More detailed information to be shown on the JLA website for the questions discussed at the final workshop.

PSP Name	**Total number of verified uncertainties identified by the PSP**	**Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)**	**Explanatory note (a plain language summary of up to 150 words, explaining key points of the uncertainty and why it is important, for research funders to begin working on. PSPs may wish to include examples of the original survey submissions here)**	**Date of the priority setting workshop**	**Rank of the uncertainty at the final workshop. (If no rank was agreed, please indicate)**
Myeloma (Canada) PSP	59	How can we cure myeloma?	Ultimately, myeloma patients, caregivers, and healthcare providers would like to see a cure for multiple myeloma. While current treatment options have led to prolonged remissions and improved quality of life, patients must continue with treatments and live a "tiring existence" with myeloma. Many look forward to a day when there will be a cure for myeloma. In the meantime, they would like to be updated of progress towards this goal.	28-Apr-21	1
Myeloma (Canada) PSP	59	Are novel immunotherapies (e.g., CAR T) effective for the treatment of myeloma?	In the absence of a cure, people affected by myeloma would like to see new treatments for myeloma. Specifically, participants pointed to novel immunotherapies as a promising area of research that they would like to be explored. Indeed, many participants were wondering about the effectiveness of chimeric antigen receptor therapy (CAR T), and the role that this treatment will have for future treatment of myeloma.	28-Apr-21	2
Myeloma (Canada) PSP	59	How can we improve the diagnosing (e.g., faster, less invasive) of myeloma, and what is the impact of earlier diagnosis on patient outcomes (e.g., organ damage, bone deterioration)?	Many patients and caregivers reported that myeloma was diagnosed late and expressed a need for the earlier diagnosis of myeloma. Healthcare providers also wondered about the best way to diagnose the disease. Furthermore, participants speculated about the impact of earlier diagnosis on myeloma outcomes, such as bone deterioration or kidney damage. Many patients also reported a desire for a less invasive test to diagnosis myeloma (compared to bone marrow biopsy). Proposed avenues for research to explore include: improving general practitioners knowledge of myeloma, the use of routine tests that can be ordered by GPs, new criteria for the diagnosing of myeloma, and a definitive blood test to diagnosis myeloma.	28-Apr-21	3
Myeloma (Canada) PSP	59	What are new treatments for myeloma patients that will improve life expectancy with fewer adverse side effects (e.g., pain, nausea, neuropathy, immune suppression)?	Participants are eager for new treatments at all stages of the disease that will improve the progression-free and overall survival; minimize the side effects of treatment, such as pain, nausea, neuropathy, and immune supression; and improve their quality of life.	28-Apr-21	4

Myeloma (Canada) PSP	59	How can we personalize a patient's treatment based on their type of myeloma and genetic profile, and what is the impact of personalized medicine on treatment efficacy and disease outcomes?	Participants expressed a need to get away from the "one size fits all" approach to treatment and advocated for the use of personalized treatment which is based on their overall health status and specific type or sub-type of myeloma (e.g., IgM myeloma, kappa light chain) and customized to their unique genetic profile.	28-Apr-21	5
Myeloma (Canada) PSP	59	How can we prevent bone deterioration and/or repair bones that have been damaged without negative side effects (like those associated with bisphosphonates) or surgery?	Myeloma often causes bone deterioration which results in pain and frequent fractures or breaks. The pain associated with myeloma related bone disease often persists even after the myeloma is under control. Participants would like to see ways to prevent bone deterioration or repair the bones after treatment. However, according to our evidence check, bone deterioration is often treated using bisphosphonates which have their own side effects or surgery. Therefore, better treatments are needed to manage myeloma related bone deterioration.	28-Apr-21	6
Myeloma (Canada) PSP	59	How can we safely reduce, cycle, or stop the use of medications (e.g., Dexamethasone and Revlimid) to reduce the side effects of treatment and maintain control over myeloma?	Myeloma patients will often undergo frontline treatment and achieve remission. However, most patients continue to take maintenance medications indefinitely to prevent or slow down a relapse of myeloma. Many participants reported a desire to reduce the dose of their medications to decrease the side-effects, to stop taking maintenance medications when in remission, or to incorporate "treatment vacations." In particular many participants commented on the frequent use of revlimid and dexamethasone and wondered whether these treatments are always necessary and whether their dose can be adjusted to reduce the side effects of treatment while maintaining control of the disease.	28-Apr-21	7
Myeloma (Canada) PSP	59	How can we reduce or manage the short-term effects (e.g., diarrhea, nausea, fatigue, emotional challenges, skin reactions) and long-term effects (e.g., vision loss, loss of muscle strength) of myeloma treatment?	Myeloma treatments are associated with a host of adverse short- and long-term side effects (including diarrhea, nausea, fatigue, anxiety, rash, vision loss, loss of muscle strength, kidney damage, etc). Participants report that these side-effects lead to reduced quality of life and would like ways to reduce or manage these effects such as replacing current treatments (such as dexamethasone) with newer alternatives, the development of new prescription drugs to treat specific side effects, or recommendations for over the counter drugs that would help in the management of these effects.	28-Apr-21	8
Myeloma (Canada) PSP	59	What is the most effective way (i.e., drug combinations, sequence, frequency, and intensity) to treat refractory, relapsed, and drug resistant myeloma?	Participants would like to know the most effective ways to treat myeloma that is refractory or resistent to treatment from the outset as well as ways to treat the disease once it has relapsed. Specific concerns have to do with the re-combining treatments, the sequence of drugs, and when to re-start treatment.	28-Apr-21	9

Myeloma (Canada) PSP	59	Can we develop treatments specifically for high risk or aggressive myeloma that will improve outcomes for these patients?	High risk or aggressive myeloma is defined by disease stage, chromosomal abnormalities, disease biology, and gene expression, and is associated with worse outcomes. Participants want to know about the current treatment options and the new treatments for patients with high risk or aggressive myeloma (including those with genetic abnormalities, deletions, etc.) that will improve outcomes for these patients?	28-Apr-21	10
Myeloma (Canada) PSP	59	What is the impact of physical activity on myeloma symptoms (e.g., bone health), mental health, and outcomes (e.g., treatment response, life expectancy)?	Many participants remarked on the positive impact that physical activity had on their mental and physical health (e.g. bone health) and/or wondered about the effects of physical activity on their physical and/or mental health and disease outcomes such as treatment effectiveness, progression free survival, and overall survival.	28-Apr-21	11
Myeloma (Canada) PSP	59	What genes are associated with the development of myeloma, and how can genetic testing be incorporated into the diagnosis and treatment of myeloma?	Participants wondered whether myeloma is genetic and, if so, what genes are implicated in its development. Furthermore, participants wanted to see increased use of genetic testing in the diagnosis and treatment of myeloma. Specifically, they asked about the use of genetic testing to predict the onset of myeloma, the role of genetics in the diagnosis of myeloma, treatments based on genetics, and the effects of genetics on treatment response and prognosis.	28-Apr-21	12
Myeloma (Canada) PSP	59	What are new ways to monitor and/or treat the initial stages of myeloma (e.g. MGUS and smoldering myeloma) to delay or prevent the development of active myeloma?	Monoclonal gammopathy of undetermined significance (MGUS) is a condition in which patients have M-protein present in their blood, but do not have multiple myeloma. Approximately 1% of patients with MGUS will develop myeloma each year. Smoldering myeloma is an early, asymptomatic form of myeloma before the onset of active disease. Participants wanted to see new ways to monitor and treat (e.g., chemotherapy, stem cell transplant) these precursors and prevent the development of active myeloma.	28-Apr-21	13
Myeloma (Canada) PSP	59	How can we restore myeloma patients' immune functioning (e.g., IgG treatment) so that they might resume their daily activities (e.g., travel, work) without fear of infections?	Participants worried about the effects of myeloma treatment on patients' immune system and the resulting impact on their daily activities including working, socializing, and travelling. Some expressed a fear of infection and wanted more information on the use of IgG treatment, mask wearing, and vaccinations, as well as new treatments that do not supress the immune system.	28-Apr-21	14
Myeloma (Canada) PSP	59	How can we prevent decline in memory and mental functioning associated with myeloma and its treatment among myeloma patients?	Both myeloma and its treatment can have adverse effects on memory and cognitive functioning (e.g., "chemo brain"). These challenges can affect patients' relationships, work, and daily living. Participants wanted to know which drugs were associated with these effects, how long the effects will last, and new ways to prevent or manage these issues.	28-Apr-21	15

Myeloma (Canada) PSP	59	How can we prevent and/or manage the neuropathy associated with myeloma and its treatment?	Peripheral neuropathy can occur as a result of myeloma and its treatment. A common side-effect of myeloma treatment, neuropathy warranted its own indicative questions because it can also occur as a result of the disease (in the abence of treatment) and because of the volume of responses associated with it. Participants would like new ways to prevent, reduce, or manage neuropathy and new treatments that do not have this side-effect.	28-Apr-21	16
Myeloma (Canada) PSP	59	How can minimal residual disease testing be applied in myeloma treatment to improve treatment efficacy and prognosis among people with myeloma?	Participants would like more research about the application of minimal residual disease (MRD) testing in the treatment of myeloma, including its use to tailor intensity and length of therapy, how to monitor MRD, and its role in prognosticating the disease.	28-Apr-21	17
Myeloma (Canada) PSP	59	What is the risk to blood relatives of people with myeloma, and should they be monitored or tested routinely?	Participants wanted research into the risk of developing myeloma for family members of persons with myeloma. Many reported relatives who also had the disease. Patients wondered about the risk to their children and wondered whether they should be monitored or tested routinely.	28-Apr-21	18

Data management spreadsheet for use by Priority Setting Partnerships for all questions received. Spreadsheet to be published on the JLA website at www.jla.nihr.ac.uk on completion of the PSP.				
ID	**Uncertainty (PICO formatted indicative uncertainty where possible. Advised minimum requirements are 'Population' and 'Intervention'. Not all submissions may be suitable for PICO structure, but they should be in a format that will ultimately be of value to the research community)**	**Original uncertainty (examples)**	**Evidence (reference, and weblink where available, to the most recent relevant systematic review identified by the PSP, plus a maximum of 2 other systematic reviews, including protocols for future systematic reviews, that the PSP considers relevant.)**	**Notes, if applicable**
Access	*What is the impact of timely access to myeloma care, including health services, supportive care, treatments, and clinical trials, for all patients, including those in rural areas?*	Access to those outside large population centres * clinical trail available regardless of where you live in Canada * We had a referral to a hematologist but waited a long time * How can we improve patient access to vital & expensive treatments? * I want to see more hospitals equipped with the necessary machines to do the stem cell transplants * Better access to supportive therapy. Mental health, pain control, physical therapy * More open time for the centre I attend. Currently on open Monday to Friday, no weekend treatment scheduled? * Which models of health care are most effective in ensuring myeloma patient access to required services? * Could transplants be available more quickly? (Translated from French) * Are treatments available for people who live far from major hospitals? Do those people make as much progress? (Translated from French) * Access to the newest drugs for treatment		
Age at Diagnosis	*How does the age at which a patient is diagnosed impact the signs, symptoms, and type of myeloma a patient develops?*	Some patients are diagnosed in their 40s or 50s with MM. Is it the case that these patients have poorer overall outcomes (i.e. shorter response duration) compared to older patients? * Do younger patients tend to have more aggressive myeloma than older patients? * Is it a given the younger you are diagnosed the fewer years you will have? * Differences in signs, symptoms and outcomes between younger patient populations (30-50 yo) vs senior patient populations. Im was 46yo when I was diagnosed and could not find any research talking about my age group. The only info I could find was on senior populations with multiple other modalities as well. * Taking age into consideration, does that life span increase if you are a younger patient	Manapuram S, Hashmi H. Treatment of multiple myeloma in elderly patients: a review of literature and practice guidelines. Cureus. 2018 Dec;10(12).	Answered by evidence check
Age for ASCT	*Can otherwise healthy older (i.e., 70 years +) myeloma patients be safely and effectively treated with ASCT?*	I would like see Stem Cell Transplants based on biological age not chronological age. Many of us MM people are in good shape, no heart problems, no diabetes, no obesity and yet because we are too old, we do not qualify for SCT. * Why after the age of 60 is it not allowed to have a Transplant? * If stem cell is available, don't use chronological age as a cut off. Look at the whole person. Many 70 year olds are healthier than their younger MM patients. For example, 70 year olds with MM and no obesity, no diabetes, no heart problems, no kidney problems are refused Stem Cell transplant because of agism. * I would like to know, at what age do doctors stop considering a stem cell transplant as a viable treatment option. My 77 year old dad had been denied that option. * What reasons are there for not offering SCT over 70? Are there exceptions?	Manapuram S, Hashmi H. Treatment of multiple myeloma in elderly patients: a review of literature and practice guidelines. Cureus. 2018 Dec;10(12).	Answered by evidence check
Alternative Medicine	*Can alternative medicines and therapies (e.g., electromagnetic therapy, mistletoe, curcumin, acupuncture, massage, transcranial magnetic stimulation, meditation, and reiki) be used to manage the symptoms and side effects of myeloma, reduce pain, improve immune system functioning, and improve outcomes among myeloma patients?*	Does the use of natural remedies like mistletoe stop myeloma? * What is the role of complementary and alternative medicine? * Does Acupuncture, Massage, TCM or other traditional medicines help? * Why is it always just chemo, rather than some natural approaches such as MGN3, etc * Alternate forms of healing such as meditation, rheiki etc. * Also pain management is a big issue with myeloma. Are there alternatives to drugs that help with pain management ? * Recommendations for alternative treatments to relieve side effects (supplements, probiotics, acupuncture, etc.) * Is it true that circumin is helpful for myeloma patients? * Effect of complimentary medicine to improve symptom management? * What naturopathic treatments are proven useful for the treatment of side effects, symptoms etc of MM. * Are PFS or OS rates improved with meditation, herbs?		
Amyloidosis	*What is the relation between myeloma and amyloidosis and how can amyloidosis be detected and treated in myeloma patients?*	The relationship between MM and amyloidosis. * doing better treatment for amyloidosis and kidney failure. * can research reach out for mm and amyloidosis testing at the same time when being diagnosed * More trials on amyloidosis would be great, both from a treatment and symptom management perspective. for example, co-manage with cardio-oncology for cardiac amyloid	https://www.albertahealthservices.ca/assets/info/hp/cancer/if-hp-cancer-guide-lyhe003-multi-myeloma.pdf	Answered by evidence check
Better Diagnosis	*How can we improve the diagnosing (e.g., faster, less invasive) of myeloma, and what is the impact of earlier diagnosis on patient outcomes (e.g., organ damage, bone deterioration)?*	Are we finding ways to diagnose sooner? * Could the myeloma been detected earlier preventing a lot of the side effects and making treatment easier. * Why does it take so long to diagnose? * For future patients - there needs to be a better system to diagnose MM. * How can myeloma be diagnosed earlier, before it damages the kidneys or other organs? * Diagnosing as early as possible is important so any research leading to a simple method to diagnose very early in the disease progression would be important. * It took 18 months to get diagnosed. The definitive tests seem to be expensive and intrusive. It would be good to develop quicker, easier tests. * How can initial diagnosis be speeded up * I would like an easy blood test that could diagnose Myeloma early. * is there a way to diagnose when people do not have any of the 'slim CRAB' criteria outside of a PET scan? * More routine tests that GPs can administer for early identification. * A a diagnosis be made by a blood test rather than a bone marrow biopsy? * Can Myeloma be diagnosed more quickly and without an invasive biopsy. * Are there easier tests, apart from a bone marrow extraction, that could be used when there is MM suspicion? * Why is FISH testing not a standard practice? * Is a bone marrow biopsy the best and most accurate way to diagnose myeloma?		
Better Induction	*How can we make induction therapy quicker so that patients may get ASCT sooner?*	Can the induction phase be accelerated or made more certainly effective * Is there another drug that is as effective as Melphalan to condition for autologous stem cell transplant but without the severe side effects most patients suffer? * Is there a way to do a better job of cleaning up a person's stem cells before an autologous stem cell transplant? * Myeloma is heterogenous at diagnosis with up to 6-7 different clones. Can their identification, risk stratify Induction treatment.		
Bone Health	*How can we prevent bone deterioration and/or repair bones that have been damaged without adverse side effects (like those associated with bisphosphonates) or surgery?*	How can bone holes be repaired or prevented? * What stops the deterioration of bone once treatments are done and you are in very good partial remission? * After the bisophosomate treatments are finished, do the bones still deteriorate? * Bone deterioration and pain...does it continue after you are in remission? * Are there ways to prevent calcium loss when strengthening bones with various meds. * What can one do to strengthen the bones? * When your M spike is low and the disease is well controlled do your bones continue to repair themselves as they normally would? * Is there not something that can be done about injuries to bones before they do take place? * Can treatments improve bone strength at the same time as treating myeloma? * Can bone issues be reversed? * What treatment should I follow in order to delay bone deterioration? (Translated from French)		

Cannabis	*Can cannabis be used to manage the symptoms and side effects of myeloma, reduce pain, improve sleep, and treat myeloma?*	The uprising of medicinal cannabis and what people are suggesting is the safest types for myeloma patients for pain and sleep. * Is there a cannaboid that is effective in helping with myeloma? * Does CBD and THC have a place in the treatment of myeloma and the side effects from the medication. * How can marijuana help with side effects. * In addition to opioids for pain management can CBD and/or THC play a safe role? * Move away from opiates to cannabinoids to better manage pain, nausea, etc.? * Does cannibus THC or CBD have antimyeloma effects * Can Cannibis help with side effects sleep, mood pain vs narcotics and antibiotics.		
Care Coordination	*What is the impact of better care coordination among all healthcare providers (e.g., oncologists, hematologists, general practitioners, psychiatrists, physiotherapists, dieticians) to ensure patient safety, treatment efficacy, and well-being?*	How can we better coordinate among all our care providers to ensure patient safety, well-being and success? * Can research suggest better coordination of MM resources to meet patient needs? * Have a complete team meet with a newly diagnosed, not just oncologist but emotional support team. * How much information is a family doctor receiving from a patient's oncologist? * Is there a way to ensure that blood test results are read and shared with specialists over the weekends? * Why is the treatment not including the circle of care such as pain management, mental, orthopedic, vs only oncology * How do we take more of a multiple disciplinary approach to treatment to have the oncologist not working in isolation from other specialists? * More communication between all doctors involved in this patient. GP, cardiologist, internist, radiation oncologist,urologist. patient is often in limbo wondering who he should turn to when he has concerns. * Better communication between all stakeholders * A more coordinated approach to help patients navigate the health care system to deal with every aspect of their disease. * How to communicate more effectively with patients. How to streamline services so not so many different departments? Set up of an easy call line.		Question was combined with "Service Navigation" following evidence check to produce the question: How can we improve the patients’ experience with myeloma care through better care coordination and supports to navigate the healthcare system, and what is the impact of improved care experience on patients’ well-being?
Caregiver Impact	*What is the impact (physical, mental, social, financial) of myeloma on caregivers, and how can we effectively support them (e.g., respite care, educational programs) to reduce their burden?*	How can caregivers to us Myeloma people be best supported in their ongoing efforts? This of course means physical, mental, social and financial needs caused by Myeloma. * How can caregivers be given respite, training and a treat such as a massage once in a while? * What are the difficult and prevalent issues facing spouses and primary care givers during treatments and when living with a MM patient? * More suggestions for caregiver changing role and stress brought about by the disease. * More effective support and educational programs for caregivers. * Does providing a caregiver support program including help with exercise and leisure pursuits result is better outcomes for caregivers and patients? * How does treatment of the patient effect the care giver and family. What is the level of burden to family. * How are caregivers impacted by myeloma? * Would a organized, structured program aimed at caregivers of patients with multiple myeloma be developed that is available across the county decrease caregiver burnout? * Research into how most caregivers respond to the diagnosis and care of the patient and published to both. * How to reduce the burden on caregivers. * More supports for caregivers? * In addition, it's hard for the spouse to cope with all of this, they need help and support too (Translated from French)		
Caregiver Support	*What is the impact of a supportive caregiver on the outcomes of myeloma patients, and how can we help patients without caregivers manage without this support?*	A good caregiver is the key to continuous recovery. * Being accompanied by a support person to help us learn to live with the spectre of myeloma which overshadows everything, even when in remission. (Translated from French) * Mention that support from a spouse will be essential to tolerate the treatments and that many hours will be necessary. * I know I would have 'fallen through the cracks' in the health system if my physician husband hadn't done research and been my constant advocate and helper.		
Causes	*What are the causes (e.g., environmental [e.g., radon, fertilizers, chemical exposure], physiological [e.g., life style, smoking, alcohol], and genetic) of myeloma?*	What are the environmental conditions that lead to this condition. * What is the root cause of multiple myeloma * Do any or all of environmental, physiological, or heredity play a role in the predisposition of an individual to multiple myeloma? * Is there a genetic link to people who get myeloma, environmental factors, job related myeloma * Is being overweight a risk factor in multiple myeloma? * Are there foods/environmental reasons/hereditary reasons/other, as examples, which put one at a higher risk for myeloma? * Are there environmental, genetic, race, gender or age factors that cause MM? * Why? What is the cause? It seems more and more people are diagnosed with mm. Is it environmental ? Genetic? * Does exposure to certain substances increase the risk of myeloma? * My husband is an avid golfer. Could fertilizers be a trigger? * Was there anything in my life style or environment that contributed to getting this disease. * If theres anything that spurs this - can there be things to avoid? It says pesticides can cause it. My husband who has MM is a farmer * Why. Is the disease genetic, or related to environmental toxins, or some other reason? What causes Myeloma? Environment? Chemicals? Exposures? Genetics? And narrowed down to what caused my Myeloma? * Which are the most likely causes of multiple myeloma in terms of environmental factors (exposure to chemicals, radiation, etc.? * How did this kind of Cancer attack a person body when theres no smoking or alcohol is involved ?		
Clinical Process and Trials	*What clinical trials are available and how can the clinical research process be improved to speed up the approval of new drugs?*	Can we get Health Canada to approve ahead of instead of behind the FDA for new drugs to treat myeloma on the market? Canada is always a follower. If cannot get ahead of the US in drug approvals, can we get the research approved by Health Canada in a quicker manner. * How can the most promising treatments be advanced the most quickly through all the trials and approvals? * Why are clinical trials not available for myeloma/amyloid patients? What other clinical trials aimed at developing the next generation of multiple myeloma drugs are currently underway in Canada? * Is there any way to speed up the lengthy process of getting new drugs approved for active treatment here in Canada? * How do patients get into clinical trials. * How does one get advised of all appropriate trials? * And are there clinical trials available. * More clinical trials for elderly patients * How can we speed up the process for promising and cutting-edge treatments so that people battling myeloma can have a chance to be cured? (Translated from French)		Out of scope
Cognitive Functioning	*How can we prevent decline in memory and cognitive functioning associated with myeloma and its treatment among myeloma patients?*	What effects does myeloma have on mental status. * How can the effects of 'chemo-brain' be reduced? * Can memory issues be prevented? * Frustration with memory loss and its effects on relationships, work, and tasks for daily living * Help with brain fog * Effects of high-dose chemotherapy on memory and mental acuity. (Translated from French) * Being in my late thirties, does memory come back or will it be permanently affected? (Translated from French) * Fatigue and impact on the brain. (Translated from French)		

Comorbidities	*What is the relation between myeloma and comorbid health conditions (e.g., diabetes, HIV, and osteoporosis), and how can these conditions be effectively managed while undergoing myeloma treatment?*	How do we deal with patients who are diabetic and drugs that worsens their blood sugar reading * Is there a relationship between HIV and MM? * The need to understand how MM interacts with other health disorders. * Long term co-morbidity management * Does the treatment for Myeloma affect the progression of osteoarthritis (make it progress faster) ?		
Costs	*What are the costs of myeloma to the patient and the healthcare system, and can the costs to patients be covered by private or public health insurance?*	What cost to the healthcare system? * Is there a cost associated that is not paid by cancer funds? * How many patients cannot afford myeloma treatment? * The financial impact on families. * Why is the cost for treatment so expensive? * Health care utilization costs * Data to support funding and availability of more treatment options, drugs and other. * More drug treatments developed that are sold to Canadians at a lower cost than they are now. * Is it necessary to pay large sum of money for maintenance therapy drugs * How are patients impacted by the costs of treatment (drugs/ distance to treatment/ parking/job loss etc.?) * Are all treatments, medications and medical interventions covered by the healthcare system or by private insurers.		Out of scope
Cure	*How can we cure myeloma?*	What is a cure for Myeloma? * Can myeloma be cured? * Why is there no cure yet? * Of couse the 'holy grail' of research would be to get an answer on a cure for this disease. * Of course a cure ultimately. Understanding the disease better through historical data may help lead to this. * How to cure * Keep looking for a cure I know you can do it ! * Do you think there will ever be a cure. Living with Myeloma is a painful, tiring existence. * Obviously how to permanently cure it * Pursuit of curative therapy. * Research dollars please to go toward eradication of this disease		
Daily Living	*What is the impact of myeloma and myeloma treatment on patients' daily living (e.g., independence, leisure, work), and how can patients be helped to return to their daily routines?*	What I can expect to be able to do physically with myeloma. * What will be the immediate effects on or changes to lifestyle? * I would like to know how to live with myeloma and still be a normal person mentally and physically. * Understanding the new normal! Living with pain and management * Are patients with myeloma able to live 'normal lives' when on treatment of should they expect to always have symptoms. * How will the myeloma effect my daily routine * If able can I keep working. * Ability to have strength to go to leisure pursuits. * What helps them to keep their ADL at their best? * Return to active living * What impact will myeloma have on my life style and day-to-day activities * What activities are best to pursue when energy is down? Keep living as normal as possible * Impact on work, can we continue to work during treatments (Translated from French) * Is it possible to resume a normal life after myeloma? Which sports can one play? Must one fear having friends or intimate relationships? (Translated from French)		
Database	*How can a database of patient data be used to understand the experience of Canadian patients with myeloma?*	To me, the priority is collating the patient data. Being able to recognize quickly what has worked well on an MM patient previously to aid with the treatment plan for a newly diagnosed patient with similar MM markers may lead to a better outcome. * How can Myeloma Canada Research Network (MCRN) support smaller cancer centres with the fiscal infastructure challenge to ensure resources to input data to the MCRN National Myeloma Database to ensure it better reflects the national diversity as real world data from across the country? * I think that a myeloma data base would answer a lot of questions * Without compromising privacy, develop accessible data base for symptoms and symptom management. * Support of MCRN database to answer Canadian experience questions		
Diagnostic Imaging	*How can we standardize diagnostic imaging procedures to better diagnose and monitor people with myeloma?*	Should Ct Scans be used instead of X-rays to capture plasmacytomas at baseline? * Will research ask if skeletal xrays will continue to be acceptable test when a scan is more reliable? * Who needs A PET scan? Ive never had one, do I need one to investigate further diseases? * SLiM CRAB criteria recommends MRI to dx boney lesions but this is not available to everyone, what is the impact of MRI availability on the accuracy of dx and what is the clinical relevance of that impact?? * More skeletal CT scan or PET scan should be done so no big surprise and told oh if we could of caught that earlier * What about PET scans in Canada. To show MRD.	Bergstrom DJ, Kotb R, Louzada ML, Sutherland HJ, Tavoularis S, Venner CP, Côté J, LeBlanc R, Reiman A, Sebag M, Song KW. Consensus Guidelines on the Diagnosis of Multiple Myeloma and Related Disorders: Recommendations of the Myeloma Canada Research Network Consensus Guideline Consortium. Clinical Lymphoma Myeloma and Leukemia. 2020 Feb 4. ~ Chantry A, Kazmi M, Barrington S, Goh V, Mulholland N, Streetly M, Lai M, Pratt G, British Society for Haematology Guidelines. Guidelines for the use of imaging in the management of patients with myeloma. British journal of haematology. 2017 Aug;178(3):380-93.	Answered by evidence check
Diet and Vitamins	*How does healthy eating, various diets (e.g., keto, sugar free, organic, vegetarian), vitamins, and supplements improve side effects and symptoms and disease outcomes (e.g., complete response, remission).*	Does a keto diet help with symptom relief of myeloma? * Does a sugar free diet help control myeloma cells? * What about the best diet for prolonging life for these patients. * Nutrition, organic food impact. * Would a specific diet... aid in the remission? Dietary tips for eating to better prevent a recurrence or diagnosis of myeloma. * Can diet help with symptoms/living well - what to avoid - what to increase * What are the best practices in lifestyle and diet to manage myeloma for long term survival? * More on the right diet,exercise,vitamins * What vitamins and minerals can minimize symptoms and side effects? * Are PFS or OS rates improved with certain diets? * I would like research to provide scientific data on the best nutritional diet to have. Questions on vegetarianism, etc. (Translated from French) * Would a specific … vitamin aid in the remission? * Why not study supplements that could help myeloma? Like iron? Vit D? Omega oils? B vitamins?		
Dose Reduction/Treatment Cessation	*How can we safely reduce, cycle, or stop the use of medications (e.g., Dexamethasone and Revlimid) to reduce the side effects of treatment and maintain control over myeloma?*	Limiting dexamethasone dose/duration to decrease side effects * Impact of dose reductions of various magnitude on the outcome of therapy * Could the dosages of chemo be regulated so the myeloma is just kept in check? * When is it 'safe' to terminate maintenance chemo? When is a drug holiday an acceptable option? * Can lower doses of dexamethasone still control the myeloma? * For patients in 'remission', what are the implications of reducing, cycling, or stopping medication? * Rev and Dex have lots of side effects. I would like to see research into the effectiveness of reduced dosing. * when to stop treatment to give body a rest, when to continue full treatment, when to scale back to maintenance? Can less medications / chemo be given and be effective?		
Early Symptoms	*What are the early, presenting symptoms of myeloma that people with myeloma and healthcare providers should be aware of?*	Are there early signs that myeloma may develop? * Symptoms to look for early. * Recognize efforts continue to educate doctors to the signs and symptoms * What early symptoms can one watch for? * What is the most predominant sign that Myeloma is present? I.e., calcium?, low blood cell counts * A greater public awareness and health provider awareness of signs/symptoms. E.g. on going nausea/loss of appetite.		

Familial Risk	*What is the risk to family members of people with myeloma, and should they be monitored or tested routinely?*	Is there a significant familial clustering of myeloma? * Are there benefits to early intervention in cases where there is significant family history of the disease? * Should my family be tested for it? * Do our children need to be monitored more closely? * Can we consider screening the adult children of MM patients at a certain age? * Are family members at risk to develop? * How can my family prevent it? * Is there a test to be given family members to see if they are at risk? * Can my children be tested for the cancer? * Do my children need to be mindful of symptoms? * Should my children inform their doctors of myeloma being in the family? * Are there any preventive screening tests for our loved ones (children) (Translated from French) * Should my children undergo screening tests and, if so, from what age? (Translated from French)		
Genetic Link	*Is myeloma genetic? If so, are there specific genes associated with the development of myeloma?*	What are the underlying genetic links which may lead to a propensity to develop myeloma? * How many different genetic mutations have been identified? * Is there a genetic component to MM? * Are there any genetic anomalies that are the root cause of the myeloma mutation? * Is there a genetic connection to multiple myeloma? * Chromosomal abnormalities, are they cause or effect, do they affect outcome. * Are there genetic expressions which can best predict that an individual may develop myeloma? *		Questions combined after evidence check to produce question: What genes are associated with the development of myeloma, and how can genetic testing be incorporated into the diagnosis and treatment of myeloma?
Genetics for Diagnosis and Treatment	*Can genetic testing be used to inform the diagnosis and treatment of myeloma and improve treatment efficacy?*	Genetic information on the various forms of Myeloma treatments based on genetics * Linking treatment to genetic information on the disease * Is there genetic research that can specifically identify myeloma and indicate treatment options for individuals ? * Is there genetic testing available to diagnose myeloma and identify treatment options for individuals ? * Can genetic tests lead to better treatment choices. * Can side effects be predicted by a patients genetic profile. * Treatment is so varied. I would like to see more genetics involved. * The ways in which multiple myeloma interacts with the patient's own genetic make-up, and how this affects the progression of the disease in the individual. * Need a diagnosis that provides clarity on the genomic profile and risk assessment. * How can genetic studies benefit diagnosis? I would like to have more information about how the genetics associated with myeloma corresponds to specific diagnosis . Eg: high risk vs standard risk		Questions combined after evidence check to produce question: What genes are associated with the development of myeloma, and how can genetic testing be incorporated into the diagnosis and treatment of myeloma?
Healthcare Provider Knowledge	*How can we increase healthcare providers knowledge of myeloma, especially the knowledge of general practitioners about the signs and symptoms of myeloma and how to diagnose it?*	How can a GP or any other investigating doctor easily know to test for Myeloma? We have way too much missed or delayed diagnosis resulting in serious pain, suffering and early death. * It seems like many Doctors do not know the disease nor how it presents itself. * How well are general practioners equipped to diagnose myeloma? * How can we inform/ educate family doctors and public about need and factors for an early diagnosis? * First, that more general practitioners (MDs) be made aware of indications of multiple myeloma, and how to diagnose it. * Improve knowledge in the medical profession so that earlier diagnosis can be made. * How to identify earlier and educate GP's on early symptoms and diagnosis * We need to be researching how many family physicians are comfortable or knowledgeable diagnosing myeloma patients. * Why arent doctors more informed about this disease. * How can we educate our primary care professionals to detect/diagnose multiple myeloma in routine check up? * Family doctors being more aware of symptoms and signs in order to diagnose at an earlier stage. * I realize myeloma is not the same with everyone but there doesn't seem to be consensus between doctors of how/when to treat. * Eduction of primary health providers in identification.		Out of scope
High Risk/Aggressive	*Can we develop treatments specifically for high risk or aggressive myeloma that will improve outcomes for these patients?*	Are there individual drugs that can be isolated to the treatment of specific myeloma conditions such as high risk factors? * How can outcomes be better for those with high risk myeloma (genetic abnormalities, deletions, etc) * More research for specific treatments for high risk myeloma Results of larger studies broken down to show results for high risk patients separately from regular myeloma patients * What treatments are most effective for those living with a P53 diagnosis. * My partner has 'high risk' myeloma (deletion 17p and gain of 1q), we are not aware of any research being conducted for these high risk issues or whether the treatment we are receiving are optimum. * What's a protocol for treating extremely aggressive forms of myeloma that blow through the traditional drugs? * What is the best treatment for aggressive myeloma? * What is most effective treatment for P17 deletion and other aggressive forms?		
Holistic Approach	*What is the impact of a holistic approach to myeloma management (i.e., psychological, mental, faith and family, professional, and community life) on outcomes among myeloma patients?*	What is the role of faith in treating MM? * How can MM oncologists take a more holistic approach to patients while treating their current roster of patients effectively? * I would like to see a more complete picture. In other words the focus shouldnt be just on the myeloma, it should be on the whole person. * Take the time to do a thorough review of the patients physical, psychological, mental, spiritual, and their family, professional and community life * How can we make more supports for folks living with myeloma outside of the 65+ demographics and especially for folks with social/caregiver/food/financial needs to provide a better continuum of holistic support that will result in better adherence to treatment options and therefore longer survival living with myeloma * Need integrative treatments to support body (protocols to address lymphedema, supplements to replenish nutrients being depleted by treatments, etc.) and integrative therapies to support entire person * How one would get a custom tailored/individualized treatment to mental health, relationships and leisure etc? Employment, family, social life: these have just as much an impact on understanding a patient's reactions and behaviour. (Translated from French)		

Immune Functioning	*How can we restore myeloma patients' immune functioning (e.g., IgG treatment) so that they might resume their daily activities (e.g., travel, work, social interaction) without fear of infections?*	How can you disable the immune system with the drugs that slow the growth of this cancer (such as revlimid) and expect the body to be able to regenerate. * I worry about my future with myeloma and about where I should be going to interact with others in case of infections etc. Research on this would be good. * Building their Immune system the giving of a more quality of life without loss of appetite, diarrhea * More focus on immune system re-programming to do it's compete job which was compromised with the initial onslaught of the disease? * Feeling that the immune system is back to normal (not just the cancer numbers) so the it permits you to live a normal active life again (e.g. travel and contact with public) without always worrying about risks. * Should more people be on IGG treatment to reduce the risk of infection. Should it be implemented prior to there being a problem? * How to improve vaccination rates of preventable illness associated with multiple myeloma? * With poor immunity and low neut/WBC counts how can research normalize the client's social and work climates related to travel, meetings with co-workers and contagion. * After having all the vaccines can we go out and live our lives without worrying about getting an infection and dying? * How much more we are susceptable to flu, common colds, mosquito bites etc. * How much protection do you really get from wearing masks when in a situation where there are crowds ? * Besides those recommended for family caregivers, what other measures are to be taken, both at the hospital and at home, to help avoid infections and other issues resulting from a low immune system. (Translated from French) * Additional measures to take in order to avoid infections and other problems following a bone marrow transplant when social life and work resume. (Translated from French)		
Immunotherapies	*Are novel immunotherapies (e.g., CAR T) effective for the treatment of myeloma?*	I'd like to see if CAR-T cell therapy would be effective in treating myeloma. * More research and access to immunotherapy. * Possible immunotherapy treatment options * The effectiveness of Cart-Tcells treatment. * Would BCMA CAR T-cells be more effective in earlier lines of therapy? * More novel and targeted therapies eg Car-T cell. * Immunotherapy or other experimental treatments * Advances in the area of immunotherapies (Translated from French) * Develop immunotherapy because chemotherapy destroys many organs (Translated from French) What are the hopes and expectations for myeloma in the field of immunotherapy? (Translated from French)		
Increasing Incidence	*What is the annual incidence of myeloma in Canada and is it increasing?*	What percentage of the population has been diagnosed with Myeloma and how much has it increased over the last 20 years? * How many cases of myeloma are diagnosed in a given year? Is this number increasing and, if so, do we know why? * How many individuals are diagnosed in Canada in a year? Is this number rising?		Out of scope
International Differences	*What research and treatments are underway in other countries (e.g., USA, Europe, and China) and can they be adopted in Canada?*	What other countries are doing and getting results. * I catch bits and pieces of different trials and research going on in different countries. It would be interesting to see an outline of what different countries are experimenting with and where the future of MM research may be headed. A lot of it obviously won't come to fruition but it is very encouraging and interesting to know that there is great hope for MM survivors and that this disease is acknowledged and researched around the world. Helps with the whole positive thinking process * We have heard of treatments that are available in the US but, they are not yet offered in Canada. If medical treatment is really doing well in the US, why can't they become part of the treatment plans in Canada? * Is the new treatment in China going to become available in Canada? * I talk a lot with MM patients in the USA. They get a lot of info that we don't. * Why does Canada seem to lag behind other countries with treatment and can we become more unified and inclusive with global research to move forward at a faster pace? *Why are treatments different in other countries, notably in Europe. * The importance of Canadian, American and European myeloma associations and of pooling together their respective research.		Out of scope
Kidneys	*What is the impact of myeloma and its treatment on kidney functioning, and how can we reduce the negative effects on the kidneys?*	What is the link between myeloma and the adverse impact on the kidneys?* Does myeloma lead to heart conditions and kidney failure? * Doing better treatment for amyloidosis and kidney failure * Are there any other organs that can be affected, such as the liver and kidneys? (Translated from French) * Stop kidney failure (Translated from French) * In the case of my spouse, his kidneys stopped working…Could this situation have been avoided? (Translated from French)	Dimopoulos MA, Kastritis E, Terpos E, Sonneveld P, Leung N, Rajkumar SV, Orlowski RZ, Vesole DH, Richardson PG, Durie BG, Merlini G. International Myeloma Working Group recommendations for the diagnosis and management of myeloma-related renal impairment. Journal of Clinical Oncology. 2016 May 1;34(13):1544-57.	Answered by evidence check
Living Well	*How can we improve quality of life among people with myeloma (e.g., better treatments, side effect reduction, support resources) to enable them to live well with the disease?*	Does being occupied (whether through work, hobbies, family) improve a patients opportunity to live well? * Is there a way to enrich the lives of myeloma patients such that they are better prepared to deal or live with the disease? * Quality of life is critical. You do not fight myeloma you accommodate to it. Developing options for patients would be good. * While a lot of research in done into new treatments, not enough is done in the psycho-social area. How can quality of life measures be better integrated into treatment protocols? At what point does the loss of quality of life because of treatment outweigh the benefit of overall survival? * Best and recommended practices for good quality of life. What are resources for myeloma patients? * Relationship between utilizing resources and quality of life. * While the number one goal of treatment for me is achieving a really long remission, quality of life issues are what counts on a day to day basis. * Quality of life with or without treatment. * If research can minimize the side effects it would lead to better quality of life. * I feel the minimization of side effects are important to living well.		
Maintenance	*What is the impact of maintenance medications (e.g., Revlimid) on length of remission and likelihood of relapse?*	Maintenance treatment verse no Maintenance after SCT. * Is maintenance necessary? * What are the statistics about taking Revlamid vs not taking it. What is the percentage of relapse in people taking it and not taking it. * Efficacy of maintenance therapy for patients *	Gay F, Jackson G, Rosiñol L, Holstein SA, Moreau P, Spada S, Davies F, Lahuerta JJ, Leleu X, Bringhen S, Evangelista A. Maintenance treatment and survival in patients with myeloma: a systematic review and network meta-analysis. JAMA oncology. 2018 Oct 1;4(10):1389-97.	Answered by evidence check
Medication Adherence	*How compliant are myeloma patients with their medications, and what is the impact of medication adherence on disease outcomes?*	Research on medication adherence could result in patients living longer or having a better quality of life. * How does medication compliance affect outcome? * How compliant are patients in taking their medication? * What are the impacts of missing one or more injections / infusions?		

Mental Health	*How can we integrate mental health services into the treatment of myeloma to help patients and their families manage the psychological effects of myeloma and its treatment (e.g., stress, depression, anxiety, fear)? What is the impact of improving mental health on disease outcomes and life expectancy?*	Can we coordinate better mental health services as part of our treatment regimens? * How can MH services be incorporated into the MM journey more effectively? * Does stress reduction improve treatment outcomes? * How to deal with depression, anger, pain, & sadness. * Why is support for mental health seams to be an after thought and seldom offered or provided? * Huge need for less anxiety while living with myeloma. * Mental health appointments along with physical health ones.* How could treatment automatically incorporate a short mental health treatment session? With relapse this becomes more important. * What role does mental health play in managing myeloma? * What is the correlation between access to good mental health services and improved treatment outcomes for myeloma patients? * Does having good mental health help one live longer (Translated from French)		
MGUS/Smoldering	*What are new ways to monitor and/or treat the antecedents of myeloma (i.e., MGUS and smouldering myeloma) to delay or prevent the development of active myeloma?*	Can smouldering myeloma be treated to prevent or delay it from becoming active? * Should people who have been diagnosed with MGUS start active therapy? * Can treatment start when you are MGUS or smouldering? * Will treating smouldering myeloma slow the progression of the disease? * I would like to know how early MGUS can be detected in a person. * It seems better to track the MGUS, as it may go on to being SMM AND then active myeloma. * Is there an advantage to adjuvant chemotherapy in the treatment of solitary plasmacytoma, MGUS & smouldering MM that will prevent disease progression to systemic/active myeloma? * Should we treat myeloma sooner (e.g. treat when MGUS diagnosed rather than waiting for myeloma criteria) * Does early treatment of MGUS prevent disease progression? * With individuals diagnosed in the MGUS stage, what factors can predict which cases are high risk to develop active MM? * Is there a treatment for individuals with MGUS which can stop to reduce the chance of the disease developing ? * Can routine tests detect the MGUS stage? And don't wait until the disease has progressed too far. (Translated from French)		
Mode of Administration	*What is the best way to administer drug therapy (e.g., infusion, subcutaneous, orally) that balances treatment efficacy and patient quality of life?*	Is there a reason why there arent many oral treatments available for MM? * The pills are horrible wish we could just get a needle instead of so much pills * On going treatment, the pills taken for years * I would like to see research into more mobile treatment options, especially oral options. When you live hours away from your cancer centre, weekly IV treatment severely affects quality of life. If there were oral options then you would only have monthly doctors appointments. * As well less frequent or less intrusive treatments (ie. monthly instead of weekly - pills instead of IV) * Is it possible to have more treatments that you can do at home...many want to be able to travel. * Can medication be administered more quickly? A full day in the chair is both time consuming for the patient and ties up hospital resources. * Why does it take so long to change from infusion to subcutaneous after research shows subcutaneous to be just as effective.* How could more treatment be moved toward pill form administered at home? * Why does infusion work better than subcutanious? * Can a lot of present drugs be taking orally versus IV * More oral or subcutaneous versus infusion.		
Monitoring	*How can we best monitor myeloma (both active and in remission) that balances sensitivity to changes in the disease and burden on patients?*	What frequency should bone marrow biopsy be done to look for changes/disease advancement? * The frequency of when it is useful to repeat CT scans MRIs and why pet scans are not commonly used in Canada for myeloma. * How do you monitor treatment response while undergoing chemotherapy. * When a person is in remission, how often should quality monitoring of MM occur * How often will I need to have follow-up exams and imaging test? * Extending the duration between visits when on maintenance. * Monitoring of labs results, when indication of change of management * How often and if bone scans be done. * How is disease progression best monitored? * Follow-ups after transplant, how frequent must the monitoring be (Translated from French) * Symptoms, a more strict monitoring even if blood tests are fine. It would be more reassuring for the patient, less anxiety (Translated from French) * Establish monitoring via regular blood tests to reassure the person with myeloma and to avoid unnecessary stress because there is constant fear that the myeloma will return (Translated from French)		
MRD	*How can minimal residual disease testing be incorporated into myeloma treatment to improve treatment efficacy and prognosis among people with myeloma?*	How best to determine treatment effectiveness through next gen MRD testing. * MRD guided therapy to tailor to intensity and length of therapy. * Further studies which may improve the sensitivity of MRD testing in peripheral blood sample * Without knowing MRD , are we being overdosed or underdosed? * What is the long term prognosis for people with low M proteins that remain stable? * Why isn't every patient tested to see if they have residual disease in their body? * Does it make any difference if you have no Mprotein detectable or if you have any in your blood after transplant? * What about PET scans in Canada. To show MRD.		
Neuropathy	*How can we prevent and/or manage the neuropathy associated with myeloma and its treatment?*	chemo that was less prone to neuropathy * How to prevent and/or treat chemo driven peripheral neuropathy. * The biggest problem with current treatments is peripheral neuropathy. What is the best way to avoid this. * How can we stop the neuropathy that results from Chemo therapy? * Is there anything a patient can do to help alleviate the symptoms of neuropathy in the feet and hands. * Vitamin B supplementation to help with Peripheral Neuropathy? * Treatment of neuropathy, how to reduce it * Do vitamins really help decrease or prevent neuropathy? * Can neuropathy be avoided with any drug administration? * What can be done to address neuropathy and weakness in legs so patients can walk? * Peripheral neuropathy relief would be helpful. * I would like to know how to manage neuropathy before it starts. *		
New Treatments	*Develop new treatments for myeloma patients that will improve life expectancy with fewer adverse side effects (e.g., pain, nausea, neuropathy, immune suppression)?*	More treatment options are needed, I think, as our doctor says there are only 5 drugs. * Can we get a drug that does not cause a multitude of side effects that impact quality of life. * life expectancy improvements thru new drug therapy. * Create drugs that don't have such awful side effects. * Extension of survival through new treatments? * Continue research into new therapies and improve therapies and medications that have been successful. * Finding treatment meds that don't have to suppress your immune system. * Development of new agents which have less adverse side effects. * Side effects is a big issue. Coming up with treatments that minimize side effects is worthwhile. * Side effects is a big issue. Coming up with treatments that minimize side effects is worthwhile. * Treatments that are easier on the body. * Improved treatments with less side effects and longer term outcomes. * A treatment that does not have painful side effects. * Need treatments or drugs that don't cause nausea and vomiting! * Treatments that dont damage other organs and nerves such as neuropathy.		

Novel Transplant	*How effective are novel transplant procedures (e.g., allo or cord blood, donor SCT)?*	What about allo and cord blood transplants they seem to be doing in Quebec. * Why arent more Allo SCT not being done especially if a perfect or near perfect match is available * Effectiveness of tandem transplants and longevity for high risk patients. * Also are using another person's stem cells more effective than your own? We need to find this out. What about allo scts? * If a donor stem cell transplant can cure MM, why arent they done regularly? * Benefits of umbilical cord blood (Translated from French) * Why a second stem cell transplant after several weeks? (Translated from French)		
Optimal Treatment	*How can we further refine the optimal drug regimen for myeloma (e.g. drug combinations, sequence, frequency, and intensity)?*	Is quadruplet therapy better then triplet therapy * Does different combinations of treatment/therapy prolong progression free survival? * What is the best way of sequencing treatments? * Is it possible to develop one 'super' drug rather than use triplets i.e. three drugs in combination. * What is the most effective and least time consuming treatment? * Would less of the harsh drugs work just as well as the high dose in the treatment of myeloma * Find treatments that don't require weekly visits to chemo. * What triple therapy is the most beneficial? * What is the optimal schedule of daratumumab based triplets? * Is weekly bortezomib + daratumumab + dexamethasone as effective as twice weekly bortezomib + daratumumab + dexamethasone * Identify the optimal treatment with the least intervention. * Optimization of treatment protocols and drug combination treatments * Stepped treatments? Hit hard all at once? Save some treatments? What is the best strategy? * evidence based sequencing * What is the real world evidence on the impact of the sequencing of drugs? * Duration of treatments (Translated from French) * Determine the best treatment possible (Translated from French) * Is it possible to receive the treatment in a shorter time frame? (Translated from French)		
Other Cancers	*Are people with myeloma more likely to develop another type of cancer such as melanoma?*	Are your chances greater of getting another type of cancer if you have Myeloma cancer? * Well since my diagnosis in 2013 it has occurred to me that this type of cancer has been compared to melanoma, is there any similarities at all between the two? * More information required as to whether multiple myeloma is related to having had other cancers cancers. * What other cancers are they at higher risk to develop?	Musto P, Anderson KC, Attal M, Richardson PG, Badros A, Hou J, Comenzo R, Du J, Durie BG, San Miguel J, Einsele H. Second primary malignancies in multiple myeloma: an overview and IMWG consensus. Annals of Oncology. 2017 Feb 1;28(2):228-45.	Answered by evidence check
Pain Management	*What are some non-opioid pain management strategies or medications to reduce pain among people with myeloma?*	How to lessen muscle, skin and bone pain * Pain has been my biggest challenge. What other ways of managing pain are available? * A more comprehensive approach to pain management. * What is the impact of pain and the effective use of pain control? * Particular pathway for people living with chronic pain other than opiods. (Translated from French) * Advice on how to control bone pain. (Translated from French) * How to manage pain caused by myeloma, while at the same time preventing the person from being too affected by the medication (Translated from French) * Being able to reassure patients by having effective pain treatments (Translated from French)		
Palliative Care	*Does the earlier introduction to the palliative care team and regular follow-up improve outcomes (e.g., decrease fear, improve mental health, improve family communication) compared to end of life care only?*	Does the introduction to palliative care team at diagnosis and regular follow-up decrease fear, improve mental health, communication, barriers, family vs end of life only? * When is palliative care given as an option in early diagnosis of Multiple Myeloma? * How palliative care benefits patients even earlier in their treatment. Who will provide it? * Palliative care should be discussed right away by the doctors. * Explain palliative care earlier and in detail. * If the disease is progressing and not getting better, ways of palliative care should be explored. * At what point during treatment do patients want to learn about palliative care concepts? Early vs later? With so many treatment options in an incurable setting this topic is hard to raise but so important		
Patient and Caregiver Knowledge	*How can we improve patient and caregiver knowledge of the diagnosis (e.g., type of myeloma and stage), treatment (e.g., treatment options, what to expect when on treatment), management (e.g., symptom management), and living well (e.g., availability of support resources)*	Insufficient information about the treatment to be expected. * How to educate the family about the disease. * More information needs to be given when you first find out that you have myeloma. How the chemo will affect you and how all the medications will alter your emotions * More information about the type of myeloma and what treatments would work better. * Myeloma is a broad term for a disease that has different forms and treatments. Newly diagnosed and those already under treatment should be given the information as to their type of Myeloma and potential outcomes. * Who do I go to for timely answers? * Greater information in plain talk about how the various options for treatment can be used. * A list of side effects, the percentage of time they occur, and how best to counteract them. * A list of symptoms * Would newly diagnosed patients handle their diagnosis more easily if given all the information and resources that are available right when they are diagnosed? * Simpler booklets for families to understand the emotional part of myeloma. * What and how many different types of myeloma are effecting people today * Better services for educating and updating patient's concerns re symptoms and side effects of treatments. * What exactly is myeloma and and what stage is one in on diagnosis. * More information on what myeloma is as when I was diagnosed I had never heard of it * It would be helpful if different treatment plans were laid out in an easier to understand list for the patient and caregiver . * Is it possible to get a written standardized summary of diagnosis complete with treatment options? * Understanding details of disease, understanding blood tests, understanding prognoses * Could information on myeloma, in the form of small booklets, be more readily available? (Translated from French) * Learn the results of ongoing studies. (Translated from French) * Organize information sessions on myeloma and not on cancer in general, as is currently the case, so as to allow for better patient management from the very moment the diagosis is established. (Translated from French) * Organize information sessions, live or pre-taped web conferences, and give the floor to patients and their loved ones, invite specialists who will answer their questions (Translated from French)		
Patient Empowerment	*How can we empower people with myeloma and their caregivers to play an activist role in the prevention, support, treatment, and research of myeloma?*	How can people living with MM be empowered to play a greater activist role in prevention, support, treatment and research? * Involve MM patients in all research as advisers as well as participants. * allowing the families to give their ideas to help, give feed back & ideas with to the medical team. * How can a patient advocate for improvements in managing myeloma? * More access to patient power programs. * What role does the voice of the patient play in treatment? * What control does the patient have over the treatment and its effects? * Ongoing improvement of patient information to allow patients to make informed decisions.		

Patient Healthcare Provider Relationship	*How important is the patient healthcare provider relationship to the management of myeloma and how can we improve this relationship (e.g., consistent healthcare provider, open communication about treatment options, acknowledging patient concerns)?*	How can oncologists and hematologists understand that a myeloma diagnosis needs to be done only in person and with a support person present to help with the shock, questions and listening? No more phone diagnosis! * How important is the patient doctor relationship in managing the disease? * I would rather have information presented by a specialist (one on one). I don't want to be learning through the internet. * Discussions with my treatment team seem isolating at times, and dismissive of other patient's problems and solutions (like saying everyone is unique). * Can all treatment options be discussed openly with the patient / caregiver team? * Side effects are not taken seriously enough by health care workers. * Consistency with seeing same hematologist especially once numbers are lowering. At my site, once the numbers drop I am referred to Associates, Nurse Practictioners, etc. it is a tough journey and the relationship developed helps with the care and healing. * I would like to know that after receiving the diagnosis there would be someone to explain what it means. I was told in a 5 minute few sentences that I had myeloma with no instruction about what happens next. I read somethings about it and was sure I would die in the next 5 years.		
Patient Variation	*What are the underlying differences that contribute to patient variation in terms of symptoms and treatment responses and how can we account for these differences in the diagnosis and treatment of myeloma?*	Why is it that different myeloma patients have differ symptoms * Lots of varying symptoms individually for drugs. Why do some drugs work for some people but not others. * There seems to be a lot of varying patient symptoms in myeloma diagnosis. (ie. some present with kidney problems, others with bone issues etc,) Are there different strains / types of myeloma currently presented under one umbrella ? * Why is treatment not always the same for all MM patients * So, what is it *that makes one patient respond so well to a drug whereas others don't respond well at all?Is this genetically based? * Seems everyone experiences side effects differently. If there were more precise predictions of side effects, it would be better to manage. For example, perhaps people over 70 experience similar side effects? * Why do patients relapse at different times and live with different number of years on a treatment? * Disparities in treatment outcomes among different groups * Why do some people get good results and others dont when taking same drug. Why?		
Personalized Treatment	*How can we personalize a patient's treatment based on their type of myeloma and genetic profile, and what is the impact of personalized medicine on treatment efficacy and disease outcomes?*	The possibility to get precise target therapy * If it is too uncertain at this stage that is fine but wondering if different treatments per the type of myeloma have been researched. * Research find a way to determine which drugs would be best for me and my type of Myeloma. * I would like to better understand the genetic makeup of my myeloma cells to understand my prognosis and individually targeted treatment(s) * Is this treatment protocol for all relatively healthy patients? Is it based on any other factors? * My myeloma is different from someone elses. So if my MM is genetically then my treatment can be geared to me specifically. * Which treatments are best for which type of myeloma (per cytogenetic risk factors) * I would like to better understand how myeloma treatment could be made more effective by personalizing treatments based on the individuals unique DNA analysis. * Are we headed towards precision medicine - are we choosing treatment strategies with a good understanding of the patient's own particular disease ? * Continue research of treatments that target myeloma at the genetic level of the individual. * Need targeted treatments linked to genetic profile and outcomes supported by clinical evidence. * Research on treatment regimens - myeloma patients disease is not a one size fits all, yes treatments need to be almost personalized. * How to match up the right drug for your type of myeloma? * Treatment tailored to the genetic profile of the patients myeloma. * Refined risk stratification. Better targets for targetted therapy and rationale for personalized approaches. * Treatment according to the type of Myeloma (individually) to match with the DNA of the Myeloma		
Physical Activity	*What is the impact of physical activity on myeloma symptoms (e.g., bone health), mental health, and outcomes (e.g., treatment response, life expectancy)?*	Does increased physical activity play a role to improve ones day-to-day life? * What is the role of exercise in treating MM, side effects or depression? * Does physical activity play a role in Myeloma survival? * What is the role of exercise in myeloma and is it effective. * Does regular exercise lead to better outcomes? * Exercise in myeloma and it's effect on bone protection * What has been found with exercise / mental health benefits * How does exercise affect long term management of myeloma? * Is exercise actually effective in increasing chemo effectivenes * How important is exercise and physical fitness in fighting the effects of mm * Does exercise help with long term survival and outcomes * The effects that being physically active have on pretty well all other aspects of mental health, relationships, etc. * Are PFS or OS rates improved with exercise? * More research on the value of lifestyle (exercise) in the management of the disease. * Can optimal exercise programs reduce side effects from myeloma drugs?		
Prevention	*What steps can individuals (e.g., lifestyle) and the healthcare system (e.g., vaccinations) take to prevent myeloma from developing?*	What steps would a person take to avoid getting myeloma? * Can we prevent MM? * Can we vaccinate against MM or are there other ways to prevent MM in the general population? * Are there any indications of who might be susceptible to this disease so that possible measures could be taken for prevention. * And is there any way an individual can help prevent it? * Is there work on vaccines to help prevent myeloma? * How to prevent myeloma through early detection? * I realize that this may seem out of reach for now, but in my opinion it would be beneficial to consider the possible causes of multiple myeloma, so as to draw some useful prevention measures from them.		
Prognosis	*How can we better communicate information regarding prognosis to patients?*	Dealing with fear of future. What is likely course of MM for me? * Provide a clearer understanding of a patients type of Myeloma and the markers used to track it's progression. * Would want to know what a prognosis is * An overview on how the MM is likely to evolve. I had to research on line to get this information. * Description of later symptoms to ensure opportunities aren't missed due to decline of well being. * What will my journey look like? (Translated from French) * What is the prognosis? (how many years do I have left to live?) (Translated from French) * What are the symptoms of deteriorating health due to myeloma. (Translated from French) * Describe the typical path of a person diagnosed with myeloma (Translated from French) * What will my journey look like?		

Provincial Variation	*What are the provincial and geographical differences in the incidence of myeloma and how it is treated and paid for across Canada?*	What is the variation of standards of care across the country? * Differences in approval and funding for different parts of Canada. * Does living in a certain province mean you will live longer (i.e.: Does having better access to drugs = longer overall survival?) * Which province has patients living longer? * Which province has patients who report the best quality of life? and Why? * Why are some provinces so slow to get a drug approved? * We need governments to approve the newer better drugs quicker. * Outcomes of current provincial standards? * Opportunity of getting treatment in another Province * We need drugs that can be covered by our provincial health authorities * Hot spots in Canada or places * I would like to see more research being done on regions that have a higher incidence of myeloma		Out of scope
Public Awareness	*How can we increase public awareness of myeloma and the research being conducted to treat it?*	I would like more publicity about myeloma, more and faster research, more information to patients and caregivers, and nurses. * Summarize the policy recommendations based on evidence and circulate to everyone involved in Myeloma to advocate for.* Myeloma is an invisible cancer how do we make it be seen? * Why has/had no one ever heard of multiple myeloma? * Knowledge translation - No one knows about MM - What's up with that? Everyone is aware of breast cancer yet no one including me had ever heard of MM. * Greater public awareness. * Share results in the media more often or share the results with us, as well as advances made to date. Are there any current clinical trials (Translated from French) * Stories of how other myeloma patients deal with their myeloma on a daily basis		Out of scope
Relationship Impact	*What is the impact of myeloma on the person's relationships with family and friends, and what can be done to help with this?*	Asking patients and caregivers more questions in steroid use and its effects on relationships? * The emotional impact on families. * What it does to family dynamics.* Relationships (Translated from French) * As is the case with all major diseases, friends and loved ones suffer greatly from changes brought on by the disease, the couple, the family, loved ones, reconstructing one's life… (Translated from French) * Is it possible to resume a normal life after myeloma? Which sports can one play? Must one fear having friends or intimate relationships? * Life on steroids...a physiological explanation of how they affect the emotions and how to cope for both patient and family. * As for relationship people move away due to alway tire sleepy vomiting, they cant handle it		
Remission/Relapse	*How can we prolong remission/prevent relapse among people with myeloma?*	How can myeloma be stopped from relapse * What is the best treatment for the longest most complete remission? * What is the best combination treatment for longest lasting remission? * How long can remission be expected to last? * Is there a treatment that can prevent return of myeloma? * Are there any preventative steps I could have taken to protect myself from it coming back out of remission? * How many years can one expect from each treatment regime until relapse? * Are periods of remission being lengthened? * How long does is the treatment likely to control myeloma, before a relapse? * Improve the length and depth of remission. (Translated from French)		Combined with Maintenance after evidence check
Retreating/Relapsed/Refractory	*What is the most effective way (i.e., drug combinations, sequence, frequency, and intensity) to treat refractory, relapsed, and drug resistant myeloma?*	Is there another drug that could specifically target the cells that are resistant? * Options given treatment failure. * What will we do if the treatment doesn't work or if the cancer recurs?What are the optimal sequencing options for relapse/refractory treatment? * More data on retreating/recombining drugs that stopped working before. * How to treat relapsed myeloma * What treatments are available after the first occurrence of the disease? * Continue to investigate new drugs in the relapse setting. * A safer treatment solution for when a first relapse occurs. * Very key to me is research on timing of when to issue the next treatment based on a so called relapse. * What could I have done, before I went completely out of remission before I had to start treatments.		
Safe Activites	*What are recommended exercises for people with myeloma and what physical activities can a person with myeloma safely participate in (e.g., golf, weightlifting, biking)?*	More information on physical capabilities based on the thousands of patients histories. Build a data base if one doesn't exist. The comment from the physician that 'let your body tell you what you can do' is not sufficient. * Recommendations for appropriate exercise limits, more access to physiotherapists/ trainers to learn appropriate work outs * To what degree level can one go in more intense sports. * How to exercise more safely * Exercise, what is the best exercises to do especially ifs it your bones are effected fractures, lesions * Is there a minimum/optimum level of exercise/activity recommended for patients? * This might need to be based on the individual. For instance... when is it safe to resume exercise, lifting weights, taking supplements, etc. * What exercises can I do apart from walking and going on a stationaty bike? * Exercise - what is safe to do? how much weight is safe to lift following vertebroplasty and ongoing maintenance? ie - no more than 50 lbs * Leisure and fitness.... if you are feeling well how far should you push yourself to keep your same fitness level the same as pre diagnosis. Can you do harm to your body? * I would like more information on what type of exercise and activity is the best when you are dealing with myeloma. Is it better to keep pushing yourself or take it easy? * With many bone lesions is it safe to play golf for instance ? * It would also be helpful to provide patients and caregivers with a more comprehensive outline of how to return to daily life. For example, after a burst fracture, what activities can you partake in? Yoga, swimming, etc.		
Screening	*What is the impact of screening for myeloma in routine care (like mammogram or colonoscopy) on early detection?*	More info on the effect of early screening and treatment. * Should there be earlier screening to detect the disease? * When should screening be done? How early? * What about a regular test? Once a year or so like other Cancers? * What is a good age fora regular blood test to start including the specific one to include the multiple myeloma blood test * Since Myeloma is the fastest growing cancer, would there be a benefit in screening for it during your annual medical checkup? * Can a full CBC be mandated as part of the annual medical after a certain age, say 60 or 65 * Can we pre-screen for MM to catch before disease advances * Is there better ways to screen for early myeloma rather than waiting until the patient can't support their own body weight? * Would early screening be effective in providing an earlier diagnosis and thereby improving long term outcomes * Early screening of patients by their family doctor. * Is there a way to prescreen or predict if someone is going to get myeloma? * Is there an economic screening test that will identify at risk individuals when they are at the MGUS stage. * Can we detect myeloma earlier by making certain tests standard part of CBC/yearly bloodwork? i.e. add serum protein test to standard bloodwork (test for gamma globulin and protein monoclonal band) * Would it be necessary to include blood tests to detect myeloma in annual blood tests, similar to what is done for cholesterol, diabetes…? (Translated from French)		

Self-Help	*Besides cancer treatment, how can patients take control over the management of their myeloma (e.g., physical activity, diet, meditation, spirituality) to improve survival?*	What are the most typically helpful lifestyle patterns (fitness, nutrition, rhythm of life, etc.) for myeloma patients? * Besides chemo and other treatments, is there anything I can do day-to-day that would help with my treatment? * Strategies for patient and care giver for managing diet, fatigue and emotional support . * What can a patient do to make a treatment more effective? * How can I help myself? * What can a patient do to increase their treatment effectiveness and life expectancy? * How can the patient take some control of managing their cancer? * How to keep yourself as healthy as possible during and after treatment. * Are there lifestyle changes that can be made to help with myeloma patients? * Is there something I can do, other than turn myself over to health professionals, to maintain my health? * What steps can I take in my day-to-day activities to help the team of specialists improve my personal situation? I want to be active and not passive! (Translated from French) * More information on what I can do to better manage the situation myself (Translated from French) * Besides medical management, what are the best practices in terms of disease management? (Translated from French)		
Self-Monitoring	*How can we improve patients' access to their laboratory results and educate them about what results and symptoms they should monitor to track their myeloma and overall health?*	Can you explain my bloodwork results so I can grasp a better understanding about how I'm responding to treatment? * What to look for on your blood work readings to make sure you are not jeopardizing the rest of your body. * What should I be on alert for in changes in my blood or well being? * Which blood cell numbers are most important to watch to diagnose Myeloma becoming active again? * How to interpret trends (rising or lowering of numbers etc) of the blood tests etc. towards recovery? * What lab results to look at and to be able to self track * Which bloodwork analysis points matter and what to what for on 'MyChart'		
Service Navigation	*How can we make it easier for people with myeloma to navigate the healthcare system (e.g., a healthcare navigator)?*	A better navigation and communication system of options for patients and caregivers would be much appreciated. The healthcare system should be more patient centric, not just in terms of words but in actions and making it easier for patients to understand the process and bureaucracy associated with the healthcare system and making it more efficient in its processes and spending the funds toward patient care and services. * How does a patient navigate the myeloma journey without an advocate or caregiver? * Why is there not a set program developed for navigation through the health system for each and every patient upon entering the myeloma journey? * Navigating the health services which can be confusing and quite daunting especially when this may be the first time someone has had any need to navigate the health system. * How can we make it easier to navigate the health system so that patients can be educated about what is available to to us * I would like to see more details on navigating health services, what to expect? * How can patients who live alone receive all of the care they need and attend their numerous appointments? (Translated from French)		Question was combined with "Care Coordination" following evidence check to produce the question: How can we improve the patients' experience with myeloma care through better care coordination and supports to navigate the healthcare system, and what is the impact of improved care experience on patients' well-being?
Sexual Health	*What is the impact of myeloma and its treatment on sexual health (e.g., sex drive, use of erectile dysfunction medications and contraception, risk of secondary cancers), and how can we help people with myeloma and their partners have healthy sex lives?*	Sex and a healthy libido were some of the best indicators of healing, yet it is completely ignored in MM literature. Why? Is it safe to take ED medications or birth control with MM maintenance therapies? * How to deal with the loss of sex drive due to treatment protocols * Why is the sex drive decrease? * Does anyone address the gynaecological health of women, especially the side effects of drugs?		
Side Effect Management	*How can we reduce or manage the short (e.g., diarrhea, nausea, fatigue, emotional dysregulation, skin reactions, neuropathy, anxiety) and long term (e.g., vision deterioration, loss of muscle strength, kidney failure) effects of myeloma treatment?*	Can we do research into long term side affects on vision deterioration and muscle strength reduction as side effects? * What are the impacts of long-term lenalidomide usage in myeloma patients whom have received a stem cell transplant, and are on maintenance therapy? * How can diseases and treatment side effects be treated or minimized? This includes fatigue, skin rash and peripheral neuropathy. * Vitamin B supplementation to help mitigate PN during treatment from Velcade. * Why is there no recommendation of OTC treatments for side effects? * Side effects....GI problems seems to be a huge consequence for many patients. What possible additives to existing treatments might be used to relief these nagging symptoms? * More specifics on side effects and their long term effects on organs, health. For example, the side effects of Revlimid and dexamethasone on kidneys and how to delay kidney failure. * If research can minimize the side effects it would lead to better quality of life. The side effects can be quite debilitating. * Relieve the anxiety produced by the drugs!!! * Do side effects which impact quality of life, such as management of diarrhea, affect a patient's mental health and prognosis? * How to prevent kidney malfunction when on chemotherapy. (besides drinking lots of water). * How can we minimize the impact of side effects such as feeling tired all the time in ways other than changing the dose. * Side effects: need a better choice of anti nausea drugs as Ondansetron does not work for me. * How to deal with potential depression caused by a reaction to drugs used * How can competing side effects be managed better? (My Mom had cardiac amyloidosis which needed fluid restriction, but then she went into kidney failure and needed to hydrate - it was always a choice between taking care of her lungs and her heart). * What medications are available to off set side effects of ongoing treatment * Wouldnt it be great if all the drugs didnt come with 400 pages of possible side effects? Can they work towards making effective drugs to control this disease without dealing with side effects that harm and make things worse? * Effective remedies for the post chemo days diarrhea, vomiting, sleeplessness. * How would the side effects of anxiety, fatigue and chemo brain etc. will be treated along with myeloma treatment?		

Social Support	*What is the impact of social support (e.g., family, friends, healthcare providers, support groups) on the mental and physical health of persons with myeloma and their caregivers?*	More information needed to help patients and families deal with uncertainty of multiple myeloma as well as how to talk about the disease. * If emotional or social support is provided as part of the treatment how does this affect the outcome? * Link patients to the nearest multiple myeloma support group. * How effect are support groups (very) * The importance of support groups in the lives of people with myeloma and their caregivers. * How many patients undergo myeloma treatment alone, and if so, what resources can we provide them with to improve their outcomes? * For me what has been very helpful is being a part of a support group and more importantly having the support of family and friends. Without this it would be near impossible to deal with myeloma * I wish the doctors and nurses had more time to talk to show caring, to share information. Not enough support and no support groups depending on where you live. Feeling alone. * How does social support or group support affect outcomes for myeloma patients * The importance of support provided by family and friends (Translated from French) * Mental health information, support, access no one seems to address these issues. Conflicting information on line, where I seem to have to go to get much information or support. * How can Myeloma people be brought to understanding of the need for a caregiver helper and the benefit of support groups from the diagnosis forward? * Mental health: anxiety, group support is so important.		
Supports and Resources	*What supports and resources (e.g., psychosocial, helpline) are currently available to people with myeloma and their caregivers and what are the gaps in services?*	Is there professional help available. * What non-medical supports have helped MM patients? * When will there be a myeloma helpline? * What health care resources are available for patients and families. * What programs and support are available? * What health services are available for myeloma patients? * Better support for patients and their loved ones? (Translated from French) * Resources available in the health system (Translated from French)		Out of scope
Symptom Management	*How can the symptoms of myeloma (e.g., decreased physical and cognitive functioning, constipation) be managed?*	Best practices for symptom management, like diarrhea constipation and fatigue * What is the best treatment with regards to symptoms. * What symptoms occur most often? * Symptom management (guidelines/ support) * Symptom identification and management * What helps to appease symptoms when symptoms are severe (Translated from French) * How to help the symptoms (Translated from French)		
Symptoms vs Side Effects	*How can a person with myeloma differentiate between myeloma symptoms and the side effects of treatment?*	Yes not sure at times if something I feel is a symptom of the disease or a side effect of the drugs administered. I would like more research and articles about this. * What to expect regarding various symptoms and their side effects * I like to know when my body shows side effects what is causing them...the cancer or the drugs? * How do I know if certain physical symptoms are related to the myeloma or other issues? Ie. Back pain, neuropathy, etc * How to decide between symptoms of the disease and the side of effects of treatments…in order to have a better quality of life. (Translated from French)		Out of scope
Travel	*Is it safe for people with myeloma to travel and, if so, what precautions should they take?*	Being able to travel without worrying about health care. * Are there considerations/procedures I should be aware of in order to travel? * Is it safe to travel by plane? * Travel precautions i.e. meds * Still concerned about travel especially out of Canada * Incurable cancer now... this causes a huge travel insurance issue! * Can one travel safely to help the spirit rise? * Where to get the best travel insurance for mm		Out of scope
Treatment Options and Effectiveness	*What are the current treatment options for myeloma in Canada and how effective are they at improving patient outcomes (e.g., remission rates, life expectancy, quality of life)?*	What is the prognosis of various treatment options? * What is the most effective treatment regime? * What does 'success' look like for the line of treatment you're prescribing? * Predictions on the efficacy of various treatments. * What is the difference between the various drug options that are offered? * What choices are available in each stage of treatment. * Which treatment supports a longer and healthier life? * Drug choices in Canada * How effective is the current treatment of myeloma? * What is the success rate for various treatments? * What treatment has the least side effects with the greatest survival rate? * Best route to go to get the best possible results with minimal side effects and impact on quality of life. * What is the best treatment for prolonged quality of life with myeloma? * What are the first-line treatements? Second-line treatments, etc.? (Translated from French)		