The Massachusetts Department of Mental Health

- 1. Develop training materials and offer in-person training to DMH, ACCS and BHCP clinicians and staff on key topics including:
 - Managing cancer in individuals with SMI: screening, access to cancer care, informed consent, completing cancer diagnostic assessment, and initiating and sustaining cancer treatment
 - b. Palliative care: education, aging in place, and end of life care, including collaboration with hospice
- 2. Offer consultation and technical assistance to DMH, ACCS and BHCP clinicians and staff on managing specific cases of individuals with SMI and cancer
- 3. Collaborate with the DMH Center of Excellence at MGH to develop strategies for studying outcomes for individuals with SMI and cancer

National Alliance on Mental Illness - Massachusetts

- 1. Reduce stigma (discrimination based on diagnosis which causes people to give up on their dreams and desires for their lives)
- 2. Increase advocacy at all three levels: Self, Family, Community
- 3. Increase funding for mental health services
- 4. Support self-determination in treatment
- 5. Commit to programs that are both peer-driven and family-driven
- 6. Address housing issues for persons challenged by mental health issues
- 7. Support early intervention for youth experiencing mental health issues
- 8. Provide accurate information and referrals for people seeking help for themselves or others
- 9. Continue and expand caregiver support programs

Lorraine Drapek, DNP FNP-BC AOCNP – Radiation Oncology

Chang (2013) and Lin (2016) respectively reported studies of mentally ill patients with a diagnosis of head and neck cancer and lung cancer which demonstrated significant disparities in overall survival. Patients with mental illness were more likely to be diagnosed with later stage disease at presentation. Radiation therapy is often part of curative therapy for patients. In some diseases such as HPV cancers, it is definitive therapy along with chemotherapy to achieve cure.

The key challenges faced by staff in radiation oncology is assisting patients with mental health challenges in the following areas:

- 1. Enabling patients to understand the importance of consistently coming to daily treatment appointments
- 2. Enabling patients to tolerate being alone or immobilized in a radiation treatment room for several minutes- allowing patients to feel safe.
- 3. Teaching patients self- care measures in creative ways that are not challenging for this population to follow.
- 4. Feeling comfortable and confident in helping this population through treatment and having awareness of available resources.
- 5. Achieving the goal of successful completion of radiation therapy treatment, especially without hospital admission.

Stefanie London, Patient and Caregiver Stakeholder

As person with lived experience as both a patient and a caregiver, my priorities include:

- 1. Reducing stigma to counter uneasy and unequal relationships between doctors and their patients with SMI.
- 2. Advocacy with the goal of increasing awareness and education for both care providers and patient communities so the mortality gap for mentally ill individuals is recognized as the human rights issue that it is.
- 3. Education for providers about mental illness, in order to cultivate understanding (and empathy) of issues that can be an obstacle to good care for people with SMI. For example: anxiety & fear, response to stigma, lack of organization, miscommunication.
- 4. Find effective ways of making cancer screening and prevention accessible to people with SMI. Bring care to the patient (for example, a mammogram truck to a group home, a home visit, routine screening at inpatient facilities...). Adapt to address the specific needs of people with SMI.
- 5. Structural changes in the system to support a team approach in which all caregivers have a seat at the table. Identify and remove barriers to communication.
- 6. Provide support to the entire team. For example,
 - a. Identify needs of families, or caregivers who function as families, both emotional and logistical.
 - b. Compensate professional caregivers adequately so there is less turnover.
 - c. Provide a central case manager with understanding of both mental illness & cancer to help bridge the divide.

Cameron Ware, Caregiver Stakeholder

Main Gaps -

- 1. Established and consistent access to caregiving individuals and also related realms of wellness services for patients
- 2. The need to prioritize emotional well-being and overall wellness, even at times involving a challenging medical status, wellness for both patients and caregivers
- 3. The importance of emphasis on supporting the transfer of helpful personal (appropriate) knowledge between caregivers and between professionals, in order to support relationship building among patients, caregivers, and other staff

Priorities -

- 1. Review and build a caregiving team involving professionals related to the Collaborative and individuals that are specific to each patient's life, (think creatively and ask "Who is missing?")
- 2. Consider establishing an available group of peer mentors for the collaborative as part of the caregiving team
- 3. Develop a summary of common well-being-related issues that arise for the group of Collaborative patients to ensure effective current and future support
- 4. Choose a wellness tool to use to build a wellness model with measures *For example: Use WRAP (Wellness Recovery Action Plan by Mary Ellen Copeland) tool to provide focus on areas to consider to promote balance and wellness?
- 5. Develop a chart of common areas to address/discuss (to be used by caregivers /staff) that come up specifically during caregiving work, chart should serve as a reference point *For example, the area of referral to well-being resources like support group recommendations
- 6. Consider and name all realms of caregiving (i.e. spiritual, emotional...) document these determined areas and add them to a "map" of the components of caregiving

Benjamin Macri, Psychiatric Nurse Practitioner

I represent a community mental health agency. My priorities are:

- 1. Providing high quality psychiatric care and assisting patients in accessing high quality care from primary and specialty care
- 2. Improving patient education
- 3. Supporting the recovery and improving the quality of life of patients of all types, especially those with serious mental illness
- 4. Reducing the stigma and burden of mental illness in the communities of Revere, Chelsea, Winthrop, and the Greater Boston area

I represent family members of those with serious mental illness. As a family member my priorities are

1. Advocating for the equitable treatment of those with serious mental illness in all phases of treatment

- 2. Advocating for improving communication with and support for the families of those with serious mental illness
- 3. Advocating for increasing the budget for mental health services for the seriously mentally ill
- 4. As a family member the main gaps in care delivery appear to be limited access to high quality psychiatric care and lack of funding

I represent advance practice nurses as a psychiatric mental health nurse practitioner. As a nurse my priorities are

- 1. Improving communication with other providers at all levels.
- 2. Advocating for the inclusion of mid-level practitioners as equal stakeholders in the care continuum
- 3. Increasing representation of the seriously mentally ill in nursing research

Beriline Akwe, Community Outreach Nurse

As a community outreach nurse, my priorities include:

- 1. Patient empowerment and shared decision-making process
- 2. Building a more sustainable partnership with community mental health providers and leverage their connections for increase in cancer screening rates among people with SMI
- 3. Understanding how to provide palliative and hospice care efficiently and effectively
- 4. Getting top management involved
- 5. Emotional support to the frontline staff
- 6. Improving communication among providers and care continuity