

British Columbia Ministry of Health

Patients as Partners Initiative

Family Caregiver Engagement Tip Sheet

Our health system works well, but there are challenges – such as an aging population, more chronic diseases and an over-reliance on hospitals. As the health care system develops initiatives to address these challenges, the need to engage patients, families and caregivers in specific population groups can be anticipated. With this in mind, we have developed a series of tip sheets on engagement processes and for engaging patient population groups including: people who receive primary care services, caregivers, older adults that have complex medical conditions or are frail, people experiencing mental health or substance use, people who will receive surgical services, people in rural or remote locations, and multicultural populations.

The purpose of the tip sheets is to provide guidance and support to health-care organizations in their patient, family and community engagement activities. The tip sheets are intended for use by engagement staff, health service practitioners, program managers, community development officers, and any health-care staff across the B.C. health system who works on engagement projects related to the co-design of health care. This tip sheet is designed as a companion to other Patients as Partners tip sheets and applies to all three domains of health system engagement: individual care, program and community services, and system redesign.

Who Are Family Caregivers?

Family caregivers are family and friends who provide over 80% of care to people with health-related needs, often because of chronic health conditions and frailty due to aging. The care can be provided in any setting, from home to a care facility. Over 70% are also employed. In B.C., there are over one million family caregivers and their numbers are growing as our population ages. They are an integral part of the health system, supporting people to live at home longer and with a better quality of life in any setting.

Why Engage Family Caregivers?

Family caregivers are extremely invested in helping to improve the health system. Through their time and effort, they contribute to happier and healthier people.

They support people to live as independently as possible. They support activities of daily life, including personal care, medication management, securing health care, shopping, cooking, doing laundry, paying bills, socializing and maintaining a home. This means less facility-based care, reduced home-care service, and fewer hospital and emergency visits.

1. Their knowledge of the patient supports better case management.

Aside from the patient, the caregiver knows the patient best, and can provide helpful information and insight into care plan implementation. Ensuring there is good communications with both the patient and family results in more accurate interventions with better health outcomes.

2. They can help identify what is working or not working in the health system.

Engaging both family caregivers and patients in health system improvement efforts means the right voices are represented. Family caregivers are not the same voice as the patient. Their needs and circumstances are different.

3. It's an opportunity to promote caregiver health and recognize their role.

Many caregivers are in distress, with risk of depression, poor self-care and isolation. Recognition and referral for support, education and information is critical to keep family caregivers from becoming patients themselves.

Who are the stakeholders?

Patients needing primary care	Caregivers of adults living in community
Older adults, those with complex medical and frailty conditions and patients needing cancer care	Caregivers of older adults who are frail, have chronic medical conditions, cancer or with acute medical conditions
Patients needing mental health and substance use care	Caregivers of adults living in community with mental health and substance use issues
Patients needing surgery	Caregivers of adults living in community awaiting surgery and/or recovering post-surgery
Patients needing rural health care services	Caregivers living in rural and remote communities who may be supporting adults in any of the above categories

How to Engage Family Caregivers

- ✓ **Identify Needs for Family Caregiver Input**
 - Clarify the level and type of engagement required (refer to IAP2 Spectrum of Engagement).

- ✓ **Define Desired Attributes of Family Caregivers**
 - Define the desired attributes of family caregivers for your specific engagement opportunity.
 - Family caregivers are unique and have different needs so it is important to understand as much as possible about them before recruiting. For example, 70% of family caregivers are working full-time, young caregivers may still be in school (elementary, high school or postsecondary), full-time caregivers may need care support services in order to participate in an engagement activity.
 - Consider the needs of the caregiver groupings in terms of scheduling and methods of engagement (e.g., evening by phone, online).
 - The ability to participate remotely is important for many family caregivers.

- ✓ **Outline the Engagement Opportunity**
 - Document the opportunity and the desired attributes of family caregivers.
 - To the extent possible, describe how the engagement will occur.

✓ **Recruit Family Caregivers for the engagement opportunity**

- Do it yourself. Good places for recruiting family caregivers for engagement may include local pharmacies, libraries and through employers. A portion of family caregivers have been called ‘wired for health.’ They look for information online and can be recruited online. Family caregivers often do not identify with the term family caregiver. Instead, ask them if they are helping to look after someone.
- Expect and plan for last minute cancellations. Over-invite participants because last minute cancellations are likely, due to caregiving situations.
- **Reach out to organizations who will recruit for you:**
 - Patient Voices Network: <https://patientvoicesbc.ca/>
 - Family Caregivers of British Columbia: www.familycaregiversbc.ca

