



**TVN Ethical Framework:**  
***MindMergeMeeting***

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*By*

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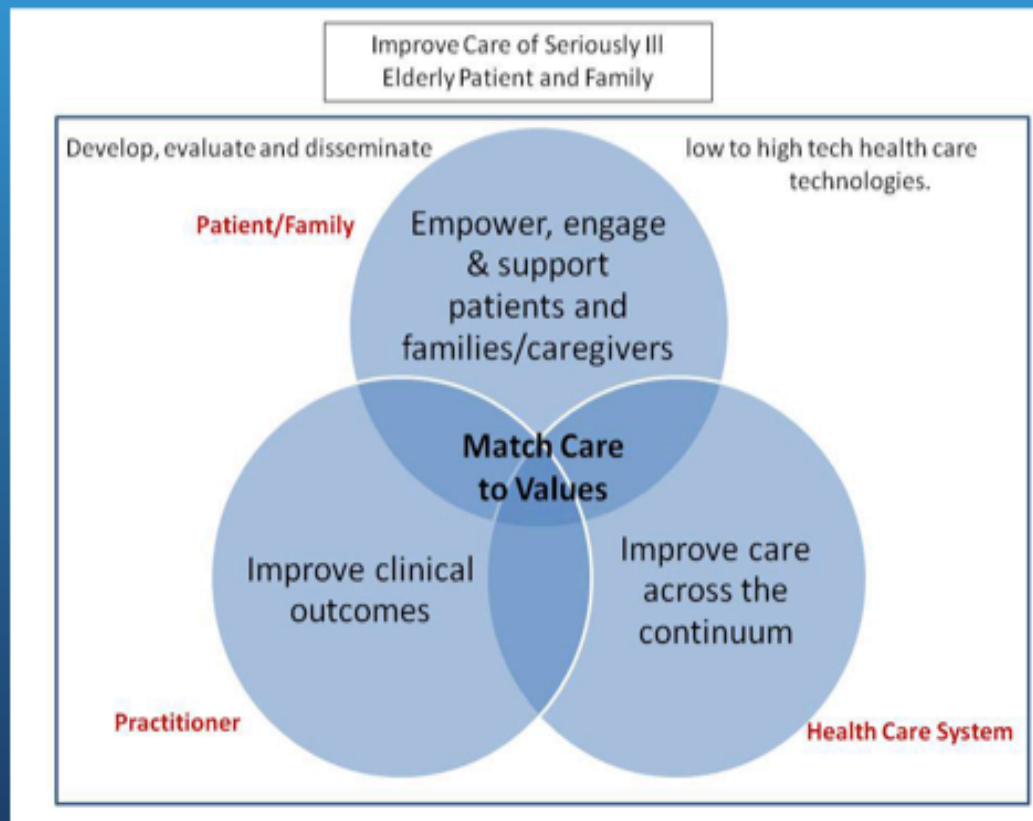
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## Objectives

- 1. Commit to the importance of ethics in health care and health research;*
- 2. Review the meaning and utility of an ethical framework;*
- 3. Operationalize an ethical framework for the seriously ill elderly and their families/caregivers for all levels of TVN activity;*
- 4. Confirm the foundational values necessary for an ethical framework specific to the TVN.*

## ***TechValueNet Research Priorities 2013-14:***

- Foster matching care to values,
- Empower, engage and support patients and families/caregivers,
- Improve clinical outcomes, and
- Improve care across the continuum.



## Part C. Some Thoughts on Values and Ethical Frameworks

**Values:** “principles or standards of importance; judgments of what is important in life”; “important and lasting beliefs or ideals shared by a culture regarding the good and bad or desirable and undesirable.”

**Principles:** *guides* to decision and action embodying sets of values. Ethical frameworks are not a theoretical task; they are directed to guide *practical* decisions and actions.

The TechValueNet Board task is to *explicate the values/principles* most relevant to *this* grant. The values *ought* to be reflected in any approved project and in the subsequent knowledge translation activities generated by each project.



## Part D. Working Toward an Ethical Framework

### *The Population: Fragile and Seriously Ill Elderly*

- The importance of *dignity and identity* in limitations and losses (as well as opportunities) in old age.
- *Stereotypes and discrimination* against the elderly, especially dependent elderly (“un-successful” aging).
- For many, there is *cognitive decline and impairment of judgment and decision-making capability* with dependence in care and in decision-making.
- *Advance care planning* to promote and extend patient values even in decline; the importance of *third-party support* for care and decisions.
- The importance of the distinction between *decisional and executional competence*.
- The prevalence of *ageism*, especially regarding fears of strained resource allocation in an aging society.
- High incidence of *co-morbidities and fragmentation of care*.

*The Circumstance:*  
*Dying and End-of-Life Care*

An ethical framework ought to address:

- An important and vulnerable time for the dying person and their loved ones: the “value of life at end of life” and acceptance of increased risk in the face of death.
- Distress re: duty and obligations; grief and third-party decisions.
- Lack of awareness of and/or limitations of meaningful, well-supported options for care of the dying maintain focus on acute, hospital care.
- Different trajectories of dying with dominance of the chronic illness/organ failure and frailty/dementia trajectories.

## *The Focus: Technology Assessment*

An ethical framework ought to work in the context of:

- A widespread belief in modern health technology, which creates unrealistic societal expectations.
- Technology is generally understood as drugs, devices and aggressive intervention but is not as well understood in terms of human systems of health care delivery (from home to hospital to long term care).
- The lack of evidence regarding benefit in this population of seriously ill older adults is not well understood.
- Health Technology Assessment (HTA) is itself multi-disciplinary and value-laden: what ends/goals are chosen (e.g. prolongation of life; improved function and quality of life; a peaceful death; economic efficiency); what methods are used? (e.g. quantitative, qualitative)



## *The Need: System Efficiency, Effectiveness, and Compassion*

An ethical framework ought to provide moral guidance because:

- The public imagination is captured by acute care, high-technology 'fix' and cure.
- The importance of human care and quality of life at the end of life is not visible enough.
- The importance of a full continuum of care tends not to be realized until it is experienced.
- Patients/families dealing with their own crises are not amenable to thinking of the needs of others or the common good--should be undertaken at policy/system levels.
- Thoughtful stewardship of resources (vs. rationing) is essential to respond to human need and to create system sustainability and to better support the seriously ill elderly, their families/caregivers, & health care providers.





# TVN Values Framework

- Respect for the dignity, diversity and autonomy of the frail elderly and their families/caregivers, especially at the end of life.
- This respect acknowledges differences in physical and cognitive health; socio-cultural contexts; family and community supports; and sites of residence and care. It is expressed in collaborative health care decision making, health care practices and policies, health care research, and health care knowledge translation.

# TVN Values Framework

- Empowerment of the frail elderly and their families/caregivers in all levels of care and decision-making.
- This is supported by timely, comprehensible, and evidence-informed communication which is sensitive to patient/caregiver needs, values, beliefs and cultural backgrounds, and actively engages the frail elderly and their families/caregivers. Practice and policies take into account the burdens that different decisions place on families/caregivers as well as the complex and sensitive circumstances in which family members and others assume responsibility to support the frail elderly.

# Values Framework

- Equity of access to care that addresses substantive differences in the situations of the frail elderly and their families/caregivers in order to work toward the best possible health/ health care outcomes.
- This is demonstrated in improved health status and/or improved quality of life for all frail elderly. Equity requires non-discrimination as well as positive actions to address systemic barriers to access such as ageism, racism, poverty, and rural/remote locations.

# Values Framework

- Collaboration in meaningful relationships and projects at all levels of decision-making and care.
- This requires inclusiveness and transparency in decision making so that trust is built and accountability is shared at all levels of research and clinical work. It is manifest in respectful inter-disciplinarity and systematic support of the frail elderly and their families/caregivers, health care professionals, researchers, policy makers and public representatives.

# Values Framework

- Innovation in a participatory, cohesive, transformative, solution-driven program of research
- This is demonstrated in productive, creative and ethical research which addresses directly the effectiveness and efficiency of technologies in the care of the frail elderly and their families/caregivers. The program of research is based on consultations with diverse communities to identify strengths and gaps in current research related to complex issues of end of life decision-making and care. It results in the promotion of networks to accelerate utilization of research results and catalyzes change in health care practices and health care policies, thereby addressing the health and care needs of an aging Canadian society.