Mary Pack Arthritis Program

Client and Community Feedback

January 2016

Overview

In consultation with stakeholders, Mary Pack Arthritis Program (MPAP) recently undertook a process to identify **10 key directions** for their program to focus on over the upcoming years. Community Engagement support was requested to engage clients to ensure that the list of directions is complete and not missing anything important. Mary Pack also wanted to hear from patients about their priorities for tackling these new directions; and frame the directions chosen in a way that is patient-centric.

To address these engagement needs, VCH's Community Engagement department held 2 focus groups with participation from 10 individuals from the Vancouver area. In addition, phone interviews were conducted with 18 individuals from across the province, including Metro Vancouver, Trail, and Prince George. A total of **28 people** were consulted over a one and a half month period in December 2015 and January 2016. There was a good mix of people with rheumatoid arthritis and osteoarthritis, and a handful with other related autoimmune conditions.

Consultation by the Numbers

10 people participated in 2 focus groups (December 2015 & January 2016)

18 people participated in telephone interviews

OVERALL FINDINGS

Participants were overall very supportive of the proposed future directions of arthritis care in BC and overall quite satisfied with the current treatment and care they receive through Mary Pack. There were however many suggestions on how services and programs could be improved and enhanced, particularly in the areas of: access to quality care, with an emphasis on access in rural and remote communities; evidence-based education for patients and providers; and empowering clients to self-manage. Participants also felt strongly that a focus on prevention, early identification and intervention was important moving forward.

PRIORITIZING KEY DIRECTIONS

Participants were asked to rank order what they felt were the most important key tasks/directions moving forward with arthritis care in BC based on the 10 identified by MPAP. Of the 28 participants, 25 participants completed this activity and the following are the average scores among respondents, with low numbers indicating highest priority and higher numbers indicating lesser priority.

	Key Direction	**Average rank**
1.	Prevention, early identification and intervention	**1.43**
2.	Improve access to quality care at MPAP and across the province	**2.71**

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3.	Accessible, evidence-based, coordinated education for patients and providers	**4.36**
4.	Empower clients to navigate the health care system and take charge of their own care	**4.5**
5.	Enhance interdisciplinary, coordinated care along continuum	**4.93**
6.	Explore new models of care	**5.57**
7.	Embrace continuous quality improvement	**5.79**
8.	Mary Pack as a Centre for Excellence	**5.86**
9.	Foster relationships and partnerships with stakeholders across the system	**6.23**
10.	Respect, reflect and address gaps in care related to diversity	**7.29**

SUMMARY OF KEY DISCUSSIONS

Participants were asked to provide feedback on priorities for tackling six particular key task areas or directions. The following is a list of the key points raised for system improvement in these six areas.

1. Prevention, early identification, and intervention

- Increase awareness about early warning signs among providers and patients. GPs are not adequately educated to detect early signs and are not always sending patients to Rheumatologists.

- Prevention and interventions needs to include lifestyle changes (yoga, diet, meditation); explore emotional issues associated with outcomes.

- Increase awareness of ‘red flags’ – consider public awareness campaigns –something like successful FACE campaign for recognizing signs of stroke.

- Promote alternative therapies; there are barriers to accessing these therapies due to stigma and lack of awareness.

- Conduct more research in the area of prevention, early identification and diagnostic tools.

- Better tools are needed for diagnosis, e.g. checklists, diagnostic screening.

- Replicate screening techniques like the McKenzie process used in the United States.

“I was already at a moderate stage when I was diagnosed, would be much better if this would have been earlier.”

“Public awareness campaigns are needed so that people know how to recognize early warning signs and seek help.”

“I received top notch care at Mary Pack. There is a huge amount of knowledge among specialists at Mary Pack, lots of expertise in the area.”

2. Improved access to quality care at MPAP and across

- Increase number of Rheumatologists in BC, particularly outside of urban areas.

- Reduce wait times to see a Rheumatologist (less than 3 month wait maximum, less than 1 month wait ideal).

- Reduce wait times for surgery.

- There is a need for more arthritis-trained therapists, specifically those than can actively treat rheumatoid arthritis.

- Financial support is needed for people to access care as well as medical items such as braces, reachers, mobility aids. This could alleviate more expensive costs later on.

- Improve access to alternative therapies. Increase collaboration with alternative health providers and reduce stigma around alternative therapies.
- Provide more care and supports for depression associated with disease.
- Offer satellite centres. Make it easier for people to access services closer to home. Location is important. Someplace central, consider operating hours.
- The current clients treated at Mary Pack are not the sickest; not everyone can access Mary Pack, particularly First Nations communities.
- Self-referrals needed, particularly in remote sites.
- Increase access to appropriate drugs – discuss what will work best with patient (patient-centric).
- Conduct ongoing patient satisfaction surveys, focus groups, online surveys following care, phone call follow-ups etc.
- Create a diverse patient reference group for Mary Pack.

"My Doctor was not aware of Mary Pack."

"I could only receive 5-10 therapy sessions; it is not possible to treat Rheumatoid Arthritis in that time."

"My wait time for surgery was too long. Four months to just have initial consult and then 7 months until surgery."

"Found the program accessible, there are waiting times, but that was to be expected."

3. Accessible education for patients and providers

- Use patients as educators.
- Offer specialized training for arthritis.
- More information and education around osteoarthritis needed; conduct more research on osteoarthritis.
- More information and research needed around pain management.
- Increase public awareness of disease. We need to show real people suffering from the disease. People need to understand how bad it can get.
- Improve information and education in remote areas.
- Train and educate more OTs and PTs to treat arthritis, particularly rheumatoid arthritis.
- More education/information on programs that are out there. There are good programs and services offered, but most patients and health providers aren't aware.
- GPs need specific training and education in arthritis and autoimmune diseases, also chronic pain conditions.
- Increase continuing education opportunities for health providers, including alternative therapies.
- Share results of research and use it to promote awareness and education among health providers.
- Promote Arthritis month, "The Bones Parade."

"I felt I had all the arthritis information that I needed."

"We have to show real people with the real disease; stop using stock photos!"

> ***"There was not a pamphlet in the public health unit here in Prince George."***
>
> ***"Osteoarthritis is not taken as seriously, but it can be just as debilitating."***

4. Interdisciplinary, coordinated care along the continuum

- More guidance and resources needed to support people along the continuum.
- Improve communication among health providers. Everyone should have access to the same notes.
- Reduce stigma around alternative therapies. Many people are scared to tell their Rheumatologist about it.
- Support individualized holistic treatment plans. Increase flexibility around prescribing drugs and exercise programs for example. Community programs, satellite programs and services need to wrap around the patient.
- Need to be diligent with patient records and always keep tabs on past and current clients.
- Patients need to feel respected and acknowledged. Avoid bullying behaviours.
- Staff should meet objectives related to handover of patients to next stage of care or between providers. Staff must do their homework, no assumptions.

> ***"Following the patient is not the key, intervening is."***
>
> ***"Someone should know that I am out here and I should be followed along the way."***
>
> ***"The pathways have worked very well. Everyone is communicating. My GP is up to date on everything in my life."***

5. Respecting, reflecting and addressing gaps in care related to diversity

- More information available in different languages.
- Recruit more health professionals that speak different languages.
- Focused effort to reach ALL population groups equally.
- First Nations care and outreach needs to be a priority. A lot of First Nations members don't have access to early identification and prevention.
- Link and collaborate with First Nations Health Authority.
- Provide outreach to remote communities and people that really need it. People with mild forms of the disease should not be treated at Mary Pack and using up resources of those that are really sick with the disease.
- Decrease stigma associated with the disease in the community and among family members. Intervene in schools and work settings to reduce stigma. Only half of people with arthritis tell their work.
- Create a "How to Talk to People about your Disease" package and toolkit.

"The people using Mary Pack services do not reflect the incidence of the disease. It seems that there are all white people at Mary Pack."

"There is very little participation from Aboriginal members in public education classes."

"We are over-treating people with mild disease and under treating those with the severe forms. The most appalling joint conditions and deformities that I have seen have been among the First Nations population."

"Mary Pack has been very good at honouring cultures and diversity."

6. Empowering clients to navigate the health care system & self-manage

- Provide people with all their own documentation.
- Encourage people with their wellness, not illness.
- Teach self-management skills in schools, e.g. preparing for appointments, how to talk to your doctor.
- Promote existing self-management programs and classes. Keep programs up and running and don't cut anything.
- Continue offering classes for chronic pain, e.g. yoga therapy.
- Educate health providers on how to empower their patients, encourage them to ask questions.
- Develop new apps to help people self-diagnose.
- Increase people's control over the disease. People are less likely to have depression if they feel they have control.
- More self-management programs needed geared towards rheumatoid arthritis.
- Osteoarthritis patients should be self-managing better.
- Resurrect the Arthritis Self-Management Program. Since it has become an UVic chronic disease self-management program, we have lost some really important arthritis content.
- Educate about pain management. People need to know when to use pain medication to get better so they can fully participate in their rehab.

"There are lots of offers for workshops. They are doing a very good job with that."

"Osteoarthritis patients need to self-manage as much as possible."

"Too many self-management programs are geared towards people with osteoarthritis; there is no space for someone like me with severe Rheumatoid Arthritis."

NEXT STEPS

This valuable patient feedback will be used to inform and validate future directions for arthritis care at Mary Pack and across the province.

Moving forward, Mary Pack will continue to collaborate with people living with arthritis in an ongoing way. Several participants from these focus groups and phone interviews indicated interest in future involvement. There is also some initial consideration and planning around the development of a diverse patient reference group to help guide and inform the work at Mary Pack on an ongoing basis.