

Patient and Family Advisory Council – Cancer Care Program
March 7th, 2018
Dr. H. Bliss Murphy Cancer Centre, Room #2044, Administration

MINUTES

PRESENT: 16 members in attendance.

1.0 Approval of Agenda

The Agenda was approved as circulated.

2.0 Approval of Previous Minutes – February 7th, 2018

The Minutes of February 7th, 2018 were approved as circulated.

3.0 Safety Moment

Signage for Slips and Falls have been placed in all front entrances to Eastern Health. A telephone number is listed so that patients, families and staff will report any slips or falls on the grounds of Eastern Health.

4.0 New Business

4.1 Presentation – Living with Cancer: A Report on the Patient Experience

Clinical Epidemiologist presented an overview of the “Living with Cancer: A Report on the Patient Experience”. A number of slides were shown which included jurisdictional results specific to wait times from an abnormal fecal test to follow-up for colonoscopy and wait times from an abnormal breast screen to resolution which showed a synopsis on how Newfoundland and Labrador compared to other Provinces.

Some of the highlights were as follows:

- Newfoundland and Labrador showed the best performance for colon screening partly due to the dedicated time slots for colonoscopy.
- Breast screening wait time is 8 weeks. The Cancer Care Program is in the process of working with MUN to do a Breast Screening Project on patient bookings and the reasons for delay.
- Breast Disease Site Group is reviewing the wait times from abnormal breast screen to diagnosis with biopsy. Newfoundland and Labrador wait time is 15 weeks.

Other jurisdictional results specific to hearing “you have cancer” include:

- Patients being told of their cancer diagnosis sensitively – 97.1%
- Referred to a care provider for help with their anxieties and fears when they are diagnosed – 67.7%.

This was discussed further and Social Work and Cancer Patient Navigator roles can assist. Members expected there is a lack of

continuity in care i.e. same person for patient care for Nursing, Social Work, etc.

- No one discusses treatment options with them – 13.2%
It was noted that it is hard to get a referral to an Oncologist and also that the consult is with the specialist however no consult with the patient. Communication with the patient was noted as being very important.
- Some report that they are not able to discuss their worries or concerns before treatment with their care providers – 7.4%
- Not given enough information about cancer treatments, though some describe a need more information to make an informed decision – 5.1%
- Patients who have to travel for tests or treatments report that their care providers do not consider their travel concerns when planning their treatment – 11.4%

Jurisdictional results specific to Radiation Therapy Wait Times:

- People are receiving radiation therapy quickly – 98.6% within 28 days or less.

5.0 Business Arising

5.1 CPAC Update

A member of PFAC attended the CPAC Meeting entitled “Transforming the System: Understanding the Pre-Diagnosis Cancer Experience” on February 22nd, 2018 in Toronto, ON. An overview was provided to the group regarding the objective of this meeting which included:

1. To obtain a variety of perspectives to gain a deeper understanding of healthcare system gaps and leading interventions for the pre-diagnosis phase of the individual’s cancer experience.
2. Discuss key issues and complexities faced by individuals in Canada and articulate the desired future state.
3. Build on existing evidence and knowledge to begin co-creation of a collaborative, systems-level approach to improving the pre-diagnosis phase in the cancer experience.

A number of presentations were provided to the group and individual experiences were noted and who they looked to for support during their cancer journey. The CPAC Report Living with Cancer was discussed at this meeting with a lot of great information and the perspective from patients and care givers. An Executive Summary – Leading Practices to Create a Seamless Patient Experience for the Pre-diagnosis Phase of Care: An Environmental Scan was reviewed and discussed as well.

The biggest take away from the meeting however was that the majority of the problems/issues that we have here in NL are similar across the country and internationally. Other issues identified were:

- Transition from diagnosis to treatment
- Wait Times is an issue
- Missed Diagnosed – delay in accessing treatment

- Physician complacency
- No Family Physician
- Duplication of testing – self scheduling

Next Steps – A larger CPAC group consisting of both working groups will be brought together to look at international program and see how they work.

5.2 Cancer Care Program Website

A Focus Group reviewed the Cancer Care Program's Website and provided excellent feedback. The Cancer Care Program will be identified on top of the website page. Pictures will scroll across the home page. Cancer Patient Navigator link will be placed on most of the web pages. The main headings across the top of the website will be revised.

Financial Program Brochure is presently being updated and sent to members for review. This brochure will be placed on the website and sent out to various clinics across the Province. Hematology to follow-up with Leukemia and Lymphoma Society regarding funding that is directly available to patients. It was also suggested to include Helpful Tips such as keeping appointment documentation, airfare as well as accommodation receipts.

ACTION: Revisions to be completed to Financial Program Brochure. Hematology to follow-up on funding available to patients.

5.3 Provincial Screening Task Force Update

Ongoing work is being completed on the development of a Provincial Screening Model for Colon, Breast and Cervical Screening. Managers are looking at a process as for recruitment of patients into the screening programs.

Item to be removed from the Agenda.

5.4 Promotion of Cancer Patient Navigator Role

An Action Plan was developed for the Promotion of the Cancer Patient Navigator Role which includes internal and external strategies. New Physicians within Eastern Health attend a three hour general orientation. The Chair spoke with the Clinical Chief for Family Physicians and he felt that the Patient Navigator brochures need to be sent to Family Physicians regularly. NLMA will email updated information regarding Cancer Patient Navigators to Family Physicians across the Province.

The Cancer Patient Navigator Brochure is being revised.

Breast Screening Program has agreed to pilot Cancer Patient Navigator information in their appointment letters.

Cancer Patient Navigators will present at Mental Health Workshop and the brochure will be sent to the Health Line as a resource of information.

ACTION: Cancer Patient Navigator brochure revisions.

6.0 Other Business

6.1 Site Visit – Central Region

Program Director, Clinical Chief and Manager of Nursing completed a site visit in Central Region. A meeting was held with the Medical Director in Central Region and discussed access to port insertions in Central. They will contact Radiology to see if a visiting clinic can be organized to do this procedure in Central. The group expressed it may be helpful to have a map outlining the cancer care services throughout the Province. This can be explored for the website in the future.

6.2 Insurance – Volunteers

Patient and Family representatives on the PFAC are insured as part of volunteer services through HIROC (Healthcare Insurance Reciprocal of Canada).

6.3 Patient Passport

Discussion was held regarding an insert from ATU in the Patient Passport. Working with Medicine Program on this item.

6.4 Healthcare Foundation

The Health Care Foundation has agreed to provide access to services for Ambulatory Care, i.e. coffee station, and chemo chairs/beds.

7.0 Keep in View

- **Cancer Care Program Stats**
A Provincial Cancer Care Program Report is being completed and we will ask to have this presented at this Committee.
- **FNIM Initiatives**
A CPAC FNIM Proposal has been submitted for approval.
- **Provincial Screening Programs – Discussed previously.**
- **Glossary of Terms for Advisors**
The Glossary of Terms will be updated on a regular basis. *Item to be removed from the Agenda*

5.0 Next Meeting – Wednesday, June 27th, 2018



Janet Templeton
Co-Chair

February 27, 2018

Date