Consumer and Community Involvement Program

WAHTN
Western Australian Health Translation Network

LIVING WITH BONE & JOINT CONDITIONS

COMMUNITY CONVERSATION SUMMARY REPORT

MARCH 2026

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Western Australian Future Health Research & Innovation Fund

Cancer Council WA

THE UNIVERSITY OF WESTERN AUSTRALIA

Harry Perkins Institute of Medical Research

CONTENTS

02.
Acknowledgements

03.
Background

06.
What is a Community Conversation?

07.
About the Community Conversation

08.
Promotion

09.
Agenda

10.
Structure and Process

11.
Key Insights of the Community Conversation

12.
Key Themes of the Community Conversation

13.
Community Conversation Questions and Responses

16.
Event Summary
What's next for the project

ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIProgram acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders, both past and present, and pay respect to Aboriginal communities of today.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

We extend our heartfelt gratitude to the consumers and community members who shared their lived experiences of bone and joint conditions.

BACKGROUND

Bone and joint conditions can have substantial impacts on mobility, independence, pain, mental wellbeing, participation in daily activities, and overall quality of life. These conditions affect people across the lifespan and may include osteoporosis and fractures, osteoarthritis, bone cancer or cancer that has spread to bone, and bone growth or development conditions.

The skeleton is a living organ made up of different types of bone cells that continually work together to maintain bone strength, structure, repair, and adaptation. In healthy bone, these cells use nutrients such as proteins, sugars, and fats in a coordinated and balanced way. However, in skeletal disease, this balance can become disrupted, contributing to changes in bone health, function, and repair processes.

The research team is investigating how bone and joint cells function in health and disease, with a particular focus on understanding how cellular metabolism changes during disease processes. Their work includes developing advanced imaging technologies that allow researchers to examine how individual cells within bone and joint tissues use nutrients at a high level of detail. The research aims to better understand which cellular pathways change first in disease and explore opportunities for more targeted and precise future treatments.

This Community Conversation was developed to bring together members of the community with lived experience of skeletal disorders, as well as family members and carers, to share their experiences and perspectives with researchers. The discussion aimed to better understand the real-world impacts of these conditions, identify priorities for future research, and ensure that future research directions remain relevant to the needs, priorities, and everyday experiences of consumers. The research team emphasised that lived experience is critical in helping researchers understand what outcomes matter most to people, including pain reduction, independence, mobility, confidence, and quality of life.

THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIProgram is a team committed to building connections between researchers, consumers, and organisations. This team provides tailored support, guidance, and resources to ensure consumer involvement is an integral part of research design, implementation, and translation.

By championing consumer and community involvement at local, state, and national levels, the CCIProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.

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Consumer and Community Involvement Program

THE RESEARCH TEAM

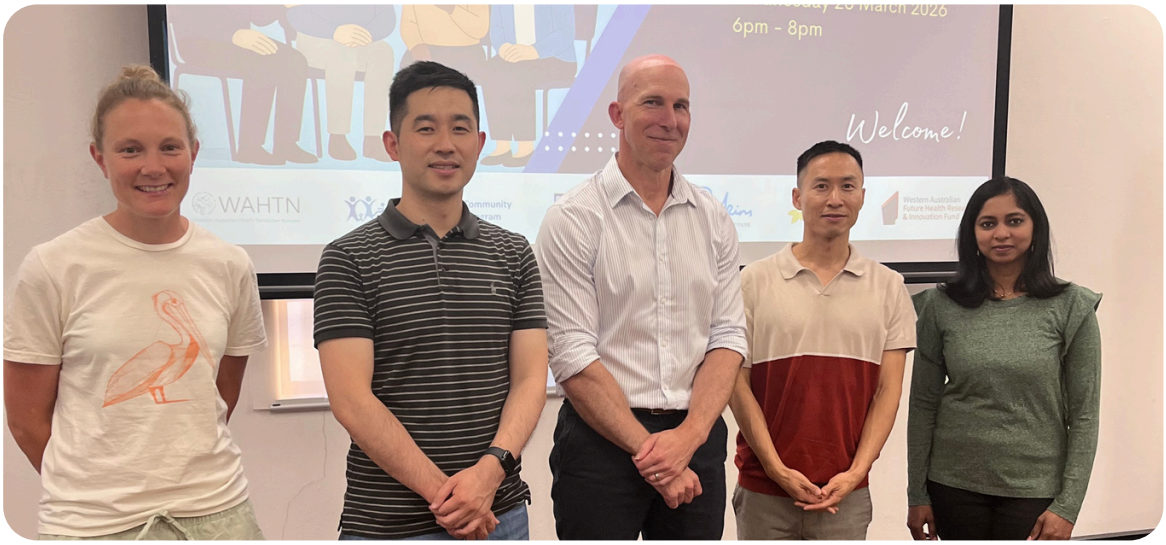
Dr Kai Chen
Dr Kai Chen is an Australian Research Council (ARC) Fellow and Laboratory Head at the Unviersity of Western Australia. With a background in medicine and biomedical science, his research sits at the intersection of advanced imaging, skeletal biology, and translational medicine. Dr Chen leads a team developing advanced imaging technologies to study how cells and tissues function in health and disease, and how this knowledge can support the development of improved therapies for conditions such as osteoarthritis and cancer.

Dr Bo He
Dr Bo He is a postdoctoral researcher at the Harry Perkins Institute for Medical Research. He completed his PhD at UWA, where his research focused on bone diseases including osteoarthritis and osteoporosis. During his postdoctoral training, Dr He expanded his expertise into ageing-related diseases, blood vessel biology, and cancer immunotherapy, with a focus on translating laboratory discoveries into improved treatments. He currently leads multiple consumer-oriented research projects and works closely with consumers and community members to help ensure research priorities align with real-world needs and lived experience perspectives.

Professor Nathan Pavlos
Professor Nathan Pavlos from UWA works closely with the research team in the areas of skeletal biology and translational musculoskeletal research.

The research team was supported during the Community Conversation by colleagues who assisted as scribes during the table discussions, including:

- Dr Marion Mundt, Edith Cowan University
- Dr Haritha Kirla, Harry Perkins Institute



WHAT IS A COMMUNITY CONVERSATION?

A Community Conversation is an event using an abridged version of the Word Café Method[1] and allows for the facilitation of informal, open conversations around a specific topic of importance. This method allows researchers to informally obtain a range of communal ideas from a group of people with lived experience around a particular topic specified prior to the event.[2],[3] Additionally, a Community Conversation provides an opportunity for attendees to reflect upon their own relevant experiences and contribute in meaningful discussions within a safe and comfortable space.

[1] Brown, J., & Isaacs, D. (2005). The World Cafe ́: Shaping our futures through conversations that matter. Barrett-Koehler
[2] Chieh-Ling Yang, Delphine Labbé, Brodie M. Sakakibara, Janneke Vissers & Marie-Louise Bird (2022) World Café- a community conversation: a Canadian perspective on stroke survivors needs for community integration, Topics in Stroke Rehabilitation, 29:5, 392- 400.
[3] Carter, E. W., Schutz, M. A., Gajjar, S. A., Maves, E. A., Bumble, J. L., & McMillan, E. D. (2021). Using Community Conversations to Inform Transition Education in Rural Communities. The Journal of Special Education, 55(3), 131–142.

ABOUT THE COMMUNITY CONVERSATION

The Community Conversation was held on 25 March 2026 and included twenty-two consumers from Western Australia, four members of the Consumer and Community Involvement Program, and five members of the research team. Members of the research team presented an overview of their project and acted as scribes within the table discussions.

The Community Conversation was designed to explore the lived experience of people affected by bone and joint conditions and identify priorities for future research. Discussions focused on the impacts of these conditions on everyday life, experiences of care and treatment, and areas where research could make the greatest difference over the next 10–15 years. Consumer insights will help inform future research directions and support research that is relevant to the needs and priorities of the community.

What parts of daily life are most affected by your bone or joint condition (or the condition of the person you care for), in ways that really matter to you?

Thinking about the care or treatments you've received, what has genuinely made a positive difference and what has felt like effort or burden without enough benefit?

If research could realistically improve one or two things for people with bone or joint conditions over the next 10–15 years, what should it focus on to make the biggest difference to everyday life?

How would you like people with lived experience to be involved in shaping or guiding this kind of research?

PROMOTION

The Research Team worked closely with the CCIProgram to recruit members of the West Australian community who had lived experience of bone and joint conditions to hear their experiences living with bone and joint conditons. We shared promotional communications across multiple channels.

Community Conversation - Living with Bone and Joint Conditions

Dr Kai Chen, Senior Research Fellow
School of Biomedical Sciences,
The University of Western Australia

Bone and joint conditions can affect pain, mobility, independence, work, sleep, and overall quality of life. While we have many treatments, people often still experience ongoing symptoms, side effects, or uncertainty about what will help. A big reason is that we don't always know exactly what is changing inside tissues during disease, particularly which cell types change first, and how those cells use energy and nutrients.

A simple idea: different cells "eat" differently. Our skeleton is living tissue. It contains different cell types with different jobs, including bone-building cells (osteoblasts) – make and repair bone, bone-resorbing cells (osteoclasts) – remove old bone, bone-sensing cells (osteocytes) – coordinate repair and adaptation. Because their jobs are different, these cells may use protein (amino acids), sugar (glucose), and fats (lipids) differently.

Health vs disease. In health, nutrient use across these cells is generally balanced and well-coordinated. In disease, the pattern can shift. For example:
- **Osteoporosis**: bone-building can slow down while bone breakdown becomes relatively more active, contributing to bone loss and fracture risk.
- **Osteoarthritis:** joint tissues can develop persistent inflammation and cartilage can deteriorate; how cells use nutrients may change as the joint environment becomes stressed.
- **Cancer in bone:** tumor cells can invade bone and may compete for nutrients to support their growth, which can also disturb normal bone renewal.

Our research approach. We are developing novel imaging technologies that help us directly see what is happening inside bone and joint tissues. Where nutrients go (into which cells, and where inside the cell)? Which cells change first during disease? How different cell types respond to inflammation, aging, or cancer? If we can measure changes in the right place (the right cell type, at the right time), we can identify more precise targets for treatment.

What we hope to learn from you? This event is about listening to lived experience. Your input helps ensure research addresses real priorities. We would especially like to understand:
1. What parts of daily life are most affected, in ways that really matter to you
2. What has genuinely helped — and what has felt burdensome without enough benefit
3. What research should prioritise over the next 10–15 years to make the biggest difference

Important note: This session is for discussion and research planning. It is not a medical appointment and we cannot give personal medical advice. Please share only what you feel comfortable sharing.

Contact: Dr Kai Chen, kai.chen@uwa.edu.au ; Dr Bo He, bo.he@perkins.org.au; Professor Nathan Pavlos, nathan.pavlos@uwa.edu.au

Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

AGENDA

5.45pm	**Registrations**	**All**
6.00pm	**Welcome** • Acknowledgement of Country & Acknowledgement of Lived Experience • Welcome to the workshop • Introductions	**Caroline Jones**
6.10pm	**Presentation**	**Dr Kai Chen**
6.25pm	**Process of the evening**	**Caroline Jones**
6.30pm	**Question 1**: What parts of daily life are most affected by your bone or joint condition (or the condition of the person you care for), in ways that really matter to you?	**All**
6.50pm	**Question 2**: Thinking about the care or treatments you've received, what has genuinely made a positive difference and what has felt like effort or burden without enough benefit?	**All**
7.10pm	**Question 3**: If research could realistically improve one or two things for people with bone or joint conditions over the next 10–15 years, what should it focus on to make the biggest difference to everyday life? How would you like people with lived experience to be involved in shaping or guiding this kind of research?	**All**
7.30pm	**Table facilitator feedback**	**Table facilitators**
7.45pm	**Next Steps**	**All**
7.55pm	**Evaluation & Honorarium information**	**All**
8pm	**Close**	

STRUCTURE AND PROCESS

Attendees joined the Community Conversation in the Margaret Fairweather Education Space at the University of Western Australia. They were introduced to the research team and the Consumer and Community Involvement Program before the 22 consumer attending were assigned to one of three tables.

Each table had a room facilitator from the CCIProgram to assist attendees and guide them through the questions and discussions. Each room also had a scribe from the research team to record the feedback provided by the attendees.

Facilitators presented 3 questions to the Consumers in each room:

- Q1. What parts of daily life are most affected by your bone or joint condition (or the condition of the person you care for), in ways that really matter to you?
- Q2. Thinking about the care or treatments you've received, what has genuinely made a positive difference and what has felt like effort or burden without enough benefit?
- Q3a. If research could realistically improve one or two things for people with bone or joint conditions over the next 10–15 years, what should it focus on to make the biggest difference to everyday life?
- Q3b. How would you like people with lived experience to be involved in shaping or guiding this kind of research?

Each question was allocated 20 minutes for discussion. Question 3 was split into 15 minutes for part a and 5 minutes for part b. The comments, feedback and suggestions were all captured by each scribe and are presented in the following pages of this report.

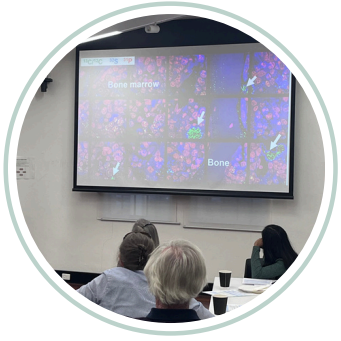
KEY INSIGHTS OF THE COMMUNITY CONVERSATION

Chronic pain affects far more than joints or mobility

Consumers consistently described bone and joint conditions as affecting nearly every aspect of life, including independence, sleep, work, relationships, mental health, motivation, social connection, and quality of life. Pain and fatigue were not discussed as isolated symptoms, but as experiences that shaped daily functioning, identity, and future outlook.

Focus on prevention, earlier intervention, and better pain management

Across discussions, attendees repeatedly prioritised research into improved pain management, preventative approaches, earlier diagnosis, and new treatments. Consumers expressed interest in therapies and interventions that could reduce pain, improve function, support healthier ageing, and provide more effective options for managing bone and joint conditions, rather than only responding once conditions become severe.



Consumers want to be listened to, believed, and meaningfully involved

A recurring and emotionally resonant discussion point was the experience of feeling dismissed, misunderstood, or not taken seriously by healthcare professionals and broader society. Consumers strongly emphasised the importance of lived experience informing research, healthcare design, communication, and decision-making, with repeated calls for consumers to have “a voice throughout the project” and to be genuinely heard.

KEY THEMES OF THE COMMUNITY CONVERSATION

Theme	Consumer Comments
Chronic pain affects all aspects of life	• “almost all part of life affected can not do daily housework” • “pain limits motivation, ability to care for loved ones” • “overall quality of life”
Consumers want more effective pain management and treatment options	• “research in pain management” • “Technology to stop the pain by block the nerve” • “an injection/ pill help stimulate cartilage growth”
Prevention and early intervention matter	• “Prevention better than cure” • “educate younger people on long term health” • “preventative therapies→ in early ages”
Consumers feel arthritis and pain are dismissed	• “even doc don’t believe the Pain was real” • “Arthritis is dismissed” • “being discriminated, need to be treated as equal, respectfully”
Consumers want holistic, person-centred care	• “See the whole person not just cells” • “Holistic - Value Based Healthcare” • “patients know their pain/condition”
Loss of independence and identity	• “losing control” • “losing freedom taken for granted before” • “don’t want to ask for help all the time but pain limits ability”
Exercise is important but difficult to sustain	• “exercise recognised as necessary and works” • “going to the gym makes you feel better” • “finding exercise routine is difficult”
Access and cost are major barriers	• “lots of barriers, not subsidised = financial burden” • “helping all kinds of treatments in easy way so anybody can access treatments without cost”

COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

The following pages contain the responses and thoughts shared by attendees at the Community Conversation.

QUESTION 1

WHAT PARTS OF DAILY LIFE ARE MOST AFFECTED BY YOUR BONE OR JOINT CONDITION (OR THE CONDITION OF THE PERSON YOU CARE FOR), IN WAYS THAT REALLY MATTER TO YOU?

PROMPTS:

- pain,
- fatigue/ reduced energy,
- mobility/ balance,
- sleep,
- mental health,
- work/roles,
- independence,
- social life,
- flare-ups,
- falls/fracture fear,
- access to services

Consumers described wide-ranging impacts on daily life arising from bone and joint conditions, with many discussions focusing on pain, mobility, fatigue, loss of independence, and the emotional burden of living with chronic and often unpredictable symptoms. While the severity and nature of impacts varied between individuals, attendees consistently described conditions affecting their ability to undertake everyday activities, maintain social connections, continue working, exercise, travel, sleep, and participate in activities that contribute to quality of life and identity. Many consumers also discussed the psychological impact of living with persistent pain and uncertainty, including stress, frustration, isolation, reduced motivation, and fear about future decline.

Mobility, Physical Function and Independence

Difficulties with mobility and movement were among the most frequently discussed impacts. Consumers described pain, stiffness, reduced flexibility, fatigue, and fear of falling affecting walking, climbing stairs, getting up from sitting positions, driving, and completing household tasks. Several attendees described needing to carefully manage or reduce activities depending on pain levels and physical capacity on a given day.

Attendees spoke about the loss of activities that were important to them personally, including dancing, gardening, cycling, travelling, caring for grandchildren, socialising, and maintaining their homes. Some attendees described frustration at no longer being able to undertake work requiring physical activity or manual hand use. Several consumers described a sense of “losing control” or “losing freedom” as their conditions progressed, particularly where mobility limitations reduced independence or increased reliance on others for support.

Question 1(cont)

Pain, Fatigue and Sleep

Persistent pain was a dominant discussion point across all groups. Consumers described chronic pain affecting nearly all aspects of daily life, including motivation, sleep, emotional wellbeing, exercise, work, and relationships. Some attendees described pain as unpredictable or occurring “for no reason”, while others noted symptoms worsening during mornings, cold weather, or seasonal changes.

Fatigue was also discussed frequently, including exhaustion associated with pain, reduced activity, poor sleep, medication use, and the effort required to undertake basic daily tasks. Some consumers described only having enough energy to complete essential activities such as hygiene, shopping, or work, with little remaining capacity for social activities, hobbies, or exercise. Several attendees discussed sleep disruption caused by pain, including frustration when unable to sleep comfortably.

Exercise, Movement and Self-Management

Exercise and movement were consistently recognised by consumers as important for maintaining mobility and managing symptoms. Attendees described yoga, stretching, walking, gym programs, cycling, and keeping active as strategies that improved physical and mental wellbeing.

Many attendees expressed a strong view that “keeping moving” was beneficial, with some attendees sharing practical strategies such as using pillows between the knees, cold packs, or tailored exercise routines to manage symptoms.
At the same time, consumers acknowledged challenges in maintaining exercise routines, particularly where pain, fatigue, gym environments, motivation, financial barriers, or fear of injury made participation difficult. Some attendees expressed interest in preventative or supported exercise programs delivered through healthcare or gym settings.

Mental Health and Emotional Impact

Consumers described significant psychological impacts associated with chronic pain and reduced function. Discussions included stress, anxiety, frustration, depression, isolation, fear about future deterioration, reduced confidence, and uncertainty about what might happen next.

Some attendees described mood changes associated with pain, including irritability, withdrawal from social interaction, and reduced motivation. A smaller number of consumers discussed suicidal thoughts or severe emotional distress linked to persistent pain and reduced quality of life. However, views varied between consumers, with some attendees stating that their condition had little impact on their mental health, while others described the emotional effects as substantial.

Question 1(cont)

Social Relationships, Identity and Daily Participation

Consumers described impacts on relationships, social involvement, travel, intimacy, and ability to engage in meaningful activities. Some attendees discussed avoiding social situations, withdrawing from activities they previously enjoyed, or feeling unable to travel due to pain associated with flying, walking, or sleeping in unfamiliar environments. Several consumers also discussed the emotional impact of needing to ask for help or becoming increasingly dependent on carers, family members, or support people. One group noted that only one attendee at their table currently had a carer, though support was described as highly valuable and often necessary.

Attendees also reflected on the broader impact of conditions on identity, confidence, and dignity, particularly where symptoms were not outwardly visible.

Experiences of Dismissal, Recognition and Financial Burden

Some consumers discussed feeling that arthritis and chronic pain conditions were not always recognised or taken seriously by others, including healthcare professionals. Attendees referred to arthritis and related conditions as “hidden diseases” and described experiences of having their pain dismissed or minimised.+

Financial impacts were also raised, including costs associated with medications, healthcare, travel to Perth for services, and accessing supports that were not subsidised. Consumers discussed frustration regarding the cumulative burden of ongoing treatment and symptom management.

A number of attendees also reflected on ageing, expressing concerns that ageing either contributed to worsening symptoms or increased vulnerability to developing bone and joint conditions over time.

QUESTION 2

THINKING ABOUT THE CARE OR TREATMENTS YOU'VE RECEIVED, WHAT HAS GENUINELY MADE A POSITIVE DIFFERENCE AND WHAT HAS FELT LIKE EFFORT OR BURDEN WITHOUT ENOUGH BENEFIT?

PROMPTS:

- getting an accuratediagnosis,
- cultural safety/ fit with your circumstances
- medications or treatments and their side effects,
- physio, exercise or lifestyle advice,
- uncertainty about whether treatment is 'working'
- bone scans,
- information quality/ explanations
- cost/time/travel,
- navigating referrals,
- support networks,
- surgery decisions

Consumers described a wide range of treatments, therapies, medications, and self-management strategies that had varying levels of effectiveness in managing pain, mobility, and quality of life. Across the discussions, there was strong recognition that no single treatment worked for everyone, with many attendees describing a process of trial and error to identify combinations of therapies that provided relief. Exercise-based approaches, hydrotherapy, medications, and supportive healthcare relationships were commonly identified as helpful, while consumers also discussed frustration with ineffective treatments, medication side effects, costs, and experiences of not feeling listened to or taken seriously by healthcare professionals.

Exercise, Movement and Physical Therapies

Exercise and movement-based therapies were among the most consistently discussed positive strategies. Consumers described gym programs, walking, swimming, cycling, yoga, pilates, chair pilates, hydrotherapy, and spa or thermal therapies as helping maintain mobility, flexibility, strength, and emotional wellbeing.
Several attendees described exercise as important for healing, maintaining movement, and easing stiffness, although some consumers noted that exercise did not necessarily reduce pain itself. Hydrotherapy was frequently discussed positively, particularly for flexibility and pain management.

Consumers also described using physiotherapy to better understand appropriate exercises and movement techniques, while some attendees discussed practical supports such as wrist bands, massage chairs, massage guns, TENS machines, and pillows between the knees as helpful symptom management tools. At the same time, some consumers stated that exercise-based approaches had limited effect for them personally, reinforcing the variability of treatment experiences.

Question 2(cont)

Medication and Pain Management

Medication use was a major area of discussion, with many consumers describing the complexity of managing multiple medications across different conditions. Attendees referred to using anti-inflammatory medications, corticosteroid injections, pain relief medications, methotrexate, low-dose radiotherapy, supplements, and monthly injections. Consumers described mixed experiences with medications and injections. Some attendees reported positive outcomes from cortisone injections, Synvisc injections, magnesium supplements, and combined medication and exercise approaches. Others described minimal benefit from medications or ongoing frustration with persistent pain despite treatment.

Several consumers discussed side effects, financial burden, and the challenges of managing medications for multiple health conditions simultaneously. Some attendees also described using complementary or alternative therapies, including turmeric, fish oil, glucosamine, collagen powder, acupuncture, rose hip supplements, and massage therapies, with varying perceptions of effectiveness.

Information, Support and Self-Advocacy

Consumers frequently discussed the importance of receiving clear information about available treatment options. Some attendees expressed frustration about not being informed of the “full scenario” of available treatments, while others described relying on internet searches or peer discussions to identify possible therapies and supports. Attendees also discussed the importance of supportive healthcare relationships and feeling listened to by clinicians. Several consumers described negative experiences where arthritis or chronic pain was not taken seriously, or where they felt dismissed, discriminated against, or treated disrespectfully by healthcare professionals.

Consumers emphasised that people living with these conditions “know their pain” and wanted healthcare providers to recognise and respect lived experience. Some attendees also reflected on the need for consumers themselves to ask questions, seek information, and advocate for appropriate care.

Question 2(cont)

Broader Challenges and Burdens

Alongside discussions of treatments that helped, consumers also described significant burdens associated with ongoing care and symptom management. These included the cost of medications and therapies, navigating multiple treatments, uncertainty about effectiveness, and the emotional exhaustion of continually trying new approaches. Some attendees described a willingness to “try anything” in search of relief, particularly where pain remained poorly controlled. Carers also reflected on the difficulty of encouraging family members or loved ones to engage in exercise or self-management strategies consistently.

A recurring discussion point across groups was that effective management often involved combining multiple approaches rather than relying on a single treatment alone.

QUESTION 3

3A. IF RESEARCH COULD REALISTICALLY IMPROVE ONE OR TWO THINGS FOR PEOPLE WITH BONE OR JOINT CONDITIONS OVER THE NEXT 10–15 YEARS, WHAT SHOULD IT FOCUS ON TO MAKE THE BIGGEST DIFFERENCE TO EVERYDAY LIFE?

3B. HOW WOULD YOU LIKE PEOPLE WITH LIVED EXPERIENCE TO BE INVOLVED IN SHAPING OR GUIDING THIS KIND OF RESEARCH?

PROMPTS:

Question 3A

- Prevention/ slowing progression,
- symptom control,
- reducing fractures,
- improving pain, fatigue or physical function
- staying independent for longer
- long term side effects of treatment
- personalized nutrition/exercise advice,
- metabolically targeted therapies,
- what “success” looks like in real life
- best ways to share results,
- barriers to participating in research.

Consumers identified a broad range of priorities for future research, with discussions focusing strongly on prevention, pain management, earlier diagnosis, access to effective treatments, education, and more personalised approaches to care. Across groups, attendees consistently linked research priorities to improving quality of life, maintaining independence, reducing pain, and making effective supports more affordable and accessible. Consumers also emphasised the importance of research that considers the “whole person” and the practical realities of everyday life, rather than focusing solely on clinical symptoms.

Pain Management and New Treatments

Pain management was one of the most frequently discussed research priorities. Consumers expressed strong interest in research exploring more effective ways to reduce or manage pain, including treatments that could reduce reliance on medications or minimise side effects.

Attendees discussed interest in new therapies and technologies, including stem cell treatments, gel injections, radiation therapy, cartilage regeneration, nerve-blocking technologies, and more personalised treatment approaches. Some consumers specifically expressed interest in treatments that could stimulate cartilage growth or delay the need for joint replacements.

Several attendees also called for more comparative research examining the effectiveness of medication, exercise, gym-based interventions, physiotherapy, and other non-pharmaceutical approaches over the longer term.

Question 3(cont)

Prevention, Early Intervention and Education

Prevention emerged as a major area of discussion across groups. Consumers described a strong desire for research and public health initiatives focused on preventing deterioration, delaying disease onset, and supporting healthier ageing.

Attendees discussed the importance of educating younger people, parents, and communities about long-term joint and bone health, including exercise, diet, injury prevention, workplace impacts, and the risks associated with some sports or repetitive physical activities. Consumers also expressed interest in research into genetic factors, family history, menopause-related changes, nutrition, traditional diets, and early interventions that may help identify or reduce future risk. Several attendees emphasised the view that “prevention is better than cure” and discussed the need for community-wide education and preventative programs delivered at low cost and across metropolitan and regional areas.

Diagnosis, Access and Healthcare Systems

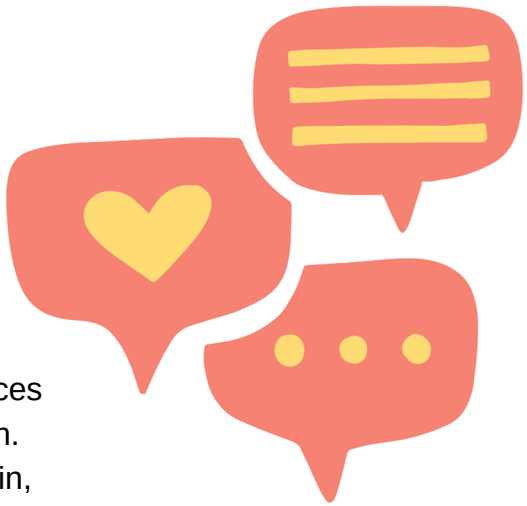
Consumers frequently discussed the importance of improving diagnosis pathways and access to knowledgeable healthcare professionals. Attendees described frustration regarding delayed diagnosis, inconsistent advice, and difficulties accessing appropriate services or supports.

Several consumers highlighted the need for greater GP education regarding arthritis, autoimmune conditions, pain management, and referral pathways. Some attendees suggested that pharmacists were at times more informed than general practitioners regarding medication management and available supports.

Consumers also called for improved access to affordable treatments, exercise programs, diagnostic services, and specialist supports. Financial burden and inequitable access were recurring discussion points, particularly for people requiring multiple treatments or living outside metropolitan areas. Some attendees described a desire for more holistic or value-based healthcare approaches that consider the broader impacts of these conditions on daily life, wellbeing, and function.

Research into Specific Populations and Lived Experience

Consumers highlighted the importance of research involving diverse populations and experiences, including younger people, Indigenous communities, people from culturally diverse backgrounds, and those experiencing menopause-related bone or joint changes. Attendees also discussed the importance of understanding the “root causes” of conditions and supporting longitudinal research to better understand progression over time.
Several consumers expressed interest in more direct interaction between researchers and people with lived experience, including opportunities for ongoing conversations and knowledge sharing.



EVENT SUMMARY

The Community Conversation provided a rich and focused discussion, enabling researchers to explore the lived experiences of people affected by bone and joint conditions in greater depth. Consumers shared a wide range of perspectives relating to pain, mobility, independence, treatment experiences, emotional wellbeing, and priorities for future research.

Attendees described the session as valuable and appreciated the opportunity to contribute directly to research discussions, connect with others living with similar conditions, and share insights drawn from their everyday experiences. Many consumers expressed interest in remaining involved in future research and consumer involvement opportunities.

The event strengthened researchers' understanding of the real-world impacts of bone and joint conditions and highlighted the importance of ensuring future research remains relevant to the needs, priorities, and lived experiences of the community.

WHAT'S NEXT FOR THIS PROJECT?

Insights gathered through the Community Conversation will help inform the future direction of the research program, including consideration of the outcomes and priorities that matter most to people living with bone and joint conditions. The findings will support the research team in strengthening the relevance and translational focus of their work, particularly in relation to pain management, prevention, quality of life, and the broader impacts of skeletal disease on everyday life.

The research team also identified the importance of continuing to involve people with lived experience as the project progresses. Consumer perspectives highlighted opportunities for future involvement in shaping research priorities, communication approaches, and translation of findings to the broader community.

The findings from this Community Conversation may also contribute to future funding applications, collaborative research activities, and ongoing consumer and community involvement initiatives associated with the project.

WANT TO KNOW MORE?

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