MOVE muscle, bone & joint health

Stakeholder consultation around the *MOVE* Research and Knowledge Exchange Strategy 2015-2019

Contents

Acknowledgements

*MOVE muscle, bone & joint health*gratefully acknowledges the stakeholders' support and contribution to the development of the Strategy. The Research and Knowledge Unit contributed to the writing of this report. The team members are Dr Andrew Briggs, Dr Debra Hopkins, Dr Kim Wark, and Lisa Bywaters. Dr Debra Hopkins and Lisa Bywaters collected the consumer stakeholder focus group data. Donna Watson provided assistance with report presentation and editing.

Suggested citation
Hopkins D (2014): Stakeholder consultation around the *MOVE muscle, bone & joint health* Research and Knowledge Exchange Strategy 2015-2019. Melbourne: *MOVE muscle, bone & joint health.*

Executive Summary

The *MOVE muscle, bone & joint health* Research and Knowledge Exchange Strategy 2015-19 (the Strategy) is a five year plan to guide the organisation's activities in research and knowledge exchange. It will help us achieve our long-term commitment - *to improve the quality of life of people who have, or are at risk of developing, musculoskeletal (MSK) conditions*.

As a key step in the development of the Strategy, *MOVE* consulted stakeholder groups. The groups were health professionals, researchers and consumers. This consultation took place between December 2013 and June 2014. *MOVE* invited feedback from stakeholder and consumer groups in order to gauge their responses to *MOVE*'s proposed five year plan for research and knowledge exchange as presented in the Strategy. The consultation involved three distinct processes: preliminary discussion and consultation with clinical and research stakeholders to inform the Strategy in draft form, verification with these same stakeholders via SurveyMonkey™, and focus group based consultation with consumers in metropolitan and rural Victoria. A pre-survey questionnaire was also disseminated to consumers.

Clinical and research stakeholders participating in the preliminary and verification phases of the consultation were asked to review the full *MOVE* Research and Knowledge Exchange Strategy 2015-2019. Consumers taking part in the focus groups were asked to review a 'Plain Language Summary' (PLS) of the Strategy developed by A&OV. Consumers also had access to the full version of the Strategy upon request.

The purpose of the consultations - via researcher and clinical stakeholder targeted SurveyMonkey, and consumer targeted pre-focus group survey and focus groups - was to elicit comment specifically on core components of the Strategy - priority areas, approaches and principles. Research and clinical stakeholders offered suggestions for adjustments to the Strategy, focusing on verification of the core components of the Strategy as identified in the preliminary discussion and drafting exercise. Consumers offered suggestions for inclusion in the Strategy of particular populations, and made recommendations for a greater focus on supporting general practice to deliver the outcomes of research and contemporary information to patients. Additionally, the consumer consultation offered valuable insights into the many considerations involved in consumer engagement.

1. Context

MOVE is increasingly establishing a research and knowledge exchange footprint in the MSK health sector, supported by donors, consumers, peak health professional and academic organisations, and researchers. As *MOVE* and its research, policy and knowledge exchange footprint continue to grow, an organisational strategy is required to inform activity and investment decisions.

The Strategy contributes to the overall organisational focus to establish a knowledge hub for MSK health and enhanced consumer participation in research. The three considerations below provide important background to the development of the Strategy.

1. A key principle of the Strategy is that in line with contemporary research practice, research activities are planned, designed and carried out with a focus on making the best use of research resources, evidence and knowledge to inform policy and practice
2. Our commitment to applying research knowledge to practice and policy domains in health care is indicated in the amended title of the document – from 'Research Strategy' to 'Research and Knowledge Exchange Strategy'
3. There is also a growing interest in how best to involve consumers in health research and policy and planning. The development of the Strategy embeds A&OV's commitment to ensuring that consumers are involved in shaping our research activities, and assists us in identifying how best to involve consumers. To this end *MOVE* asked consumers to comment on a plain language summary (PLS) of ther Strategy to provide an overlay of perspective and experience derived from living with a musculoskeletal condition

2. Research and Knowledge Exchange at A&OV

2.1 Background

MOVE has been developing a research footprint for almost twenty years. Over this period, and in response to national and international shifts in research culture and practice, we have experienced important organisational learning about research, and the ways we can achieve the best return on investment, while responding to the continually changing research environment.

Our first Research Strategy was launched to organise research activities for the period 2009-2011. It committed to developing research in the sector through provision of grants and scholarships across priority areas that had been identified through consumer surveys, program outputs and external literature reviews. Under this Strategy partnerships resulted in the production of educational materials, medical and community education, and promotion of links between organisations involved in the care and support of people with MSK conditions.

As research has become increasingly resource-heavy, scarcity of funding and increased competition for funds has resulted in research activities being increasingly and necessarily a practice of *partnerships*. This means that researchers from different institutions pool their resources to attract research funding. At the same time the nature of the problems that research addresses in the real world is changing. Importantly, solutions to health-related problems must be translated into practical resources for end users (e.g. professionals, policy makers and consumers) to improve health outcomes and system efficiencies.

2.2 Development of the *MOVE* Research and Knowledge Exchange Strategy 2015 - 2019

The Strategy has been developed through consultations with key opinion leaders in Victoria, a review of current Australian state and federal government policies and initiatives as well as comparable international strategies, and contemporary literature reporting priority research areas in MSK health and knowledge exchange.

The Strategy was developed around identifying priority areas for activity and investment in research and knowledge exchange. To this end a range of sources were accessed, and the information synthesised to deliver the priority areas for activity and investment. Sources included:

- Australian policy frameworks for prevention and management of chronic health conditions
- Data acquired from sector-specific surveys, including
    - Exploring the needs of Arthritis and Osteoporosis Victoria stakeholders: Consumers (Arthritis & Osteoporosis Victoria) [1]
    - Exploring the needs of Arthritis and Osteoporosis Victoria stakeholders: Health professionals (Arthritis & Osteoporosis Victoria) [2]
    - The ignored majority: The voice of arthritis 2011 (Arthritis Australia)[3]
    - Whose problem is it anyway?: The voice of GPs on arthritis 2012 (Arthritis Australia)[4]
- Published literature on research priorities for arthritis and MSK health[5-9] and research translation [10], [11], [12]
- The report, A problem worth solving: The rising cost of musculoskeletal conditions in Australia (A&OV)[13].

The draft was discussed internally within the Research and Knowledge Unit and Executive Management team. Comment was then invited from external clinical and research stakeholders, and thereafter consumers.

3. The Consultation

The purpose of the consultation was to deliver a multi-perspective overlay of opinion and experience to the Strategy. Providing stakeholders with an opportunity to comment on the Strategy facilitates buy in, enhancing ongoing relationship building and collaboration, and provides a potential platform for establishing new collaborations. Moreover, clinical and research stakeholders bring their varied and contextualised formal knowledge to the Strategy. This is especially valuable when it comes to ensuring that the Strategy appropriately considers the practical requirements of adopting research findings into routine practice in a range of different health care settings.

Involving clinical and research stakeholders in research activities such as planning is common. Involving consumers in such activities has, by contrast, occurred only relatively recently, and there is ongoing discussion around the best approaches to, and principles of, consumer involvement in this regard. Appendix D provides further background on some of these discussion points.

3.1 Clinical and Research Stakeholder Consultation

The clinical and research stakeholder consultation via SurveyMonkey™ followed on from preliminary discussions with local MSK clinical and research opinion leaders. It functioned as a verification process to ascertain if the important/key concepts from these stakeholder discussions were reflected in the Strategy.

In total, ten clinical and research stakeholders from Victoria completed a SurveyMonkey questionnaire (response rate: 20.8%). The questions were designed to gather feedback on the core components of the Strategy including the intent, purpose, and the identification of the priorities and guiding principles (see Appendix A). These stakeholders were purposely sampled from an existing *MOVE* database of active clinicians and researchers in MSK health in Victoria. Stakeholders represented disciplines where scope of practice included MSK health.

3.2 Consumer Consultation

In total twenty-one consumers participated in three focus groups to review the Strategy. An *Expression of Interest* advertisement was placed in our members' magazine *Update,* on our website, and was circulated through various communications to our volunteers and Peer Support Groups. Although no formal sampling strategy was devised, all attempts were made to sample participants living with a range of MSK conditions, and at various life and illness stages, and living in Melbourne and in rural or remote Victoria. Carers, family members and support people were also encouraged to participate. The consumer group who expressed interest to participate was rather narrow: people over 70 years of age and living with osteoarthritis being the most common consumer characteristics (see Appendix C).

Potential participants who responded to the *Expression of Interest* advertisement by email or phone were provided with the opportunity for open discussion around the purpose of the Strategy, the consultation process, and the use of the data. They were able to ask questions, clarify their understandings of what was involved, including the extent and nature of their involvement, their ownership over data and any other concerns. Participants were also asked to elect for either a face-to-face focus group or a focus group via conference call. Only two participants expressed a preference for the latter.

Potential participants were emailed a Participant Information brochure explaining the consultation process. They then received a follow up phone call 72 hours later to discuss the information provided. It also provided the opportunity for discussion around the importance of involving consumers in developing the Strategy, how focus groups work in practice and how the short pre-focus group survey would be used to help direct the group discussion. Once participants agreed to be involved, the PLS, pre-focus group survey and consent forms were emailed to participants, with clear instructions for completion and return.

One week before the scheduled focus group all participants were again contacted by phone in order to provide clarification around any queries about the process, to enquire about progress with reviewing the Plain Language Summary (PLS) of the Strategy and to confirm attendance. During these discussions some consumers commented that they found the Strategy 'hard going' - describing it as clunky, repetitive and 'not easy to read'. On such occasions some time was spent talking through a selected section of the Strategy, and this involved illustrating a sentence or paragraph with an example. This process appeared to help consumers' confidence in participating in the consultation.

This investment in time taken to establish a rapport with participants, by encouraging questions and listening to their motivations to participate in the consultation was rewarded with both a very high participation rate and a very high retention rate. In total 24 consumers enquired about the focus groups and 21 consumers participated in the consultation. One consumer withdrew for medical reasons, one consumer was unable to participate in the conference call on the arranged evening, and another consumer withdrew for unstated reasons. All participants completed their consent forms, twenty completed surveys.

In total three focus groups took place between 1st May and 17th June 2014. One focus group with six participants was held at the *MOVE* offices in Melbourne, another focus group with seven participants took place via conference call and the final focus group with eight participants was held at a small remote community in Victoria. One carer was recruited to the focus groups.

The first two focus groups were facilitated by two *MOVE* staff members, while the final group was facilitated by one *MOVE* staff member. Focus groups lasted for approximately 90 minutes. All focus groups were audio-recorded. One week after each focus group the participants were contacted by phone and personally thanked for their interest and contributions. They were invited to offer further, or reiterate ongoing thoughts. Field notes were collected. During these conversations participants expressed gratitude to *MOVE* for undertaking this work, and for the work that we do. About half expressed an unsolicited interest in further involvement and all were keen to receive the consultation report.

4. Findings

4.1 Clinical and Research Stakeholder Survey Data

Overall, stakeholders thought that the purpose of the Strategy was clear, as was A&OV's intended role as a MSK sector leader. All respondents agreed that we needed a Strategy. The majority of respondents agreed with the appropriateness of the priority areas, investment strategies and principles of the Strategy, with 8 of 10 agreeing or agreeing strongly with these domains of the Strategy (see Appendix A).

Respondents had an opportunity to provide additional information via free text boxes. Two respondents commented on the need for precision around the terminology used in the Strategy (e.g. distinguishing between research and implementation). The Strategy has been amended to reflect this recommendation. One stakeholder explicitly endorsed the proposed deployment of resources to support PhD scholarships and post doctoral scholarships to build capacity within the MSK sector.

4.2 Consumer Survey Data

The data from the consumer consultation is both more voluminous and dense than that for the clinical and research stakeholder consultation. The reasons for this are:

- The higher number of participants in the consumer consultation (N=21 as opposed to N=10 in the consumer and stakeholder consultations, respectively)
- There were two methods of consultation for this group
- The style of facilitation for the focus groups was loosely structured to allow for participants' diverse experiences and perspectives to be heard
- Focus group data are generated through a process of social interaction

4.2.1 Pre-focus group survey

Overall, consumers agreed with the priority areas, investment strategy and guiding principles and endorsed the need for a strategy (see Appendix C).

The free text comments raised a variety of opinions and concerns around the PLS and the consultation. The need to progress research that can help people living with a MSK condition was the overall dominant theme. Nine respondents provided additional comments, and of those five commented on the difficulty that they had in reading the Strategy, offering that it was not a 'Plain Language Summary'. This also emerged as a dominant theme in the focus group discussions.

Another issue raised in the pre-focus group survey related to the necessity for reported research findings to be critically appraised, synthesised, and provided to GPs so that they in turn could deliver up-to-date information to their clients.

Three respondents commented that they felt more or less alone in becoming informed about available treatments and the evidence base that exists around the treatments for MSK health. Two respondents commented that information relating to evidence-based treatments for people living with other chronic conditions - specifically heart disease - was more accessible than equivalent research reporting on evidence based treatments for people living with MSK conditions.

These respondents both considered that *MOVE* had a leadership role to play in assessing and compiling reported research in formats suitable for consumers (this theme was also consistently raised in all three focus groups).

Three respondents endorsed the importance of undertaking research translation within the area of non-pharmaceutical management strategies – specifically diet, fish oil and 'keeping moving'.

Much of what emerged in the additional comments free text box on the pre-focus group surveys were raised during the recruitment phone conversations, and again during the focus groups. The pre-focus group survey results have not been statistically analysed: the small number of respondents and the low variance of the data mitigate against a meaningful descriptive analysis.

4.2.2 Focus Group Data

Data from the three focus groups provided rich and thought-provoking insights into consumers' challenges in both living with a chronic MSK condition, and in navigating the health care system with its increased demands on consumer health literacy.

The most consistent response to the Strategy expressed within and across the focus groups is that the consumers found the PLS difficult to read, despite repeated readings. The PLS was viewed as unnecessarily 'clunky', management speak, repetitive and 'not a Plain Language Summary'. Despite rewriting the Strategy to remove jargon-laden phrases and words, the overall presentation of the information was considered by consumers to be unfamiliar, 'a different language', difficult to recognise and the relevance to their lived experience of their health conditions remote.

In order to facilitate the focus group discussions, and to achieve feedback on the PLS the facilitators allowed a liberal and meandering discussion, so that consumers could use their own personal experience as a platform to access the meaning and significance of the Strategy and the role of research in delivering health services. In practice this involved translation of words and phrases into a negotiated and shared definition or rewording. For example, the word ‘biopsychosocial’ was renegotiated within the group to mean ‘holistic’.

4.2.3 Consumer Comments in Detail

The intent and purpose of the Strategy was met with approval and endorsement. The consumers did, however, find the description under the heading *Purpose* unnecessary and confusing. Overall consumers were pleased that we had developed a Strategy for research and knowledge exchange. There was an enthusiastic and general approval of the shift towards addressing the ‘know-do’ gap. This was seen as a necessary step to improving the lives of people living with MSK conditions.

Six consumers expressed concern that they lacked the necessary skills and knowledge to confidently critique the PLS. One respondent noted that the lack of description and detail around the specific resources required to undertake the proposed research activities laid out in the PLS, and the source of the resources presented a barrier to interpretation. One consumer commented that the multiple boxes identified under the heading *Priority areas* were not weighted by relative emphasis or importance. This comment gained strong traction and agreement within the group.

The following section summarises the feedback according to the main headings of the Strategy.

Guiding Principles

The need to address the research challenges and opportunities across the health continuum from prevention to illness management received approval.

The identification of particular target groups received some comment. The absence of carers explicitly in the Strategy was identified across all groups, and was considered an important omission, as were people with MSK conditions who also lived with other health concerns and multiple disabilities, such as visual impairment.

There was discussion within one focus group around the need to identify general practitioners (GPs) as a key target population for research activity. This group recommended that GPs would be appropriately located under the *Guiding Principles* section of the Strategy. Notably, the perceived lack of GP skill and knowledge in the area of MSK health represented a recurring theme in each of the focus groups.

Priority Areas

Two groups discussed the need for *MOVE* to collaborate with a wider range of stakeholders including peak organisations, (e.g. Vision Australia and indigenous organisations), and the general community (through community-based organisations such as leisure centres, and local councils) in order to promote awareness of MSK conditions and the existence of A&OV. This collaboration was seen as important to contribute to an MSK sector that was proactive and responsive to the dynamic and diverse information and communication supplies, and to the demands of contemporary society. Workplaces, unions and Occupational Health and Safety regulators were identified as key locales for research and knowledge exchange in two groups, with one consumer commenting on the lack of research in the area, it being the ‘neglected and obvious’ starting point.

Two groups discussed the ‘ethics’ of identifying particular conditions. For example, in one group a participant claimed that because psoriatic arthritis is just as destructive as rheumatoid arthritis it ‘should be mentioned’. A discussion ensued within the group along the lines that as fewer people suffer from rarer conditions they should not be prioritised over investment in areas of greatest impact. Another participant addressed the issue that rarer conditions are ignored. Another respondent commented that chronic pain is the common factor to the majority of MSK conditions and it is this that should be considered.

Investment Strategies
There was general consensus across the groups that the research investment strategies should be directed towards services that improved consumer experiences and outcomes. The importance of a reciprocal relationship between GPs and *MOVE* was raised in two focus groups. On the one hand GP’s roles should include referring their patients to A&OV, while *MOVE* had a key role to play in building GP capacity in the MSK clinical area. The need for better informed GPs, supported by *MOVE* through the provision of accessible and high quality information to GPs was an enduring and universal theme across the three groups. This was generally agreed upon as a legitimate and important investment area. There was wide agreement that this would be enormously reassuring for consumers. They expressed concern that they needed to access and sift through the vast and varied volumes of information for themselves, an ongoing challenge made all the more concerning because they recognised that they lacked the necessary skills required to appraise and assess the quality of the information, and what it meant for them as individual consumers.

5. Discussion

The overall clinical and research stakeholder agreement with the Strategy is unsurprising. The process of gaining feedback may be considered a verification of the previous discussions with key MSK stakeholders to draft the Strategy.

The consumer consultation, however, was a first exposure to, and exploration of, the contents of the PLS. A comparison of clinical and research stakeholder and consumer perspectives is thus not appropriate through this process, nor was this a stated aim of the consultation. Future consultations with diverse groups might, however, benefit from designs that support comparison.

The clinical and research stakeholder consultation was limited in both number and scope. Ideally a wider range of MSK professional stakeholders representing diverse disciplines and sectors would have provided a more informed appraisal of the Strategy. Similarly, there are design limitations regarding the consumer consultation. Despite the good response and retention rates, the consumer demographic characteristic profile was skewed to people of retirement age and living with osteoarthritis. Although this does reflect the epidemiology of MSK conditions in the community,[13] it does provide a relatively narrow range of accounts and perspectives drawn from lived experiences of people with other MSK conditions. In future formal consultations, a more rigorous purposive sampling approach would be recommended, supported through a sampling strategy specifically including people of working age and young adults and a range of MSK conditions.

Consumers experienced difficulty in accessing the meaning of a strategy. Throughout the focus groups participants continually reverted back to their personal lived experience of their respective conditions and the way in which they managed their lives. This enabled them to identify and engage with the Strategy, by seeing the relevance and significance to themselves. The abstract nature of the Strategy, however, posed an ongoing challenge to the participants, who required frequent reiteration of the difference between a Strategy and a detailed implementation plan. The particular logic of planning and priority setting posed a barrier to interpreting the Strategy to all respondents in all groups.

Despite these challenges, consumers were able to contribute perspectives that were insightful and novel. The focus group participants were positive about the opportunity to express their opinions. They endorsed the relatively unstructured character of the focus groups and the supporting phone contact as providing an atmosphere of open and genuine enquiry.

An overarching theme of the consumer consultation process was that there were ‘two different languages’ being spoken: one language as represented in the PLS and another that represented consumers’ perspectives. Although the consultation process was not set up to systematically explore and analyse this finding, it does signal important insights to A&OV. These data tap into current and emerging trends in health services and applied research – how health consumers can best contribute to research and policy making, and the current and future role of the not for profit sector in the overall challenge of working for health.

This process has provided information that is useful for practical purposes in informing the finalisation of the Strategy. In addition it has put a spotlight on a whole area of enquiry that is of great significance for A&OV.

6. Strengths and Limitations of the Consultation

Despite the attention to data collection and handling involved in the consumer consultation in particular, and the respectable number of contributing consumers to the consultation, the claim to rigorous scientific merit that we can reasonably stake for the consultation process is limited. Rather the consultation occurred pragmatically, not as a research project, in order to inform the development of one of our core programmes of work and investment.

The SurveyMonkey method offers a practical and accessible method of consultation and is particularly suited to time challenged respondents. The possibility to provide supplementary qualitative data offered respondents the opportunity to qualify nominal responses. The poor uptake of this option (3 respondents out of 10) means that the scope and focus of the stakeholder’s comments remained very narrowly focused on verifying the components of the Strategy. The low response rate may be indicative of the many competing demands on their time.

Providing consumers with the PLS was, in retrospect, not the most acceptable method of extracting perspectives and feedback from consumers. However, as a result of the necessity to manage consumers’ concerns around the PLS and associated business requirements, the focus group processes ultimately enabled the consumers to participate in useful and constructive ways, and provided *MOVE* with additional insights.

7. Recommendations

Recommendations are made here according to 1) changes made to the Research and Knowledge Exchange Strategy 2015-2019 and 2) suggestions for development of future strategies, with a particular focus on approach to consumer involvement.

Recommended Changes to the Research and Knowledge Exchange Strategy 2015-2019

There are eight recommendations made to the Strategy. These recommendations and the actions taken are tabulated below.

Recommendation	**Action Taken**
• Format and style adjustments to provide clearer definition and to more closely represent the research translation process in practice	• Remove diagram on page 4 of the translate/integrate/enable process and replace with an explanatory diagram of the phases of translational research • Defining statements added into document (Canadian Institute of Health Research) • Table 1 has been revised • Terminology in Tables 1 and 2 are now consistent • Purpose and Intent have been replaced with a single term 'Goal'
• A glossary of terms should be provided as an appendix for the consumer version of the Strategy	• Glossary of terms added to consumer PLS only
• Carers should be identified as a key priority group	• Consumers now refers to consumers (including carers)
• People with multiple disabilities (e.g. vision impaired people, people with special educational needs) should be identified as a key priority group	• No uptake of recommendation due to resource constraints
• Consideration should be afforded to the feasibility and benefits of identifying general practice as a key population group/ setting	• Add *and primary care (e.g. general practice)* in the Scope of priority area 2 in Table 2.
• The number of priority areas in Table 2 should be reconsidered. The boxes entitled 'Health workforce education to improve and sustain knowledge, skills and practice behaviour' and 'Workplace wellness related to MSK health' could be merged. This would better reflect the WHO position on shared and joint responsibility for health in locations where we live, work and play	• Remove two priority areas in Table 2 ('Priority MSK conditions' and 'Facilitate knowledge translation and exchange initiatives') • Reword 'Workplace wellness related to MSK health' to 'Employee health and productivity'
• The boxes entitled 'Implementation and evaluation of evidence informed health service models for MSK health' and 'Economic evaluations for programmes or service models that address MSK health' could be merged under 'Mainstreaming evaluation in MSK health'	• No action taken: the domains were considered to fundamentally different and for this reason were not merged
• The priority area entitled 'Facilitate knowledge translation and exchange' in Table 1 should be considered as a Guiding Principle	• The priority area entitled 'Facilitate knowledge translation and exchange' in Table 1 was

	relocated to constitute an additional Guiding Principle in Table 1.

Recommendation for Future Consultations

Consumer consultations might adopt a different approach to that above. While focus groups offer good opportunities to gather opinions, views and experiences, the generation of ideas and information should begin with consumers' experiences, rather than a pre-verified synthesis of clinical and research stakeholders' perspectives. Focus group questions should be crafted with this in mind.

The stakeholder and consumer consultations should occur in tandem, rather than sequentially. Changes to a draft Strategy should incorporate feedback from both consultation groups in tandem, rather than sequentially.

Appendixes

Appendix A: Clinical and Research Stakeholder Responses via SurveyMonkey (N=10)

Question 1: In your opinion does *MOVE* need a Research Strategy?	
Responses	Respondents (N=10)
Yes	10
Unsure	-
No	-

Question 2: The purpose of the Research Strategy is clear	
Responses	Respondents (N=10)
Strongly agree	3
Agree	5
Neutral	1
Disagree	1
Strongly disagree	-

Question 3: The intended role of *MOVE* as an active organisation in the MSK research sector is clear	
Responses	Respondents (N=10)
Strongly agree	3
Agree	6
Neutral	1
Disagree	-
Strongly disagree	-

Question 4: The guiding principles of the Strategy are appropriate	
Responses	Respondents (N=10)
Strongly agree	3
Agree	5
Neutral	1
Disagree	1
Strongly disagree	-

Question 5: The priority research and innovation areas identified in the Strategy are appropriate and address contemporary need in the musculoskeletal health sector	
Responses	Respondents (N=10)
Strongly agree	3
Agree	5
Neutral	1
Disagree	1
Strongly disagree	-

Question 6: The investment strategies and their relative distributions are appropriate	
Responses	Respondents (N=10)
Strongly agree	2
Agree	6
Neutral	2
Disagree	-
Strongly disagree	-

Appendix B: Consumer Survey Results (N=20)[a]

1. In your opinion, does *MOVE* need a research strategy?	Yes No	20 -
2. Do you think that the purpose of the research strategy is clear? (0 indicates strong disagreement and 4 indicates strong agreement)	Grading 0 1 2 3 4	No of responses 8 6 6
3. Do you think that the purpose of the research strategy is clear? (0 indicates strong disagreement and 4 indicates strong agreement)	0 1 2 3 4	 4 9 7
4. Do you think that this role fits well with the stated long term commitment of the organisation? (0 indicates strong disagreement and 4 indicates strong agreement)	0 1 2 3 4	 3 9 8
5. Do you think that we have clearly identified the guiding principles and priority investment areas in the Strategy? (0 indicates strong disagreement and 4 indicates strong agreement)	0 1 2 3 4	 6 7 7
6. Do you think that the priority and innovation research investment areas are appropriate and address contemporary need in the musculoskeletal health sector? (0 indicates strong disagreement and 4 indicates strong agreement)	0 1 2 3 4	 6 7 7

---

[a] Twenty-two consumers participated in the consultation, although only twenty-one people participated in the focus groups: One consumer was unable to attend the focus group but wanted to complete the survey. The response rate is not fully captured here as one respondent answered using yes/no responses, rather than the requested sequential grading of 0 -4 where 0 indicates strong disagreement and 4 indicates strong agreement.

Appendix C: Stakeholder Characteristics

Table 1: Stakeholder SurveyMonkey Respondents by Self Identified Professional Group (N=10)

Professional group	Number of respondents
Rheumatologist	3
Orthopaedic surgeon	1
Allied health professional	1
Researcher	5

Table 2: Consumer Consultation Focus Group 1 - Characteristics by Demographics and Self Description

Gender	Location	Age	Self description
M	Melbourne Metro South eastern	70	Gout, polymyalgia rheumatica
F	Melbourne Metro South eastern	73	Osteoporosis, polymyalgia rheumatica
M	Metro Melbourne Northern	70	Does not live with MSK condition, consumer with professional interest
M	Metro Melbourne Northern	70	Osteoarthritis, rheumatoid arthritis, osteoporosis, neck pain
F	Melbourne Metro South eastern	43	RA pregnancy induced
F	Melbourne Metro North eastern	60	Severe osteoarthritis both knees

Table 3: Consumer Consultation Focus Group 2 - Characteristics by Demographics and Self Description

Gender	Location	Age	Self description
F	Rural Victoria	48	Cervical spondylitis, osteoarthritis hips, psoriatic arthritis
F	Metro Eastern	67	Osteoarthritis, pseudogout
M	Metro outer eastern	58	Rheumatoid arthritis
M	Metro Northern	60s	Osteoarthritis knees
M	Metro South eastern	70	Osteoarthritis, rheumatoid arthritis, osteoporosis, neck injury
F	Metro South eastern	55	Systemic lupus erythematosus
F	Metro inner north	70s	Osteoarthritis knees

Table 4: Consumer Consultation Focus Group 3 - Characteristics by Demographics and Self Description			
Gender	Location	Age	Self description
F	Remote Victoria	70+	Osteoarthritis hips, psoriatic arthritis
F	Remote Victoria	42	Carer
M	Remote Victoria	42	Ankylosing spondylitis, Medication induced diabetes, Disability pension
F	Remote Victoria	79	Osteoarthritis knees and hips
M	Remote Victoria	77	Osteoarthritis for 20 years
F	Remote Victoria	80+	Osteoarthritis hips and knees
F	Remote Victoria	70s	Osteoarthritis knees, diabetes type 11
F	Remote Victoria	65	Osteoarthritis self manages with exercise
	Remote Victoria	59	Osteoarthritis. Hip replacement 10 years ago with little improvement in pain and mobility. Peer support vital to self management

Appendix D: Consumer Involvement in Research

Providing the Strategy with an overlay of consumer perspectives benefits the Strategy in a number of ways. Consumers can be involved in developing healthcare policy and research through a range of processes including collaboration and consultation. Consumers may offer complementary or different perspectives to those of professionals, and they may not have the same conflicts of interests and loyalties as professionals (Nilsen et al, 2013).[14] Some scholars have focused on the value that consumers bring to the implementation considerations of healthcare delivery, including increased uptake of research findings into routine practice[15], and greater accessibility and acceptability[16]. These reasons argue for continuing with consumer involvement, while researching for better understandings of approaches to consumer involvement in health care processes as contributers to improved health outcomes.

However, Nilsen and colleagues (2013) in their systematic review of consumer involvement in developing healthcare policy and research have cautioned that these findings need to be taken in the context of the current lack of a comprehensive and rigorous evidence base in the subject area. Nonetheless, the authors suggest that there remain good reasons for involving consumers in developing healthcare policy and research, including encouraging participatory democracy, public accountability and transparency .[14]

The motivation to seek consumer feedback about the Strategy relates to those goals of transparency, accountability and participatory democracy indicated above, as well as to provide a consumer overlay of personal experiences and opinions. These goals permeate the literature surrounding the practice of sound and ethical consumer engagement and thus reflect a development area within A&OV, and an opportunity for organisational learning. To this end we are currently developing a consumer engagement strategy specific to research.

References

1. Arthritis and Osteoporosis Victoria. Exploring the needs of Arthritis and Osteoporosis Victoria's stakeholders: Consumers. Melbourne: A&OV; 2013.
2. Arthritis and Osteoporosis Victoria. Exploring the needs of Arthritis and Osteoporosis Victoria stakeholders: Health professionals. Melbourne: A&OV; 2013.
3. Arthritis Australia. The ignored majority. The voice of arthritis 2011. Sydney: Arthritis Australia; 2011.
4. Arthritis Australia. Whose problem is it anyway? The voice of GPs on arthritis. Sydney: Arthritis Australia; 2012.
5. Costa Lda C, Koes BW, Pransky G, Borkan J, Maher CG, Smeets RJ. Primary care research priorities in low back pain: an update. Spine 2013;38:148-56.
6. Foster NE, Dziedzic KS, van der Windt DA, Fritz JM, Hay EM. Research priorities for non-pharmacological therapies for common musculoskeletal problems: nationally and internationally agreed recommendations. BMC Musculoskelet Disord 2009;10:3.
7. Li LC, Bombardier C. Setting priorities in arthritis care: Care III Conference. J Rheumatol 2006;33:1891-4.
8. Vliet Vlieland TP, Li LC, MacKay C, Bombardier C, Badley EM. Current topics on models of care in the management of inflammatory arthritis. J Rheumatol 2006;33:1900-3.
9. Jacobs JJ, King TR, Klippel JH, et al. Beyond the decade: strategic priorities to reduce the burden of musculoskeletal disease. J Bone Joint Surg Am 2013;95:e1251-6.
10. Grimshaw JM, Eccles MP, Lavis JN, Hill SJ, Squires JE. Knowledge translation of research findings. Implementation Science 2012;7:50.
11. Bourne A, Whittle S, Richards B, Maher C, Buchbinder R. The scope, funding and publication of musculoskeletal clinical trials performed in Australia. Melbourne: Arthritis and Osteoporosis Victoria; 2014.
12. Bourne AM, Whittle SL, Richards BL, Maher CG, Buchbinder R. The scope, funding and publication of musculoskeletal clinical trials performed in Australia. Medical J Aust 2014;200:88-91.
13. Arthritis and Osteoporosis Victoria. A problem worth solving. The rising cost of musculoskeletal conditions in Australia. Melbourne: A&OV; 2013.
14. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. Cochrane database of systematic reviews 2006:Cd004563.
15. Whitstock MT. Seeking evidence from medical research consumers as part of the medical research process could improve the uptake of research evidence. J Eval Clin Practice 2003;9:213-24.
16. Crawford MJ, Rutter D, Manley C, et al. Systematic review of involving patients in the planning and development of health care. BMJ (Clinical research ed) 2002;325:1263.

MOVE muscle, bone & joint health

263-265 Kooyong Road Elsternwick 3185 | PO Box 130 Caulfield South 3162
Telephone: 03 8531 8000 | Help Line: 1800 263 265 | info@move.org.au | www.move.org.au