

History of the Quality End-of-Life Care Coalition

In 2000, the Senate of Canada issued the report *Quality End-of-Life Care: The Right of Every Canadian*. The first recommendation of the Senate report was that the federal government, in collaboration with the provinces, develop a national strategy for end-of-life care. In December of 2000, a group of 24 national stakeholders met in Toronto, Ontario to begin to set the groundwork for the development of a national strategy for end-of-life care. The result of this meeting was the creation of the *Quality End-of-Life Care Coalition* and the creation of a *Blueprint for Action (2000)*. Within the Quality End-of-Life Care Coalition an Executive Committee and five Working Groups were established. These groups mirror those in Health Canada's *Secretariat on Palliative End-of-Life Care*. These five working groups include Advocacy, Public Information and Awareness, Family and Caregiver Support, Professional Education Committee, and Research Committee. The Coalition is overseen by an Executive comprised of the Chairs of the five working groups and the Executive Director of the Canadian Hospice and Palliative Care Association (CHPCA) which acts as the Secretariat to the Coalition.

Mission and Mandate

The Quality End-of-Life Care Coalition believes that all Canadians have the right to quality end-of-life care that allows them to die with dignity, free of pain, surrounded by their loved ones, in a setting of their choice. The Coalition believes that to achieve quality end-of-life care for all Canadians there must be a well funded, sustainable national strategy for palliative and end-of-life care. It is the mission of the Quality End-of-Life Care Coalition to work together in partnership to achieve this goal.

Why are Coalitions Important?

Coalition is defined by the Oxford Dictionary as "A temporary alliance for combined action." As voluntary organizations are becoming more aware of the importance of adding their voices to the public policy discussion, they are acutely aware that more voices speaking to one issue have a stronger affect on influencing public policy and raising public awareness. Voluntary organizations also recognize that it takes a significant investment in time, human resources, and financial resources to participate in the public policy process. As a result, coalitions are becoming a preferred way for a number of organizations to pool their knowledge, resources and capacity to address an issue. As a coalition and its members begin to make a long-term investment, it is important that it examines what is working, what is not working, and how to address any issues in its management.

Why Evaluate the Quality End-of-Life Care Coalition

The Quality End-of-Life Care Coalition evaluation examined the workings of the Coalition including the strengths, challenges and successes of, how well the Coalition works; why it works; and how it can work better. The outcomes from the evaluation of the Coalition will not only benefit in moving its agenda forward but will also assist the broader national voluntary health organization and health professional organizations and communities.

Methodology

Twenty-three evaluation interviews were conducted with Quality End-of-Life Care Coalition member organizations over an eight-week period. Two interviews were conducted via email due to accessibility issues. These evaluations were conducted using a survey tool that asked attitudinal questions rated on a Likert scale as well as open-ended opinion questions that examined ten key areas. Those interviewed were given the opportunity to elaborate on particular areas and provide feedback and suggestions regarding ten key areas in the Coalition.

10 Key Areas Examined

1. Administration and Management
2. Non-Financial Resources
3. Financial and Other Capital Resources
4. Communication
5. Membership
6. Functionality
7. Synergy
8. Decision-Making
9. Benefits of Participation
10. Drawbacks of Participation

Key Findings: Successes of the Quality End-of-Life Care Coalition

1. **Strong Secretariat** One of the areas that benefits the Quality End-of-Life Care Coalition the most is the leadership role that CHPCA has undertaken. Throughout the survey results, it is evident that members felt that the Secretariat has provided excellent leadership in providing administrative and managerial leadership in moving things forward. Also, having a point person at the Secretariat that provides leadership in coordinating and mobilizing the Coalition is a key factor in its success.
2. **Non-financial resources are as important as financial resources** The expertise and knowledge in the policy development process and knowledge of end-of-life care issues are equally as important as the financial resources to assist the Quality End-of-Life Care Coalition in meeting its mission. Having groups representing a broad range of stakeholders and constituents adds credibility to the Quality End-of-Life Care Coalition and its role in the policy development process.
3. **Ability to "opt out" from Coalition initiatives** As organizations have varying internal processes and challenges in participating in Coalition activities, it is important that they are able to opt out of a decision and not sign their name to a particular initiative. Also, organizations that do not agree with the direction that the Coalition takes are able to not lend their name to a particular issue but come back to the table at anytime for future activities.

4. **Coalition membership has tangible benefits** Membership has to have tangible benefits that are evident and measurable to members. These benefits can include increased knowledge of a particular policy issue, networking opportunities, raising the profile of one's organization, or increasing their policy capacity. It is also important for members to note significant milestones in moving an issue forward to motivate, encourage and energize them to continue their work.
5. **Setting realistic goals and work plans** When dealing with large policy issues that are complex and can take significant amounts of time to address, setting an achievable work plan and goals that reflect the amount of work that goes in a policy issue are very important.

Key Findings: Challenges of the Quality End-of-Life Care Coalition

1. **Decision-making processes** With thirty-one voices around the table, it is difficult to establish mechanisms that ensure that all voices are heard. The Quality End-of-Life Care Coalition may wish to explore ways to connect more often to conduct focused discussions on particular issues. Also, it is important for members to understand how decisions are made and the criteria that are used to reach them.
2. **Communication mechanisms** Although electronic mechanisms have ensured that Coalition members are kept informed, communication remains a challenge. It is important that the Coalition not only remains focused on communicating externally to raise awareness, but that they also build stronger mechanisms to ensure that subcommittees are keeping each other informed and talking more together.
3. **Membership** The membership of the Quality End-of-Life Care Coalition is reflective of the mission and mandate of the Coalition. However, there is confusion among current members about what the criteria are for joining and if and why there are different levels of membership. Also membership needs to be fluid and dynamic in order to ensure that the voices that need to be heard are present around the table.

Conclusion

The Quality End-of-Life Care Coalition is working very well and can serve as an example to other coalitions. Even as the number of organizations joining the Coalition continues to grow, the Quality End-of-Life Care Coalition is able to move its agenda forward effectively in an inclusive and effective manner. It will be important as the Quality End-of-Life Care Coalition evolves to continually revisit key areas such as communication and decision-making to ensure that the Coalition is in a position to function optimally.