joint pain or stiffness, have a yarn with your doctor, health worker or physio.
- A doctor or physio doesn't need an x-ray or scan to diagnose osteoarthritis.
- They will ask you questions about your pain and look at your joints and movement.

HOW CAN I LOOK AFTER OSTEOARTHRITIS?

Some mob reckon there's not much you can do for your osteoarthritis, but with the right plan you can live well with it.

STAYING MOVING, STAYING STRONG

- Staying moving is the best way to look after your osteoarthritis. It keeps your bones, joints and muscles healthy, and is good for your mind too.



"I go to the gym and do stuff to keep me in shape, which helps with my day to day. It's when I stop exercising, that's when my knees play up" — Wotjobaluk/ Gunaikurnai man, aged 52.

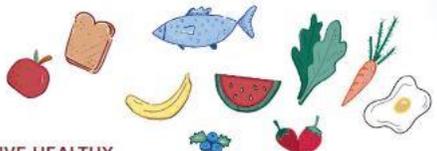
- Any movement is better than no movement. Do something you enjoy, like walking with your grannies or on Country or exercising in water.
- It's safe to be active, even if it's a bit sore at the start. Start slow and see a physio or exercise physiologist to make a plan.

MEDICINES

- Medicines can help joint aches and pains.
- Yarn with your doctor before trying medicines.
- Medicines that might help are:
 - Medicines for pain (e.g. paracetamol).
 - Medicines to help swelling (inflammation) (e.g. ibuprofen).

BUSH MEDICINE

- Bush medicines may help alongside Western medicine. Yarn with your local Aboriginal health service or Cultural Elder to find out more.



LIVE HEALTHY

- Eating healthy, being active and looking after your weight can help your osteoarthritis. Talk to your doctor or dietitian about a plan.
- Cut down, or if you can, get off the smokes. This will keep your body healthy and help with your joint pain.
- Osteoarthritis can make you feel down and frustrated. Yarn about your feelings with family, doctor or staff at your Aboriginal health service.

Figure 2: Example of the inside of an SMSS brochure. A Mulunjali visual and web designer was also engaged, Tim Buckley based in Queensland.

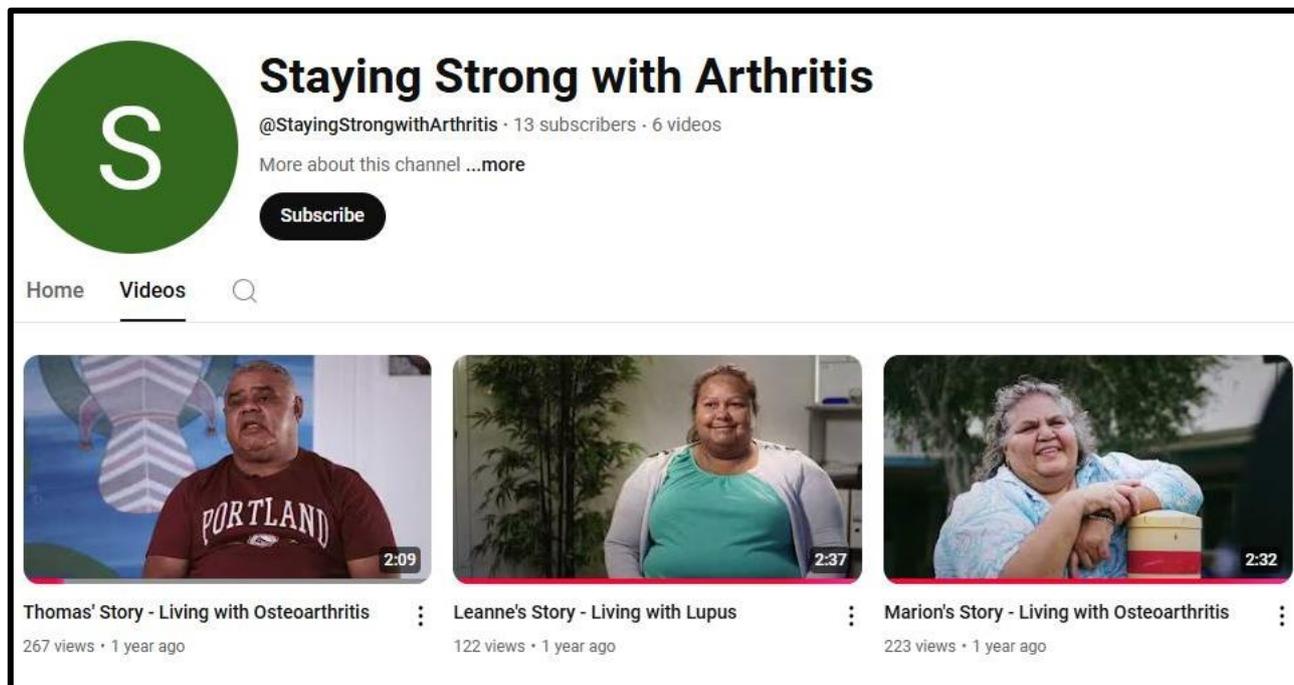


Figure 3: *The SMSS videos hosted on YouTube. Two videographers were engaged to film and edit the video resources: Tamati Smith, a Yamaji videographer and photographer based in Victoria and Luke Griffiths a videographer and editor based in Western Australia.*

Methods

Ethical approval

Ethical approvals were obtained from St Vincent’s Hospital Melbourne Human Research Ethics Committee (HREC 224/20) and the Western Australian Aboriginal Health Ethics Committee (HREC1018). All participants provided fully informed written or verbal consent prior to commencing the research.

Study context and positionality

This evaluation was conducted by the Arthritis Australia Fellow, Dr Penny O’Brien alongside a Worimi Researcher, Mr Ryan Prehn with input from a multidisciplinary team of Aboriginal and non-Aboriginal researchers and clinicians. Our diverse living experiences, values and cultural backgrounds influences the way we engage with research and as such, in the spirit of reflexivity, we offer the following positionality statement. Dr O’Brien is a woman, non-Aboriginal settler-ally, post-doctoral researcher and social scientist who worked collaboratively with Mr Prehn to ensure an Aboriginal cultural lens was prioritised. Mr Prehn is a Worimi man and Aboriginal researcher with experience in Indigenous and qualitative research methods. The wider team included Dr Brooke Conley (a Ngiyampaa woman, post-doctoral researcher and physiotherapist), Ms Jane Linton (a Gumbayngirr woman, PhD Candidate and physiotherapist), A/Prof Ivan Lin (male, non-Aboriginal senior research fellow and physiotherapist) and Dr Samantha Bunzli (woman, non-Aboriginal senior research fellow and physiotherapist). The team have collective context expertise in qualitative research methods and

co-design, Aboriginal and Torres Strait Islander health and musculoskeletal health research and live and work across various geographic locations in both metropolitan and regional locations across Australia.

Study Design

We employed a qualitative study design using yarning¹⁸ to evaluate the print and video resources co-designed and developed in the SMSS project. As first formalised by Bessarab and Ng'andu (2010), yarning as a qualitative data collection tool involves the process of sharing, listening, interpreting, and collaboratively making sense of the knowledges shared by participants.^{18, 19} This method fosters a relaxed environment that respects cultural protocols and storytelling traditions of Aboriginal peoples. Yarning can be applied in various settings, including one-on-one interactions (individual yarns) or group contexts such as yarning circles. Yarns usually incorporate four key components or phases including social yarning, research yarning, collaborative yarning, and therapeutic yarning. Our study is novel in that it embedded a think-aloud component into the 'research yarn', creating the 'think-aloud yarn.'¹⁹ 'Think-aloud' interviews are a type of cognitive interviewing technique, grounded in cognitive psychology where participants are asked to verbalise thoughts that they would ordinarily internalise while performing a given task.²⁰ This approach, often used to validate health measurement instruments and surveys, enables researchers to gain in-depth insights into the decision-making processes of participants as they complete tasks.²⁰ Although used in Western research paradigms since the mid-80s, only recently has the think-aloud technique been assessed for how well it aligns with Indigenous ways of being, knowing and doing.¹⁹ This recent assessment found that 'think-aloud' was a suitable and appropriate Indigenous method, with Aboriginal participants describing the think-aloud method as less onerous than writing down their thoughts and encouraging of critical reflection, and that these features enabled more authentic responses.¹⁹ Therefore, the think-aloud technique was deemed a suitable and appropriate method for qualitatively evaluating health resources with Aboriginal peoples.

Participants and Setting

Eligible participants were Aboriginal and/or Torres Strait Islander adults age >18 years residing in Regiontown (the pseudonym for a regional town in Western Australia with a population of <50,000) or the state of Victoria, who had a self-reported diagnosis of osteoarthritis (in any joint), rheumatoid arthritis, lupus or gout. Participants were recruited by via phone or face to face by drawing on the professional and social networks of the research team, reaching out to relevant Aboriginal health services and by distributing a recruitment flyer. A member of the research team verbally explained project information or sent additional written study information to interested individuals before offering the option of participating face to face, via phone, or teleconferencing at a time and location convenient to them. Participants received a \$50 gift voucher as reimbursement for their time and participants of the yarning circle also received a catered lunch.

Data Collection and Analysis

A combination of individual think-aloud yarns and a think-aloud yarning circle were conducted by the project coordinator, Dr O'Brien. The yarning circle was conducted at a local community centre with the support of a Yamatji community member and employee of the community centre. One individual yarn was conducted collaboratively by Dr. O'Brien and A/Prof Lin. All yarns and the yarning circle were conducted face to face, except one yarn with a Victorian participant that was conducted via videoconferencing platform Zoom. Each yarn commenced with a social yarn, enabling trust to be fostered with each participant before describing how the research yarn and think-aloud yarn would be conducted. The research yarns were performed in four phases. First, a short semi-structured research yarn was conducted to elicit participants' beliefs, living experiences and management of their condition. Second, the think-aloud yarn was conducted. In this section, participants were observed whilst they interacted with the SMSS brochures, whilst asking them to articulate their thoughts and feelings as they navigated the resources. The interviewer used prompts during the observation such as "Can you describe what you are seeing to me?", "What are you thinking when you read that" "How does what you are seeing make you feel?" to encourage participants to share their understanding and reactions to the resources. After the think-aloud yarn, participants were asked a series of seven questions which were derived in a previous study as a criteria on which to assess the cultural relevance of health resources.²¹ Lastly, participants were shown one community video and asked to retrospectively reflect on understanding, opinions, or judgements of the video resource. An example of the semi-structured yarning guide, including example think-aloud probing questions can be found in Appendix 1. The average yarn duration was 55 minutes, ranging from 30 minutes to 1 hour and 29 minutes.

All phases of data analysis were conducted collaboratively by RP and PO, with RP leading the coding and interpretation of the data to ensure an Aboriginal lens was prioritised. All yarns were audio recorded and transcribed verbatim by either RP or PO using an AI transcription application Otter.ai or by an external transcription service. Transcripts were checked for accuracy and uploaded into a qualitative data analysis software, NVivo (QSR International Pty Ltd. Version 12). Data were analysed concurrently to data collection in three steps, following a modified framework approach.²² In Step 1, both researchers became familiar with the data by reading and rereading the transcripts. In Step 2, both open coding and deductive coding were conducted. Open coding was used to identify broad concepts in relation to participants' living experiences of arthritis and their experiences of interacting with the resources, including any feedback or suggestions for change. Deductive coding was performed using the domains of the cultural relevance checklist described above,²¹ which can be found in Appendix 2. RP and PO met regularly to compare and contrast their coding before refining a list of codes into a thematic framework. Codes were grouped into the two overarching themes of 'Positive Feedback' and 'Suggestions for Change'. Under each theme, codes were grouped into five categories including Relatability – Cultural and Health Experiences, Content and Communications, Visual,

Artwork and Design, Accessibility and Utility and Usefulness. In Step 3, the thematic framework was applied to each transcript and with the coding results being summarised in Microsoft Word Tables.

Results, Scientific Achievements and Outcomes

Evaluation Results

Between June 2024 and September 2024, a total of 16 participants (12 women, 4 men) participated in either research yarns (10 participants) or the yarning circle (6 participants). Of the 16 participants, 15 identified as Aboriginal and one identified as Torres Strait Islander. The demographic and clinical characteristics of participants are described in Table 1. The results of the evaluation are presented in two sections. First, a narrative summary is provided for both the Positive Feedback and Suggestions For Change identified in the data. Results are also presented summarized in two tables (Table 2 and Table 3). Table 2 (Positive Feedback) and Table 3 (Suggestions for Change) provide a summary of the data alongside illustrative quotes organised into the five key categories of Relatability, Content & Communication, Visual, Artwork and Design, Accessibility, and Utility and Usefulness. Both tables are grouped into the same categories to enable clear comparison between them and to further highlight where adjustments could be made to enhance the resources. An additional two tables are provided (Table 3 and Table 4). These tables present a summary of the data organized by incidence, i.e. each code is ordered presented alongside a number which corresponds to the number of times this concept was mentioned by a participants.

Table 1: Participant Characteristics

Location	Participant Code	Gender	Age	Mob	Arthritis type	Seen resources previously?
VICTORIA						
<i>Regional</i>	V1	W	68	Yorta Yorta	Osteoarthritis	Yes
<i>Metro</i>	V2	W	60	Gunditjmara	Osteoarthritis	No
<i>Metro</i>	V3	W	63	Gunditjmara	Osteoarthritis	No
WESTERN AUSTRALIA						
<i>Regional</i>	W1	W	67	Unknown	Osteoarthritis	No
<i>Regional</i>	W2	M	60	Yamatji	Gout	Yes
<i>Regional</i>	W3	W	58	Yamatji	SLE*	No
<i>Regional</i>	W4	W	69	Yamatji	Osteoarthritis	No
<i>Regional</i>	W5	W	71	Nanda/Yamatji/Amangu	Rheumatoid arthritis/SLE	No
<i>Regional</i>	W6	W	62	Noongar/Yamatji	SLE	Yes
<i>Regional</i>	W7	W	67	Torres Strait Islander	Osteoarthritis	No
<i>Regional</i>	YC1	W	62	Unknown	Osteoarthritis/Gout	No
<i>Regional</i>	YC2	M	44	Noongar/Yamatji	Osteoarthritis	No
<i>Regional</i>	YC3	W	69	Nanda	Rheumatoid arthritis	No
<i>Regional</i>	YC4	M	#	Yamatji	Osteoarthritis	No

<i>Regional</i>	YC5	F	#	Yamatji	Osteoarthritis	No
<i>Regional</i>	YC6	M	59	Noongar/Yamatji (Wajjarri)	Osteoarthritis	No
TOTAL: 16 participants, 12 women, 4 men						
YC = Yarning circle participant						
*SLE = Systemic lupus Erythematosus - Lupus						
#Participant's age was unknown, not discussed during yarn or not recorded for cultural reasons.						

Positive Feedback

Relatability (Cultural & Health Experiences): Many participants in this study expressed a strong sense of relatability to the SMSS resources, both in terms of cultural relevance and their own health experiences. Participants recognised the inclusion of cultural practices (e.g. bush medicine as a management option for arthritis), the use of culturally relatable language (e.g. yarning, mob) and culturally representative artworks/illustrations as enhancing representation and cultural relevance. Most participants also felt that the resources accurately captured and affirmed their own arthritis experiences, which in turn remediated feelings of isolation, providing hope and reassurance for the future. Community based quotes about living with arthritis and the inclusion artist bios enhanced this relatability, providing cultural and community connection that resonated with participants. Videos were particularly relatable and motivating. Many participants described the relatability and a sense of motivation that came with involving community members (many who were known by participants) in the videos to model arthritis management practices: *"what she's saying, that's how I would say it too. That's how I'd feel. She, being a strong Aboriginal woman that has got it, accepted it, and she's got support... What she's saying is so true"* VIC p2.

Content and Communication: The majority of participants commended the content of the resources for its clarity and striking a balance between being easily understandable 'friendly language' and providing comprehensive and educational information. Content was described as succinct, 'strait to the point', well ordered and that information provided was holistic, challenged misconceptions about arthritis, motivated them to stay active, empowered them to engage in conversations with healthcare professionals and built their knowledge around self-management, kin and community: *"you can't look after your mob unless you look after yourself"* WA p6.

Visual, Artwork, and Design: Most participants in this study described the resources as visually 'eye catching' and that the Aboriginal artworks used on the front cover and throughout the resources made them easily identifiable as 'for Aboriginal and Torres Strait Islander peoples'. Some participants also appreciated the depiction of body parts in the artworks (i.e knee, elbow, hand, foot), as these were reflective of their conditions. Participants also noted the use of vibrant colors and a good number of appropriate, informative and storied illustrations: *"to me, the feet represent walking together on a journey to better health"* VIC p1.

Accessibility: Many participants in this study highlighted the accessibility of the resources, emphasising their potential effectiveness across diverse literacy levels and preferences. Participants appreciated the large font size, brochure size and layout, and the absence of jargon or overly complex language, which made the content approachable and easy to understand. A few participants appreciated the integration of digital accessibility features, such as the QR code, which made additional content readily available online. The use of video formats was especially impactful, catering to varying literacy levels and providing an engaging and informative alternative to text-based materials: *“you've got to think about people who can't read, and that video would be great... videos are another tool, you know, they can see real life people with this problem”* VIC p1.

Utility and Usefulness: Participants in this study identified the resources as practical and versatile tools for both healthcare providers and individuals managing arthritis. Clinicians and Aboriginal Medical Services (AMSs) were seen as key users, with the resources effectively complementing healthcare advice and supporting patient education. A few participants felt that the resources were something Aboriginal peoples would be drawn to if encountered at an AMS, due to their cultural relatability and that this could be important for individuals with undiagnosed arthritis: *“they might be reading that and thinking, ‘well, I get all these aches and pains in my joints, that might be what's wrong with me?’”* WA p2. The inclusion of physical copies was also praised in the context of supporting Aboriginal peoples without reliable internet access, while videos were seen as valuable supplemental tools to brochures. Videos were described as particularly effective in facilitating meaningful conversations: *“I think you need to use them in your yarning circles.”* VIC p2

Suggestions for Change

While participants found many aspects of the health resources as positive, relevant and appropriate, they also provided constructive feedback and suggestions for improvement that have described across the same five key categories.

Relatability (Cultural & Health Experiences): Many participants suggested expanding references to cultural practices with the most common suggestion being the inclusion of Aboriginal foods such as bush meats and kangaroo. Although this sentiment was geographically specific to participants residing in Regiontown, when prompted about the topic, Victorian participants agreed that including bushmeat would be appropriate. Some participants suggested that bush medicine should be included more explicitly alongside dietary advice. To improve cultural relevance, some participants also suggested that the resources should emphasise cultural responsibilities such as responsibility to family and kin, and further advocate for family to provide reciprocal support for Aboriginal peoples living with arthritis: *“maybe you could touch on the fact that in our culture, we have a lot of responsibility to family? Sometimes you have to restrain [yourself] from what sometimes you cannot do, and what your family expect you to do”* WA p6. Additionally, including people with unmanaged conditions in videos was suggested to create a fuller representation of living arthritis experiences.

Content and Communication: Participants offered a range of suggestions to improve the content and messaging of the brochure. A key recommendation was to provide clear, lay definitions of medical terms, including the names of the four conditions (osteoarthritis, rheumatoid arthritis, lupus, and gout) and that these could be provided on the front cover. This was seen as especially important for those who may be living with an undiagnosed arthritis condition. Some participants also emphasised the importance of explaining additional complex medical terms, such as "autoimmune disease," and these could be accompanied by further illustrations. Some participants also recommended refining the language to avoid ambiguity, for example, including more explicit advice on topics like surgical candidacy, the importance of adhering to ongoing appointments even when feeling well, providing more detailed examples of helpful, low cost exercises, as well as greater emphasis on the role of physiotherapy: *"The physio can help you do the exercises, which is going to help you get stronger. So, you haven't really talked about your physio much... The physio is important. And then you might have a bit about what the physio does"* WA p7.

Furthermore, in response to question four on the checklist (Appendix 2), participants suggested that Aboriginal peoples involvement in the creation of the resources should be explicitly acknowledged and that this may further enhance the trustworthiness of the resources.

Visual, Artwork, and Design: Several enhancements to improve the visual and cultural representation of the brochure were suggested by participants. Recommendations included using lighter, brighter colors and incorporating more color throughout the inside of the brochure. Including additional illustrations, artworks, and diagrams was also suggested to better support the content and improve clarity. To strengthen cultural representation, participants proposed including both the Aboriginal and Torres Strait Islander flags which was seen as customary across most Aboriginal health resources. Modifications to existing illustrations were also recommended to align better with cultural contexts, such as changing the clinical yarn illustration to an outdoor setting without a computer or stools. A few participants noted that the artworks including body parts did not accurately reflect their arthritis experiences and suggested adapting these to better represent symptoms. For example, participants proposed using visual markers like red spots, targets, or lightning bolts to indicate pain or swollen joints: *"I'd like to see some kind of a flash or something here to say that it's aching"* WA p4.

Accessibility: Recommendations to enhance the accessibility of the resources were also identified by participants. These included using a larger font size to improve readability, especially for older readers or those with visual impairments. Additionally, a few participants recommended increasing the physical size of the brochure and providing alternative formats, such as posters, to reach a wider audience in various settings. Recognising that not everyone has access to the internet or smart devices (especially in rural or remote locations), one participant emphasised the importance of including a 'toll-free' phone number for accessing

information, services, and support. This suggestion reflected the participants extensive experience as a health provider. To make the digital content more accessible, participants suggested adding a clear explanation of how to use the QR code: *“Not everyone is familiar with a QR code, so if you give them information about what it actually does, you know, ‘If you scan here, you’ll get all the information,’ and how to do that”* (WA yarning circle). Some participants also recommended translating the materials into different Aboriginal languages to ensure cultural and geographic appropriateness should the resources be distributed more widely.

Utility and Usefulness: Although less relevant, participants made a few suggestions in relation to improving the utility and the usefulness of the resources. Participants emphasised the importance of ensuring the resources are widely accessible by distributing them beyond medical settings to places where Aboriginal peoples gather including sporting clubs, community events, and other non-medical meeting spaces. To maximise their reach and impact, participants also stressed the need for broad dissemination to Aboriginal and Torres Strait Islander communities across Australia, rather than limiting distribution to specific regions like Victoria and Western Australia.

Table 2: Positive feedback identified

Positive Feedback					
Relatability		Content & Communication	Visual, Artwork and Design	Accessibility	Utility/Usefulness
Cultural	Health experiences				
<p>Inclusion of cultural practices, i.e., bush medicine</p> <p>Culturally relatable language, i.e., yarning, mob</p> <p>Culturally & geographically relevant artworks & illustrations</p> <p>Connection to culture and mob through quotes & artist bios: <i>“similar to the quotes, I guess, you’re still connecting with people, who had, whether it’s their arthritis or her healing, you know, it’s still that thing of how people deal with it. And you don’t, I guess, feel isolated. Yeah. ‘Cause it does feel like that sometimes”</i> WA p3</p>	<p>Captures and affirms own experiences of arthritis: <i>“it stands out. Because it’s what we go through”</i> VIC p2</p> <p>Understanding own health experience better – provides options and answers</p> <p>Provides hope and reassurance, possibility of improvement</p> <p>Provides advice that otherwise is learnt heuristically: <i>“I’m just thinking about managing your triggers. That’s good. I haven’t seen that before, knowing your triggers. I didn’t know that. I didn’t know my triggers. I’d just keep pushing, push, push until I couldn’t go no more. So that’s a good one”</i> WA p6</p>	<p>Friendly language, easily understandable</p> <p>Direct, succinct & well-ordered information: <i>“straight to the point”</i> VIC p1</p> <p>Comprehensive, educative & explanatory</p> <p>Builds confidence</p> <p>Builds motivation for management and to keep moving, get active: <i>“start moving... gotta keep on moving”</i> WA p5</p> <p>Empowers & encourages health communication between mob & with clinicians</p> <p>Provides knowledge to help self, kin & community: <i>“you can’t look after your mob unless you look after yourself”</i> WA p6</p>	<p>Eye catching, stands out</p> <p>Logical, step by step layout</p> <p>Evidently made for Aboriginal and Torres Strait Islander people</p> <p>Identifiable Aboriginal artwork</p> <p>Multiple front cover artworks make different brochures more easily distinguishable</p> <p>Body-part artworks reflective of condition</p> <p>Good number of illustrations</p> <p>Appropriate & interpretable illustrations</p> <p>Storyed illustrations: <i>“to me, the feet represent walking together on a journey to better health”</i> VIC p1</p>	<p>Good font size (large writing)</p> <p>Good brochure size</p> <p>Informative illustrations</p> <p>No jargon or overly complex information</p> <p>Dot points easy to digest information: <i>“I read a lot better with dot points”</i> WA yarning circle</p> <p>QR code makes digital content readily accessible</p> <p>Video format accounts for varying literacy proficiencies: <i>“you’ve got to think about people who can’t read, and that video would be great... videos are another tool, you know, they can see real life people with this problem”</i> VIC p1</p>	<p>Good resource for clinicians and Aboriginal Medical Services (AMS) to provide information complementary to healthcare & advice</p> <p>Revelatory for people with undiagnosed arthritis conditions; can be taken to doctor to seek diagnosis: <i>“they might be reading that and thinking ‘well, I get all these aches and pains in my joints, that might be what’s wrong with me?’”</i> WA p2</p> <p>Helpful resource when first diagnosed</p> <p>Something Aboriginal and Torres Strait Islander people would pick up if seen at AMS</p> <p>Gives you the information you need to have</p>

<p>Community representation, recognition, and relatability (videos): <i>"he was a sufferer and he went and done all the right things that helped him heal himself, pretty much. And he hasn't had a bout of gout for a while now... it's someone we know in the community"</i> WA p2</p> <p><i>"She spoke true to words... everything I related to"</i> VIC p1</p> <p><i>"she'll be the one who will tell the story, and she'll help us to listen. We'll listen to her story"</i> VIC p2</p> <p>Peer encouragement (videos): <i>"What she's saying, that's how I would say it too. That's how I'd feel. She, being a strong Aboriginal woman, that has got it, accepted it, and she's got support... What she's saying is so true"</i> VIC p2</p>	<p>Reduces isolation through shared lived experiences</p> <p>Diverse ages & body sizes represented</p> <p>Management tips from lived experience (videos): <i>"that's what other people, other sufferers probably want to hear, how do you get rid of it, how do you stop it, you know...so he started eating properly and started using Bush medicine, emu oil and things"</i> WA p2</p> <p><i>"you're hearing from the person that's happening to, you know, that's experiencing the thing, and you're getting tips from them as well. Yeah. I've never had that, you know, would have been good. If I had something like that back in the day"</i> WA p6</p>	<p>Challenges misconceptions: <i>"it can happen to anybody at any age, and we need to start educating our young"</i> VIC p1</p> <p>Addresses interrelated health & wellbeing factors, i.e., mental health, diet, smoking, sedentism, etc.</p> <p>Contains information about non-medicinal ways to manage pain, i.e., painting (artist bios)</p>	<p><i>"they've given you what kind of symptoms you can have and then you're speaking and listening and then that's your stepping stones and that's all the food you should eat"</i> WA yarning circle</p> <p>Doctor-patient equality represented in illustrations: <i>"it shows that the doctor or health worker is sitting at the same level as the patient, which is most important. You never stand above your patient"</i> VIC p1</p> <p>Nice colour scheme</p>	<p>Videos assists with understanding brochure Videos hold attention, convey more information</p> <p>Resources available online in lieu of visiting AMS, possessing physical brochure</p>	<p>Physical resource useful for people without internet access Videos useful as yarning circle resource: <i>"I think you need to use them as your yarning circles"</i> VIC p2</p> <p>Videos useful as supplemental information to brochures</p>
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Table 3: Suggestions for changed identified

Suggestions for Change					
Relatability		Content & Communication	Visual, Artwork and Design	Accessibility	Utility/Usefulness
Cultural	Health experiences				
<p>Include kangaroo & other cultural food</p> <p>Note the prevalent cultural responsibility to kin and how this is impacted: <i>"Maybe you could touch on the fact that in our culture, we have a lot of responsibility to family? Sometimes you have to restrain from what sometimes you cannot do, what your family expect you to do"</i> WA p6</p> <p>Advocate for support from family: <i>"Sometimes you need their support, you know? Instead of us supporting them, sometimes it's got to go back the other way"</i> WA p6</p>	<p>Encourage assistance in clinics from social worker or family member: <i>"they don't know what to do. They don't know how to talk to the doctor about it. So, they might like the social worker to go with them into the doctor, the social worker is like a go-between"</i> WA p7</p> <p>Stronger and more precise language to better capture pain, fatigue & mental health experiences</p> <p>Include empowering statement re: managing the pain experience: <i>"The more you can be in charge of the pain that you are experiencing, that will help with your health and wellbeing"</i> WA p7</p>	<p>Include lay definition of conditions on front cover Simplify language further and explain any complex terms in writing and illustrations i.e., autoimmune disease Refine syntax to reduce potential ambiguity</p> <p>Include statement of Aboriginal and Torres Strait Islander involvement in resource development Encourage confidence, persistence & direct language when speaking to clinicians</p> <p>Clarify surgical candidacy (OA) Encourage activity despite pain (OA): <i>"I would say 'it's safe to be active even if you are a bit sore... start slow and move up'"</i> WA p7</p> <p>Provide more explicit exercise suggestions</p>	<p>Use lighter, brighter colours; more colour throughout brochure</p> <p>Include more illustrations, artworks & diagrams throughout the brochure, i.e., of exercises, bush medicines, etc.</p> <p>Include Aboriginal and Torres Strait Islander flags</p> <p>Include Torres Strait Islander artwork</p> <p>Modify existing illustrations to enhance interpretability & cultural relevance, i.e., the clinical yarn could be depicted less formally</p> <p>Include description of artworks to confer the artists' intent</p>	<p>Larger font size</p> <p>Larger brochure</p> <p>More formats, i.e., posters</p> <p>Include a phone number for information, services & support for those who may not have computer/internet access: <i>"they need to be toll free phone numbers"</i> WA p5</p> <p>QR code explanation and guide: <i>"Not everyone is familiar with a QR code so if you give them information about what it actually does, you know, 'If you scan here, you'll get all the information', and how to do that"</i> WA yarning circle</p>	<p>Resources should be disseminated to Aboriginal and Torres Strait Islander sporting clubs, events and other non-medical meeting/gathering places: <i>"probably something good to post around our sporting events"</i> WA yarning circle</p> <p>Resources should be widely distributed to all Aboriginal and Torres Strait Islander communities (not only in VIC & WA)</p>

<p>Combine bush medicine with food recommendations Advise cost-free or low-cost food and exercise suggestions; specifically mention finance</p> <p>Include in video resources community members who have unmanaged conditions</p>	<p>Include data of condition prevalence for Aboriginal and Torres Strait Islander peoples</p>	<p>Convey importance of keeping to medication schedule and attending appointments even when feeling good: <i>“you need to see the specialist. I found out the hard way, like missing these appointments that I had with a specialist. I missed them because I was feeling good... emphasize the follow up”</i> WA p6</p> <p>Provide more health service and support options</p> <p>Provide more information about physiotherapy: <i>“the physio can help you do the exercises, which is going to help you get stronger. So, you haven't really talked about your physio much...The physio is important. And then you might have a bit what the physio does”</i> WA p7</p> <p>Provide information about diagnostic procedures, i.e., x-ray, MRI</p>	<p>Body-part artworks not always reflective of condition – represent conditions accordingly</p> <p>Use a pain signifier on limbs/joints, i.e., red spot, target, lightning bolt: <i>“I'd like to see some kind of a flash or something *here* to say that it's aching”</i> WA p4</p> <p>Include representation of swollen joints in artwork</p>	<p>Translate into different languages and dialects as culturally appropriate</p>	
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Table 3: Positive feedback results organised by incidence

Positive Feedback					
Relatability		Content & Communication	Visual, Artwork and Design	Accessibility	Utility/Usefulness
Cultural	Health experiences				
<p>(8) Inclusion of cultural practices, i.e., bush medicine: v1, v2, v3, wa1, wa2, wa3, wa4, wa5</p> <p>(7) Community representation, recognition, and relatability: v1, v2, v3, wa2, wa3, wa5, yc</p> <p>(6) Peer encouragement (videos): v1, v2, v3, wa1, wa5, yc</p> <p>(2) Culturally relatable language, i.e., yarning, mob: v1, wa7</p> <p>(2) Connection to culture and mob through quotes & artist bios: wa3, wa6</p> <p>(1) Culturally & geographically</p>	<p>(8) Captures and/or affirms own experiences of arthritis: v1, v2, wa1, wa3, wa4, wa6, wa7, yc</p> <p>(3) Diverse ages & body sizes represented: v1, wa3, yc</p> <p>(2) Management tips from lived experience (videos): wa2, wa6</p> <p>(2) Provides hope and reassurance, possibility of improvement: v1, yc</p> <p>(1) Understanding own health experience better – provides options and answers: yc</p> <p>(1) Provides advice that otherwise is learnt heuristically: wa6</p>	<p>(9) Comprehensive, educative, explanatory: v1, v2, v3, wa1, wa2, wa3, wa4, wa7, yc</p> <p>(6) Friendly language, easily understandable: v1, v2, v3, wa1, wa3, yc</p> <p>(6) Direct, succinct & well-ordered information: v1, v2, v3, wa1, wa2, yc</p> <p>(6) Builds motivation for management and to keep moving, get active: v1, v2, v3, wa1, wa5, yc</p> <p>(6) Empowers & encourages health communication between mob & with clinicians: v1, v2, v3, wa1, wa6, yc</p> <p>(5) Addresses interrelated health & wellbeing factors, i.e., mental health, diet,</p>	<p>(5) Nice colours: v1, v2, v3, wa6, yc</p> <p>(4) Eye catching, stands out: v2, v3, wa2, yc</p> <p>(4) Evidently made for Aboriginal and Torres Strait Islander people: v1, wa1, wa6, yc</p> <p>(4) Storied & informative illustrations: v1, v2, wa1, yc</p> <p>(3) Logical, step by step layout: v1, wa1, wa2</p> <p>(3) Identifiable Aboriginal artwork: v1, wa6, yc</p> <p>(3) Body-part artworks reflective of condition: v1, wa1, wa6</p>	<p>(5) Good font size (large writing): v1, v2, v3, wa2, yc</p> <p>(5) No jargon or overly complex information: v1, v2, v3, wa3, yc</p> <p>(3) Video format accounts for varying literacy proficiencies; assist with understanding brochure: v1, wa3, yc</p> <p>(2) Dot points easy to digest information: wa3, yc</p> <p>(2) Brochure size ideal: v2, yc</p> <p>(2) Videos hold attention, convey more information: wa4, yc</p> <p>(2) Resources available online in lieu of visiting</p>	<p>(6) Good resource for clinicians and Aboriginal Medical Services (AMS) to provide information complementary to healthcare & advice: v1, v2, v3, wa1, wa2, yc</p> <p>(4) Something Aboriginal and Torres Strait Islander people would pick up if seen at AMS: v1, v2, v3, yc</p> <p>(4) Gives you the information you need to have: v1, v2, v3, yc</p> <p>(3) Physical resource useful for people without internet access: wa1, wa5, wa6</p> <p>(2) Videos useful as yarning circle resource: v2, v3</p> <p>(2) Revelatory for people with undiagnosed arthritis</p>

representative artworks & illustrations: v1	(1) Reduces isolation through shared lived experiences: v1	<p>smoking, sedentism, etc.: v1, v2, v3, wa3, yc</p> <p>(3) Provides knowledge to help self, kin & community: v1, wa6, yc</p> <p>(2) Builds confidence: v1, yc</p> <p>(2) Challenges misconceptions: v1, wa1</p> <p>(1) Contains information about non-medicinal ways to manage pain, i.e., painting (artist bios): wa3</p>	<p>(3) Appropriate & interpretable illustrations: v2, wa1, wa6</p> <p>(2) Good number of illustrations: wa1, v2</p> <p>(1) Doctor-patient equality represented in illustrations: v1</p> <p>(1) Multiple front cover artworks make different brochures more easily distinguishable: yc</p>	<p>AMS, possessing physical brochure: wa2, wa3</p> <p>(2) QR code makes digital content readily accessible: wa2, yc</p>	<p>conditions; can be taken to doctor to seek diagnosis: wa2, yc</p> <p>(1) Helpful resource when first diagnosed: wa6</p> <p>(1) Videos useful as supplemental information to brochures: v1,</p>
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Table 4: Suggestion for changes organised by incidence

Suggestions for Change					
Relatability		Content & Communication	Visual, Artwork and Design	Accessibility	Utility/Usefulness
Cultural	Health experiences				
<p>(5) Include kangaroo & other cultural foods: wa1, wa4, wa5, wa7, yc</p> <p>(5) Advise cost-free or low-cost food and exercise alternatives – specifically mention</p>	<p>(3) Include data of condition prevalence for Aboriginal and Torres Strait Islander peoples: v2, v3, wa3</p> <p>(2) Stronger and more precise language to better</p>	<p>(4) Include statement of Aboriginal and Torres Strait Islander involvement in resource development: v2, v3, wa2, wa5</p>	<p>(3) Use lighter, brighter colours; more colour throughout brochure: wa1, wa4, wa7</p> <p>(3) Modify existing illustrations to enhance</p>	<p>(7) Contingent on demography of dissemination, translate into different languages and dialects as culturally appropriate: v1, v2, v3, wa2, wa3, wa5, wa6</p>	<p>(2) Resources should be disseminated to Aboriginal and Torres Strait Islander sporting clubs, events and other non-medical meeting/gathering places: v2, yc</p>

<p>finance: v1, v2, wa4, wa5, wa7</p> <p>(1) Note the prevalent cultural responsibility to kin and how this is impacted; advocate for family support: wa6</p> <p>(1) Combine bush medicine with food recommendations: wa1</p> <p>(1) Include in video resources community members who have unmanaged conditions: wa2</p>	<p>capture pain, fatigue & mental health experiences: wa3, wa7</p> <p>(1) Encourage assistance in clinics from social worker or family member: wa7 (1) Include empowering statement re: managing the pain experience: wa7</p>	<p>(4) Include lay definition of conditions on front cover: wa1, wa4, wa5, yc</p> <p>(4) Simplify language further and explain any complex terms in writing and illustrations i.e., autoimmune disease: wa1, wa4, wa5, wa7</p> <p>(3) Refine syntax to reduce potential ambiguity: wa4, wa5, wa7</p> <p>(3) Encourage confidence, persistence & direct language when speaking to clinicians: wa5, wa7, yc</p> <p>(3) Provide more health service and support options: wa3, wa4, wa6</p> <p>(2) Encourage activity despite pain (OA): v1, wa7</p> <p>(2) Provide more explicit exercise suggestions: v1, wa7</p> <p>(2) Convey importance of keeping to medication schedule and attending appointments even when feeling good: wa5, wa6</p>	<p>interpretability & cultural relevance: wa1, wa5, wa7</p> <p>(3) Add more illustrations, artworks & diagrams throughout the brochure, i.e., of exercises, bush medicines, etc.: wa4, wa5, wa6 (3) Include description of artworks to confer describe the artists' intent: wa1, wa5, wa7</p> <p>(2) The clinical yarn illustration should be modified: no computer, not on stools, outside: wa1, wa7</p> <p>(2) Include Aboriginal and Torres Strait Islander flags: wa5, wa6</p> <p>(2) Use a pain signifier on limbs/joints, i.e., red spot, target, lightning bolt: wa4, wa5</p> <p>(1) Include Torres Strait Islander artwork: wa5</p> <p>(1) Body-part artworks not always reflective of condition – represent conditions accordingly: wa4</p>	<p>(3) Larger font size: wa1, wa5, wa7</p> <p>(2) Larger brochure: wa5, wa7</p> <p>(2) More formats, i.e., posters: v2, yc</p> <p>(2) Include a phone number for information, services & support for those who may not have computer/internet access: wa5, wa6</p> <p>(2) QR code explanation and guide: wa1, yc</p>	<p>(2) Resources should be widely distributed to all Aboriginal and Torres Strait Islander communities (not only in VIC & WA): v1, wa5</p>
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		<p>(2) Provide information about diagnostic procedures, i.e., x-ray, MRI: v1, wa3</p> <p>(1) Provide more information about physiotherapy: wa7</p> <p>(1) Clarify surgical candidacy (OA): wa7</p>	<p>(1) Include representation of swollen joints in artwork: wa5</p> <p>(1) Use illustrations to convey more complex information and health messaging, i.e., medicine schedules, encouragement for community veggies gardens: wa5</p>		
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Project Strengths: Other Scientific Outputs and Achievements

Methodological Strengths

The strength of *'Relatability'* as a theme in this evaluation underscores the robustness and rigor of the SMSS project, demonstrating the effectiveness of process used to develop health resources collaboratively with Aboriginal peoples. This approach validates the co-design methodology employed, highlighting its capacity to produce culturally secure resources that resonate with the intended audience, an important consideration when designing health information and education resources. Furthermore, this methodology offers a transferable framework that can be adapted by other research groups to develop culturally adapted resources for a range of health conditions and contexts. The innovative application of the think-aloud approach in this project further justifies its appropriateness for use with Aboriginal peoples. To our knowledge, this is the first time the think-aloud methodology has been used within a yarning circle, an approach that proved to be an exceptionally rich source of data in this study. Furthermore, this project gave Dr O'Brien the opportunity to conduct research WA, an invaluable learning experience that also enabled essential relationship building with researchers and Aboriginal community members in WA.

Capacity Building

To further facilitate capacity building within the project, Dr O'Brien was successful in applying for a highly competitive University of Melbourne Early Career Research grant for \$34,338, a further scientific achievement associated with the support received from Arthritis Australia. This funding supported Mr Prehn's position and this was essential to facilitate two-way knowledge exchange and capacity building – a critical component of culturally secure and ethical Aboriginal health research. During the project Dr O'Brien mentored Mr Prehn to further build his skills in qualitative research methods, including writing his first, lead author publication (in progress). Mr Prehn identified the following specific areas he has built confidence in during the project:

- Qualitative data analysis, including coding, identifying significant data, identifying themes, interpretation and of data/findings and the use of data analysis software (NVivo)
- Strengthening interpersonal relationships including community engagement and participant recruitment
- Presenting findings and writing for qualitative research, including leading the writing of a manuscript for publication.

Mr Prehn also built the capabilities of Dr O'Brien, by providing essential cultural mentorship, guidance and learning opportunities. Mentoring Mr Prehn was also one of her first formal supervisory roles, which enabled her to build skills as a research mentor, including her first senior author paper.

Project Limitations: Problems Encountered

Three main challenges were encountered during the project in achieving the project's objectives. These included: 1) Delay in project timelines 2) Challenges in recruiting participants in Victoria and; 3) The inability to conduct follow up interviews with participants. A significant issue was a delay in project timelines, largely due to the extension of the SMSS project. The SMSS project timeline was extended by six months, with the launch of resources being delayed to mid 2024. As the fellowship activities were directly linked to the SMSS project and relied on the completion of these resources to commence evaluation, this delay necessitated an adjustment to the fellowship timeline. Additional challenges included difficulties in recruiting participants in Victoria and the inability to complete follow-up interviews, which further impacted the progress of the project. These challenges highlighted the need for flexible project planning and timelines to accommodate unforeseen delays and the need to prioritise further relationship building activities in Victoria.

Dissemination

Findings will be disseminated via a community feedback form, journal articles and conference presentations.

Community Feedback

A community feedback form (Appendix 3) will be distributed to all community members involved across any phase of SMSS.

Journal Articles/Publications

A publication describing this evaluation is currently being finalised and will be submitted to a high-impact international arthritis journal 'Arthritis Care and Research' in Q1 of 2025. A publication that describes the whole SMSS project, including the results of the evaluation is also in preparation.

Conference Presentations

Dr O'Brien and Mr Prehn will submit abstracts to co-present the results of this study at the following conferences:

- Australian Physiotherapy Association Scientific Conference (October 2025 - Adelaide)
- Ngar-wu Wanyarra Aboriginal and Torres Strait Islander Health Conference (October 2025 - Shepparton)
- Lowitja International Indigenous Health and Wellbeing Conference (June 2025 – Adelaide)

Future Plans

Culturally secure and ethical Aboriginal health research is predicated on it resulting in practical outcomes that benefit Aboriginal community members. Therefore, our next steps will involve implementing the feedback

identified in this evaluation and updating the resources accordingly. To do this, the SMSS community reference groups will be engaged to provide input into what they believe are the most important suggestions to be implemented into a new version of the resources. Additional funding opportunities will be sought to support the implementation of these changes. Funding is required to engage the graphic designer to make the relevant changes and for additional printing and distribution costs. Additional funding will also be sought to conduct an evaluation of the newly launched 'Staying Strong with Arthritis' website.

Community Feedback Summary

In line with community preferences, a community feedback infographic has been prepared and can be found in Appendix 3.

What problems did you try to solve, or gaps in knowledge did you try to fill?

A mismatch currently exists between the impact of arthritis and access to healthcare among Aboriginal and Torres Strait Islander people. Health information resources empower people to self-manage their symptoms and are an important component of arthritis care. The *Staying Moving, Staying Strong (SMSS)* project aimed to address this gap by creating health information resources specifically designed for Aboriginal peoples living with osteoarthritis, rheumatoid arthritis, lupus, and gout. These resources included brochures, videos featuring real-life stories, and a website. The final phase of this project involved evaluating these resources through feedback from Aboriginal and Torres Strait Islander participants to ensure they were culturally relevant, practical, and effective in promoting self-management of arthritis.

What did you discover during the course of the grant?

Participants found the SMSS resources highly relatable, both culturally and in terms of their arthritis experiences. They appreciated the inclusion of Aboriginal cultural practices (for example bush medicine), use of culturally relatable language, and striking Aboriginal artwork. The resources were also commended for being clear, accessible, and practical, helping users build confidence in managing their condition and engaging with healthcare providers. However, participants also suggested improvements, such as expanding references to cultural practices, such as including foods like kangaroo and emphasising the Aboriginal peoples' responsibilities to family. Participants also suggested further simplifying medical terms, providing more specific examples for exercise and surgery, using more colour, including additional illustrations, including the Aboriginal and Torres Strait Islander flags, including a statement about Aboriginal peoples; involvement in the development of the resources and translating the resources to Aboriginal languages for wider distribution.

Have the findings of the research already benefited people with musculoskeletal disease? How might the findings inform further research to help sufferers in the future?

The findings of this evaluation have benefited Aboriginal peoples living with arthritis by providing culturally secure, evidence-based resources that are identifiable and relatable. The insights gained during the evaluation will inform the development of future editions of the resources, ensuring that we are listening to community and implementing their feedback to enhance the cultural security of the resources.

Are you planning to continue the research?

This research is guided by the principle that Aboriginal health research should deliver practical benefits to Aboriginal peoples. Based on the feedback gathered during this evaluation, the resources will be updated to ensure they are as effective and culturally relevant as possible. To do this, we will ask the SMSS community reference groups for guidance. These groups will help identify the most important suggestions from the evaluation to include in the updated version of the resources. Their input will ensure that the changes reflect the needs and priorities of Aboriginal peoples. The team will also seek additional funding to support these updates. This funding will cover the costs of engaging a graphic designer to make the necessary changes, as well as printing and distributing the updated materials. Additionally, we plan to evaluate the newly launched Staying Strong with Arthritis website to ensure it meets community needs, values and preferences.

References

1. Loyola-Sanchez A, Hurd K, Barnabe C, editors. Healthcare utilization for arthritis by indigenous populations of Australia, Canada, New Zealand, and the United States: a systematic review. *Seminars in arthritis and rheumatism*; 2017: Elsevier.
2. Australian Institute of Health and Welfare. *Australia's Health 2018* Canberra: AIHW; 2018.
3. Brand CA, Harrison C, Tropea J, Hinman RS, Britt H, Bennell K. Management of osteoarthritis in general practice in Australia. *Arthritis Care Res.* 2014;66(4):551-8.
4. O'Brien P, R. Green, C. Lin, I. Flanagan, W. Conley, B. Bessarab, D. Coffin, J. Choong, PFM. Dowsey, MM. Bunzli, S. Understanding the impact and tackling the burden of osteoarthritis for Aboriginal and Torres Strait Islander people. *Arthritis Care Res.* 2022.
5. Dixon T, Urquhart DM, Berry P, Bhatia K, Wang Y, Graves S, Cicuttini FM. Variation in rates of hip and knee joint replacement in Australia based on socio-economic status, geographical locality, birthplace and indigenous status. *ANZ J Surg.* 2011;81(1-2):26-31.
6. Lin I, Green C, Bessarab D. 'Yarn with me': Applying clinical yarning to improve clinician-patient communication in Aboriginal health care. *Aust J Prim Health.* 2016;22(5):377-82.
7. Anderson K, Devitt J, Cunningham J, Preece C, Cass A. "All they said was my kidneys were dead": Indigenous Australian patients' understanding of their chronic kidney disease. *Medical Journal of Australia.* 2008;189(9):499-503.
8. Australian Government Department of Health. *The National Strategic Action Plan for Arthritis.* Canberra: Australian Government Department of Health 2019.
9. El Miedany Y, El Gaafary M, Sayed S, Palmer D, Ahmed I. Implementing shared decision making in clinical practice: outcomes of a new shared decision making aid for chronic inflammatory arthritis patients. *Journal of Patient Care.* 2016;2(2):117-23.
10. Taibanguay N, Chaiamnuay S, Asavatanabodee P, Narongroeknawin P. Effect of patient education on medication adherence of patients with rheumatoid arthritis: a randomized controlled trial. *Patient Prefer Adherence.* 2019;13:119-29.
11. Ndosu M, Adebajo A. *Patient education in rheumatoid arthritis: is the needs-based approach the way forward?* : Springer; 2015.
12. Peake RM, Jackson D, Lea J, Usher KJ. Investigating the processes used to develop and evaluate the effectiveness of health education resources for adult Indigenous people: A literature review. 2019;55(4-5):421-49.
13. O'Brien P, Conley B, Bunzli S, Bullen J, Coffin J, Persaud J, et al. Staying moving, staying strong: Protocol for developing culturally appropriate information for Aboriginal people with osteoarthritis, rheumatoid arthritis, lupus and gout. *PloS one.* 2021;16(12):e0261670.
14. Conley B, Bunzli S, Bullen J, O'Brien P, Persaud J, Gunatillake T, et al. Core Recommendations for Osteoarthritis Care: A Systematic Review of Clinical Practice Guidelines. *Arthritis Care & Research.* 2023;75(9):1897-907.
15. Conley B, Bunzli S, Bullen J, O'Brien P, Persaud J, Gunatillake T, et al. What are the core recommendations for gout management in first line and specialist care? Systematic review of clinical practice guidelines. *BMC Rheumatol.* 2023;7(1):15.
16. Conley B, Bunzli S, Bullen J, O'Brien P, Persaud J, Gunatillake T, et al. What are the core recommendations for rheumatoid arthritis care? Systematic review of clinical practice guidelines. *Clinical Rheumatology.* 2023;42(9):2267-78.

17. Conley B, Linton J, Bullen J, Lin I, Toovey R, Persaud J, et al. Integrating evidence from lived experience of Aboriginal people and clinical practice guidelines to develop arthritis educational resources: a mixed-methods study. *The Lancet Rheumatology*.
18. Bessarab D, Ng'andu B. Yarning about yarning as a legitimate method in Indigenous research. *International Journal of Critical Indigenous Studies*. 2010;3(1):37-50.
19. Gall A, Howard K, Anderson K, Diaz A, Garvey G. The Suitability and Acceptability of the Think-Aloud Method to Aboriginal and Torres Strait Islander Adults. *International Journal of Qualitative Methods*. 2023;22:16094069231182007.
20. Charters E. The use of think-aloud methods in qualitative research an introduction to think-aloud methods. *Brock Education Journal*. 2003;12(2).
21. Diaz A, McErlane J, Jeon MH, Cunningham J, Sullivan V, Garvey G. Patient Information Resources on Cardiovascular Health After Cancer Treatment: An Audit of Australian Resources. *JCO Glob Oncol*. 2023;9:e2200361.
22. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Medical Research Methodology*. 2013;13(1):117.

Appendices

Appendix 1: Example Yarning Schedule

PART 1 –INTRODUCTORY YARNING QUESTIONS	
Introduction and socio-demographics	<ul style="list-style-type: none"> • Social yarn • Acknowledgement of Country • Check received written consent and/or obtain verbal consent • Let participants know you have started the voice recorder/zoom recording • Describe structure of activity – First, recap some information about your condition and how you manage it, then we will do a think aloud activity – and we will do that with a brochure and some videos. I'll go through that process a little later.
BASELINE BELIEFS, KNOWLEDGE & MANAGEMENT	
Beliefs & Knowledge	<p>Can you tell me what you understand about your condition?</p> <ul style="list-style-type: none"> • What caused it? • Why did it start? What does it do? How does it work? • How severe is it? • What will happen over time? • What worries/fears do you have about it? • How was it diagnosed?
Management	<p>What do you do to look after it?</p> <ul style="list-style-type: none"> • Where did you learn this? • What affect does it have for you? How useful is it to you? • What do you think you need to do? (Why?)
THINK ALOUD EXERCISE	
Activity description & Example	<p>Now we are going to move into the second part of our yarn, which is called a 'think aloud' yarn. Think aloud is exactly what it sounds like, the point of this activity is for you to verbalise anything that comes to your mind as we complete an activity. In our case, the activity is looking through some health information resources, brochures and videos, that have been developed for Aboriginal people living with osteoarthritis. Doing a think aloud activity will help us to evaluate</p> <p>For the brochures, I want to get your first impressions of overall, and then we are going to move through the brochure section by section.</p>

		<p><i>Whilst you view this information can you please talk aloud everything you are thinking about as you do it? I may prompt you with some questions as you go, so as to encourage you to keep talking out loud everything you are thinking.</i></p>
<p>Prompts</p> <p>Observational</p> <p>Yarning/Think</p> <p>exercise</p>	<p>during</p> <p>Aloud</p>	<p>WHOLE BROCHURE - THEN SECTIONS</p> <ul style="list-style-type: none"> • Can you describe what you are seeing to me? • How does what you are seeing make you feel? • Does anything catch your eye or stand out? Why? <p><i>Use prompts to encourage the participant to keep talking if they stop, or if there are any non-verbal cues (stopping, frowning, concentrating, smiling, grimacing, looking distracted etc..)</i></p> <ul style="list-style-type: none"> • What are you thinking now? • What were you thinking when you stopped at ...? • I noticed you [reflect participants cue/response]. What were you thinking about then?
<p>Research Yarn Prompts after</p> <p>Think Aloud Activity:</p>		<ul style="list-style-type: none"> • What information do you take away about [condition] after viewing this material? • What will you do differently/the same as a result? • How does the information make you feel about living with [condition]? • What did you find helpful about the information? Why? • What did you find unhelpful? Why? • How could it be improved?
<p>Resource</p> <p>Checklist</p>	<p>Evaluation</p>	<ol style="list-style-type: none"> 1. Does the resource include visual aids that depict or contain information about Aboriginal and Torres Strait Islander peoples? 2. Does the resource include data about Aboriginal and Torres Strait Islander people? 3. Does the resource include Aboriginal and Torres Strait Islander design/artwork? 4. Does the resource provide evidence of leadership involvement and/or governance by Aboriginal and Torres Strait Islander people/communities and/or organisations? 5. Is there a source available in Aboriginal and Torres Strait Islander languages or is there a translation services available? 6. Is the language used strength-based and respectful to Aboriginal and Torres Strait Islander people? 7. Are consumers directed to further culturally safe support/information?
<p>VIDEOS</p>		<p>REPEAT THINK ALOUD FOR VIDEO</p>

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Appendix 2. Checklist for assessing the relevance of health information resources for Aboriginal and Torres Strait Islander peoples

1. Does the resource include visual aids (photographs, animations, infographics, and charts) that depict or contain information about Aboriginal and Torres Strait Islander people?
2. Does the resource include data about Aboriginal and Torres Strait Islander people?
3. Does the resource include Aboriginal and Torres Strait Islander design/artwork?
4. Does the resource provide evidence of leadership, involvement, and/or governance by Aboriginal and Torres Strait Islander people, communities, and/or organizations?
5. Is the resource available in Aboriginal and Torres Strait Islander languages or is there a translation service available?
6. Is the language used strengths-based and respectful to Aboriginal and Torres Strait Islander people?
7. Does the resource include a contact (phone number, e-mail, and website) for further support and information specifically for Aboriginal and Torres Strait Islander people?

Checklist developed by Gail Garvey²¹

Appendix 3: Community Feedback Infographic

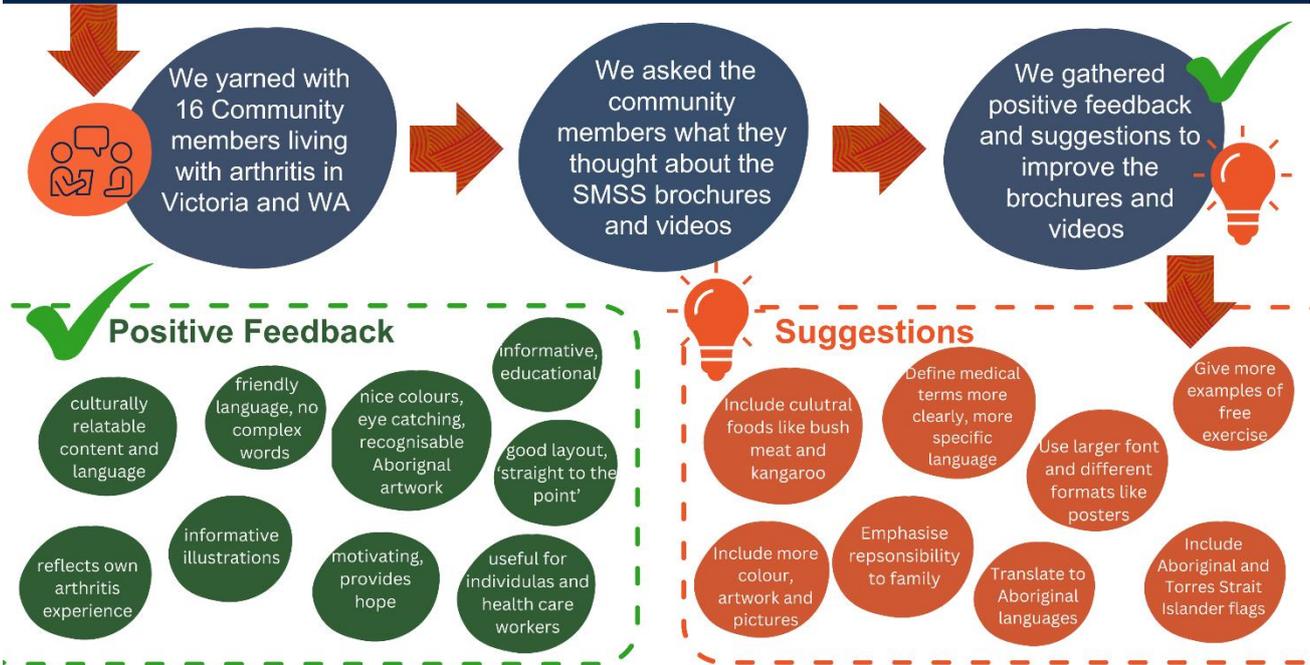


STAYING MOVING, STAYING STRONG EVALUATION: COMMUNITY FEEDBACK

Thank you for being involved in the Staying Moving Staying Strong (SMSS) evaluation project. In this project, we evaluated the brochures and community information videos developed with Aboriginal peoples with arthritis (osteoarthritis, rheumatoid arthritis, lupus and gout) in the Staying Moving Staying Strong project



Information brochures were developed for each arthritis condition, and 6 videos of community stories.



The research team will now work with the community reference groups in WA and Victoria to change the brochures and videos based on community members' feedback gathered in this project

Thank you again for being involved in this important project. If you have any questions or feedback feel free to contact Ivan Lin (WA: ivan.lin@uwa.edu.au) or Ryan Prehn (VIC: ryan.prehn@unimelb.edu.au)

Staying Moving Staying Strong artworks: Nicole Dickerson (Yamaji) & Thomas Marks (Wotjobaluk/Gunaikurnai)