

We publish this newsletter quarterly, with information on what's new in MPN care and research. Each issue we bring together MPN advances and news, and keep you up to date with the work of the Canadian MPN Group. Comments, ideas and suggestions can be sent to [info@mpncanada.com](mailto:info@mpncanada.com)

## Spotlight – Shared Care at Princess Margaret Cancer Centre

By Verna Cheung



*Verna Cheung (left) and Nancy Siddiq (right), Clinical Nurse Specialists and shared care coordinators in the Elizabeth and Tony Comper MPN Program at Princess Margaret Cancer Centre, Toronto*

The Elizabeth and Tony Comper Myeloproliferative Neoplasm (MPN) Program at Princess Margaret Cancer Centre sees 140 to 150 new MPN patients annually. Our referral profile is skewed towards patients with myelofibrosis, and MPN patients with additional medical complications, poor treatment response, or complex diagnoses.

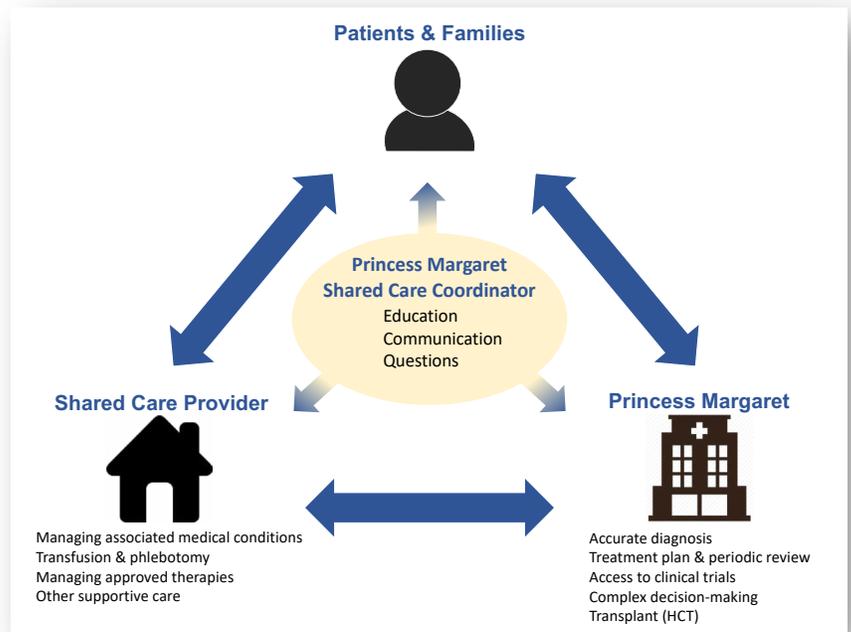
Due to the chronicity, rarity and complexity of MPNs, not all local hospitals have expertise or experience in managing patients with MPNs. The MPN Program at Princess Margaret receives referrals from across Ontario, as well as from other provinces. Given the large geographical distance and the older age of most MPN patients, travel burden and caregiver availability are challenges. To better serve our patients, a shared care model has been adapted in our practice.

### What is shared care?

Shared care is defined as the “joint participation of primary/ local and specialized care providers in the planned delivery of care for patients with chronic conditions, underpinned by enhanced information exchange”<sup>1</sup>. This model of care allows patients to access specialized care at a quaternary centre while maintaining a connection with their local care facility, and being able to receive supportive care and treatment closer to home<sup>4,5</sup>. The specialized centre may offer clinical expertise for clarification or confirmation of diagnosis, treatment options, or clinical trials, while the patient can access care such as medication dose adjustment, management of co-morbidities, transfusion supports at the local care facility.

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### The Shared Care model in the MPN Program at Princess Margaret



### The value of shared care

The partnership and collaboration between our centre and the local/primary care centres allows for knowledge translation between the two centres.

The shared-care model allows patients to receive treatment closer to home and therefore:

- Decreases travel and financial burden for patients and their caregivers
- Improves quality of life for patients and caregivers
- Allows patients to access specialized care (e.g. clinical trials) while maintaining contact with primary care team
- Increases patient knowledge and awareness of their illness through education from a specialized centre

### How does shared care work?

This diagram illustrates the key stakeholders for a shared care model, and the roles and responsibility of each stakeholder.

The role of the Princess Margaret MPN Program is to provide accurate MPN diagnosis, offer expert consultation regarding diagnostic confirmation, treatment options, clinical trials, and allogeneic stem cell transplant referral. The local shared care provider's role is to provide ongoing supportive care for the patient's MPN (e.g. count checks, transfusion support, monitor established therapy), and manage other co-morbidities the patient may have<sup>2,3</sup>. There is constant communication between the various stakeholders.

The MPN program has established the clinical nurse specialist role to ensure sharing of information, and open and consistent communication. The clinical nurse specialist is the shared care coordinator, providing a single point of contact for all stakeholders, connecting the patient to the different care providers and ensuring information is

shared across the multi-disciplinary team<sup>3</sup>. As the diagram illustrates, the communication process is cyclical; there is constant communication between all members of the shared care team.

### Shared care referral – our process

The MPN Program at Princess Margaret serves primarily as a consultation centre to our local partners. As shared care is established through patient referral to Princess Margaret, provision of adequate information with the referral is essential to ensure timely triage. Referrals are accepted only from physicians.

Information that should be included with the referral: initial consultation note, recent clinic note, imaging reports, serial lab reports, and bone marrow biopsy and cytogenetics reports. These are all important to facilitate comprehensive triage.

### Next steps and Vision

We are continuing to look at ways to improve efficiency of the delivery of care to our patients. Given that patients are referred from the entire province of Ontario, and sometimes even across Canada, geographical distance and travel burden can be challenge for our patients. Therefore, we are currently looking at technological means to provide consultation to our local partners to tackle these challenges, while protecting patient privacy and confidentiality.

We aim to become a resource centre to both our local partners and our patients. Furthermore, we wish to serve as an educational resource to our patients. This is especially important to our patients given the rarity of MPNs. We do this through developing educational material and providing information on peer support groups, so they too can be active participants and advocates in their care.



**Nancy Siddiq**  
*RN, BScN, CON (c),  
MSN in Education*

Nancy is a Clinical Nurse Specialist in the MPN Program. Nancy has completed her master’s degree in Education, and has a wealth of knowledge in malignant hematology. Nancy’s career in oncology began at Sunnybrook Health Science Centre in the oncology inpatient unit. Since then she had been in various advance practice and leadership roles, including Nurse Educator, Allogeneic Stem Cell Transplant Coordinator, and Leukemia Outreach Coordinator.



**Verna Cheung**  
*(BScN, RN, MN, CON(c))*

Verna is a Clinical Nurse Specialist in the MPN Program. Verna completed her master’s degree in Nursing at the University of Toronto. Verna’s career in oncology nursing began at Princess Margaret Cancer Centre in the System Therapy Unit. Prior to joining the Elizabeth and Tony Comper MPN Program, Verna was also an Autologous Stem Cell Transplant Coordinator at Princess Margaret.

**Referrals to the MPN Program at Princess Margaret**

Address:  
Princess Margaret Cancer Centre  
610 University Avenue  
Toronto, ON M5G 2M9  
Tel 416.946.4501 x3047  
Fax 416.946.2900

Referrals are accepted from physicians only

Contact: Nancy Siddiq

Referrals must be faxed to the New Patient Referrals Department, marked “for the attention of Nancy Siddiq”

**References**

1. Hall, S. J., Samuel, L. M., & Murchie, P. (2011). Toward shared care for people with cancer: developing the model with patients and GPs. *Family Practice*, 28, 554-564.
2. Devlin, R. & Siddiq, N. M. (2016) *Myeloproliferative Neoplasms (MPN) A guide for patients & families*. University Health Network, Toronto. ([available here](#))
3. Khera, N., Martin, P., Edsall, K., Boagura, A., Burns, L. J., Juckett, M., Majhail, N. S. (2017). Patient-centered care coordination in hematopoietic cell transplantation. *Blood Advances*, 1(19), 1617-1627.
4. Gorin, S. S., Haggstrom, D., Han, P. K. J., et al (2017). Cancer Care Coordination: a Systematic Review and Meta-Analysis of Over 30 Years of Empirical Studies. *Annals of Behavioral Medicine*, 51 (4), 532-546. .

# Clinical trials update

A full list of clinical trials in Canada and contact details for MPN centres can be found on our website.

## Currently enrolling for PV

Idasanutlin [NCT02663518] – This study is to evaluate efficacy and safety of idasanutlin therapy in patients with polycythemia vera (PV) who are resistant or intolerant to hydroxyurea therapy. Inclusion criteria include resistance or intolerance to hydroxyurea and a hematocrit of >40. Currently enrolling: Princess Margaret Cancer Centre, Toronto

## MIPSS70 – a new prognostic scoring system

Though mutation testing, including next generation sequencing, is increasingly utilized in the care of patients with myelofibrosis and knowledge about the prognostic impact of these mutations has grown, a tool integrating this knowledge into a risk stratification system has been lacking. This has changed with the recent publication of a risk stratification tool for patients with myelofibrosis, developed by a collaboration between MPN researchers at the Mayo Clinic, USA and multiple Italian MPN groups. The new tool, known as the Mutation-Enhanced International Prognostic Score System for Transplantation-Age Patients With Primary Myelofibrosis (MIPSS70) is the first to integrate mutation data into a prognostic risk stratification system. An additional scoring system called MIPSS70 Plus, published in the same article, includes cytogenetic information. The team also developed an online tool to facilitate calculation of MIPSS70 and MIPSS70 Plus, available [here](#).

MIPSS70 uses information on hemoglobin, white cell count, platelet count, circulating blasts, bone marrow fibrosis, constitutional symptoms, presence/absence of the CALR driver mutation, presence of a high molecular risk mutation (ASXL1, EZH2, SRSF2, and IDH1/2) and presence of 2 or more of these high risk mutations.

Reference: Guglielmelli et al. *Journal of Clinical Oncology*. 2018; 36(4):310-318

## MPN e-SIMPLE

The MPN e-SIMPLE app was developed with the support of Novartis. The app provides data, resources and guidance to assist Canadian physicians in daily management of MPNs. The goal is to improve the management of MPNs across Canada by providing point-of-care guidance to our colleagues on therapeutic approaches for each MPN patients.

The app includes disease risk calculators (IPSS, DIPSS, DIPSS Plus and IPVS), resources for MPN diagnosis and risk assessment, and information on treatment options. At present the app covers MF and PV, with ET coming soon. MPN e-SIMPLE can be used through your web browser or downloaded (Android & iOS, optimized for tablets) at [www.mpnesimple.ca](http://www.mpnesimple.ca)



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