

# **Submission to the Law Commission of Ontario: Improving the Last Stages of Life**

**September 2017**



*Wellesley Institute works in research and policy to improve health and health equity in the GTA through action on the social determinants of health.*

## 1 Introduction

Wellesley Institute applauds the Law Commission of Ontario (LCO) for your vital work to improve the last stages of life through law reform. The issues and questions raised by this work have a pivotal role in the lives of the people affected, their families and communities. This project has the potential to have a fundamental impact on how we see and support people during this important stage of their lives.

At Wellesley Institute, we are well positioned to comment on this issue. Our mandate as a research and policy think tank focuses on promoting health equity through action on the social determinants of health in the Greater Toronto Area.

We welcome the opportunity to share our expertise in health equity with the LCO on the critical issue of access and equity during the last stages of life (LSL). Our submission focuses on the issues which the LCO's Discussion Paper<sup>1</sup> raises related to access to justice for communities with unmet needs, approaches to LSL law reform, and health care system reform. We will not comment on all issues raised in the Discussion Paper: issues such as protocols for expected deaths in the home, withdrawal and withholding of care, and public legal education fall outside the core of our mandate.

This submission will outline a health equity approach to the LSL and draw from it specific recommendations that can address several challenging and complex issues raised in the LCO's Discussion Paper. Our approach sees health equity as a primary goal of law reform in this area: our laws and systems of supports and services should ultimately support a high quality of life, health, and well-being for *all* individuals in the LSL and their caregivers. A health equity approach effectively complements and advances the LCO's mandate of promoting access to justice. Our proposed approach provides a practical set of principles to guide reform in this complex and challenging area of law, policy and practice.

## 2 A Health Equity Approach to Improving the Last Stages of Life

The LCO's Discussion Paper outlines the values and principles that must ground reform of laws related to the LSL, including the rights and values drawn from the Ontario *Human Rights Code*, the *Charter of Rights and Freedoms*, and the LCO *Framework Principles*. It also discusses a potential public health approach to palliative care. Wellesley Institute proposes that the LCO adopt a health equity approach to the last stages of life, which is outlined in this section, rather than a public health approach, when developing recommendations for law reform to improve the LSL.

As with the public health approach to palliative care, we recognize the limits of traditional models of care and the importance of engaging diverse stakeholders.<sup>2</sup> The most valuable aspect of a public health approach to palliative care for this project is its principle of health promotion. In 1986, the founding *Ottawa Charter of Health Promotion*<sup>3</sup> defined health promotion as “the process of enabling people to increase control over, and to improve, their health,” and highlighted that promoting health cannot be done by the health care system alone. Our health equity approach embraces this concept of health promotion. However, our approach is distinct from public health approaches to palliative care as it sets health equity as a goal for law reform and recognizes that inequities in access and outcomes are caused by the social determinants of health, the upstream causes that impact health. This health equity approach complements dominant palliative care models and can be applied to the broader last stages of life as opposed to

exclusively palliative care. This health equity approach is in harmony with the legal concept of substantive equality and complements current health care reforms such as *the Excellent Care for All Act*<sup>4</sup> and the *Patients First Act* (Bill 41).<sup>5</sup>

At Wellesley Institute, we support Health Quality Ontario's (HQP) definition of health equity as a state in which "all people living in Ontario are able to reach their full health potential" and "receive quality care that is fair and appropriate to them - regardless of where they live, what their economic or social status, language, culture, gender or religion".<sup>6</sup> Health inequities or disparities occur when there are systemic, patterned and avoidable differences in health outcomes within populations. The concept of health equity is at the heart of Wellesley Institute's mandate, and is increasingly recognized as a core responsibility of health institutions. For example, Ontario's Local Health Integration Networks (LHINs), as part of their new mandates following the *Patients First* transformation, have been directed to "promote health equity and recognize the impact of social determinants of health to reduce or eliminate health disparities and inequities in the planning, design, delivery and evaluation of services,"<sup>7</sup> and new public health standards are expected to include responsibilities related to health equity.<sup>8</sup> As the LCO has noted, the concept of equity in the health care sector is aligned with LCO's understanding of substantive equality, which recognizes that discrimination can be intentional or "an *effect of global measures*."<sup>9</sup>

A key starting point for this health equity approach, and for law and policy reform, can be found in a broad understanding of health and well-being in the LSL for both individuals and caregivers. Despite serious frailty, chronic conditions, or terminal illness, people in the LSL can have quality of life, facets of good health, and a good death. The World Health Organization defines health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."<sup>10</sup> Health is a resource for everyday life<sup>11</sup> and to face life's challenges, and it can exist despite illness.<sup>12</sup> There is value in embracing this broad understanding of health and well-being when understanding the LSL. We can support, for example, individuals' psychological health, spiritual health, and ability to interact and contribute to their communities and families. This broad understanding of health in the LSL complements the Ministry of Health and Long-Term Care (MOHLTC), LHINs and Quality Hospice Palliative Care Coalition of Ontario's definition of palliative care as "a philosophy of care that aims to relieve suffering and improve the quality of living and dying."<sup>13</sup> Moreover, we can promote health and health equity for caregivers and reduce caregiving distress experienced by families.

As the LCO has noted, this vision of equity in quality of life, health, and well-being in the LSL is not a reality for many Ontarians. We know from extensive health research literature that our access to quality health care, our health experiences, and our health outcomes are shaped by the social determinants of health (SDOH). The SDOH refers to the conditions of daily life in which people are "born, grow, work, live and age" such as income, housing, discrimination, and are factors that drive health inequities.<sup>14</sup> An SDOH lens provides an important opportunity to recognize the multiple systems, institutions, and forces that affect one's resources, power and access to quality health and social services. For example, recent Wellesley Institute research found that immigrant seniors in the Greater Toronto Area receive less publicly-funded home care, report higher unmet care needs, and report poorer health and mental health compared to non-immigrant seniors.<sup>15,16</sup>

At the same time, we found that immigrant seniors and seniors whose mother tongue was not English were more likely to report receiving care from informal caregivers. Both the LCO and HQO have highlighted the stress and burnout that caregivers can experience;<sup>17</sup> these higher rates of informal caregiving among immigrants may result in higher rates of caregiver distress for these communities. Given these demonstrated disparities in access to home care, perceived needs, and caregiving, we can expect to see similar inequities in access, experiences and outcomes for individuals in the LSL and their families due to differential access to the SDOH. While there is limited data on outcomes in the LSL, HQO found that Ontarians with lower income receive different access to palliative home care<sup>18</sup> and the LCO has documented the lack of formal palliative care in particular housing types (e.g. in long-term care facilities). These inequities in access to care and health outcomes were not intended through our laws, and illustrate the importance of a health equity analysis and the adoption of health equity as a central goal of services and supports in this area. A health equity approach seeks to eliminate these systemic and avoidable differences in access, experience and outcomes caused by SDOH.

*All* Ontarians should be able to have a good quality of living even in their last stages of life. This foundational principle is echoed throughout the *Declaration of Partnership*,<sup>19</sup> which emphasizes an inclusive, equitable approach to delivering LSL care throughout the province. Yet the current systems of supports and services are not adequately designed to meet the needs of Ontarians in the LSL or the needs of their caregivers. Achieving health equity in the LSL requires a broader transformation of the LSL system.

Our proposed health equity approach to the LSL can guide system transformation through law reform. This health equity approach is distinct from a public health approach to palliative care as it foregrounds the goal of health equity in the LSL, integrates a broad understanding of health and well-being in the LSL, and consequently emphasizes the importance of addressing the SDOH, which are at the root of inequities in access to care and unmet needs in the LSL. This health equity approach is in accordance with *Code* and *Charter* principles, as well as the *LCO Framework Principles*, while also integrating an understanding of current approaches to health system reform in Ontario.

## **2.1 Principles of a Health Equity Approach**

In response to the complex realities of the LSL as highlighted by the LCO, we articulate four principles that comprise this health equity approach to the last stages of life, which can be used to guide the LCO's law reform recommendations.

- Principle 1 sets a goal for system transformation for everyone; *all* Ontarians should be able to have good quality of life, health and a sense of well-being in the LSL and *all* caregivers should be able to reach their full health potential.
- Principles 2 and 3 highlight different levels of implementation that should be considered through law reform; law reform should support cross-sectoral and cross-government action that is driven by the needs of persons in the last stages of life and their caregivers.
- Principle 4 highlights the importance of implementation, monitoring and enforcement mechanisms to ensure clear responsibility for action to reduce health inequities in the LSL.

These four principles support each other and together comprise the health equity approach to the LSL. To succeed, the principles cannot be implemented in isolation. Together these principles provide a vision for

a system of services and supports that can enable quality of life, well-being and health for all individuals in the last stages of life and their caregivers.

### **Principle 1: For everyone**

*All Ontarians should be able to have good quality of life, health, and a sense of well-being in the last stages of life. Caregivers for those in the last stages should be able to reach their full health potential.*

To achieve health equity and reduce measurable differences in health outcomes, we must proactively identify and remove barriers to equitable access to quality supports and services and equitable experiences in the LSL.

This principle aligns with human rights frameworks that incorporate inclusive design approaches. Inclusive design aims to proactively remove systemic barriers to access to services for populations experiencing inequities. Inclusive design is an approach that “considers the full range of human diversity with respect to ability, language, culture, gender, age and other forms of human difference.”<sup>20</sup> In the last stages of life, this can include, for example, addressing barriers to access to supports and services in long-term care homes or expanding public coverage for medications and equipment required by individuals receiving home care.

However, an inclusive design approach cannot fully address health disparities without a complementary targeted approach. When our goal is health equity, we must ask who is facing systemic barriers to accessing care and as a result are faring worse in the LSL. A one-size-fits-all approach is not always sufficient for addressing health disparities that marginalized individuals and communities face. Resources must be directed so that individuals and families receive the tailored supports, services, and accommodations required to meet their needs. We must design inclusive services and supports to be able to improve access across the population, while simultaneously targeting resources towards those facing the greatest barriers.

### **Principle 2: Cross-sectoral**

*Cross-governmental and cross-sectoral action is needed to meet the needs of individuals in the last stages of life and their caregivers.*

Peoples’ needs do not fit neatly inside of one area of policy or legislation – needs in the LSL are complex, overlapping, and interrelated. Therefore, cross-sectoral and cross-government action is needed to provide the range of services and supports that people need, both within the health care system and outside of it.

Through an international review, Wellesley Institute found broad recognition that cross-sectoral approaches that tackle SDOH both *within* and *beyond* the health care system are required to address health inequities and enhance health equity at the national or state/provincial level.<sup>21</sup>

Within the health care system, it is important that organizations have the capacity and mechanisms to collaborate with other sectors to meet the full needs of individuals. While the health care system has begun to consider the SDOH in general, this has yet to be systematically applied to the health care system’s approach to care in the LSL. The health care system response must be transformed to improve

equity in access, experiences, and outcomes in the LSL for both individuals and caregivers. This requires the health care system to move beyond a narrow definition of illness and instead embrace an understanding of health that encompasses physical, psychological, social, and spiritual well-being. With this foundation, health care organizations will be able to support peoples' health, even as they enter their LSL.

Health inequities cannot be addressed solely through health care systems. Given the significant role that SDOH play in the experiences of individuals and caregivers in the LSL, transformation of public policy is required across many sectors such as housing, employment protections and income supports. Law reform can support these sectors to ensure that everyone is able to achieve optimal health.

Therefore, cross-sectoral and cross-governmental action is needed to promote health for individuals in the LSL and their caregivers. It is important that the needs of *all* individuals in the LSL and their caregivers are considered when the government designs and implements services and supports across these sectors. We applaud the LCO's recognition of the intersections between the LSL and diverse areas of policy, and suggest that this principle advances the LCO's existing priorities.

### **Principle 3: Person-driven**

*Individuals in the last stages of life and their caregivers have diverse needs and experiences. Our systems of support and services must be responsive to and driven by this reality.*

Health equity requires providing services and supports that are person-driven. As the LCO has highlighted, no two people will have the same trajectories and needs in the LSL. We must understand and respond to the diverse realities, experiences, and needs of individuals and families when developing our laws and our systems of supports and services. The health of individuals and caregivers is affected by the health care they receive as well as the conditions of their day-to-day life including housing, income, social supports, and other social determinants of health. Our approach to the LSL must be responsive to these needs that occur within and beyond the health care system.

Moreover, many Ontarians face intersecting challenges in their LSL which can negatively impact their experiences and outcomes. For example, people with lower incomes may also face housing instability and food insecurity. Likewise, people with limited English proficiency may face added challenges of communicating with care providers during their LSL. Recognizing and responding to these intersecting challenges is a crucial part of a person-driven approach. A person-driven approach ensures that individuals should have the opportunity to play an active role in their health care decisions; in the LSL, an individual's autonomy should not be undermined. With health equity as a goal, we are required to be attentive to the full experiences of people in their LSL and those who care for them, regardless of who they are and where they live.

### **Principle 4: Accountable**

*Law reform must include monitoring and enforcement mechanisms for implementation that are both clear and measurable.*

The principles set out above outline an ambitious and wide-ranging approach towards strengthening Ontario's system of supports and services for individuals at the LSL and their caregivers. Yet setting the right goal is only one component of systems transformation. Achieving health equity requires action, with

clear and enforceable plans for implementation. Therefore, it is critical that legislative, regulatory and policy frameworks adequately consider the resources and tools required for implementation.<sup>22</sup>

An equitable, inclusive and responsive approach requires a clear understanding of the barriers and challenges that individuals and communities face in accessing support in their last stages of life. To this end, strong monitoring and evaluation mechanisms with clear targets are an essential ingredient for systems change. In addition, cross-sectoral collaboration requires carefully designed governance frameworks, with clearly defined roles and responsibilities. Moreover, such an approach requires policy-makers to engage with those who are impacted – those experiencing the last stages of life and their caregivers – to understand how reforms can improve their experiences and their outcomes.

***Recommendation 1: Wellesley Institute recommends that the LCO adopt this health equity approach to law reform in the last stages of life, which commits to high quality of life for everyone, enables cross-sectoral action, facilitates person-driven services, and outlines clear goals and plans for implementation.***

### **3 Integrating a Health Equity Approach into Law Reform**

In this section, we provide ways to incorporate this health equity approach into the LCO's law reform process and provide specific recommendations. By aligning with the four principles above, we can make informed recommendations to advance health equity in the last stages of life.

#### **3.1 Using Tools to Assess Health Equity**

Systematic use of tools such as the health equity impact assessment (HEIA) can strengthen the law's potential to promote health equity and reduce health disparities in the last stages of life. Such tools offer a systematic way of assessing how institutions and service providers are addressing health equity in their decision-making processes and operationalize the principles of the health equity approach outlined above. In particular, HEIA is a decision support tool that allows for a systematic appraisal of how various programs, practices, services, and policies impact the health of diverse communities.<sup>23</sup> HEIA was developed by the MOHLTC. HEIA supports organizations to proactively identify and respond to potential unintended negative health equity impacts of new policies, programs and services throughout decision-making processes.

In Ontario, the HEIA tool has been used by many organizations across the health care system, including the LHINs, community organizations and health service providers. For example, the Centre for Addiction and Mental Health (CAMH) used HEIA in its Systems Improvement through Service Collaborative initiative. The goal was to create systems level change in the mental health and addictions sector, by addressing system gaps related to mental health and addictions services for children, youth and adults in Ontario.<sup>24</sup> The initiative aimed to support local systems to improve coordination and enhance access to mental health and addiction services.<sup>25</sup> Eighteen service collaboratives were formed across Ontario, with a focus on supporting youth and children transitioning between services.<sup>26</sup> HEIA was used at different phases of planning and implementation including when engaging members, during the selection of interventions and to ensure data on health inequities informed decisions.<sup>27</sup>

HEIA can also be used by organizations outside the health care system, including those in housing, employment and education. The Ministry of Health and Long-term Care (MOHLTC) has developed supplements to the HEIA for public health units which outline special considerations for applying HEIA to the public health sector that align with the Ontario Public Health Standards.<sup>28</sup> An additional supplement for MOHLTC and LHIN staff on French Language Services outlines distinct legislative responsibilities under the French Language Services Act that should be considered when conducting a HEIA.<sup>29</sup> These additional supplements integrate legislative requirements and existing standards with a health equity analysis. The HEIA tool can be useful to the LCO in applying a health equity approach to the LSL, and will add a health lens to a substantive equality analysis under the *Code* and *Charter*.

In addition, the HEIA tool is a valuable means of embedding an equity analysis into health services planning and program development. This can be an important lever for advancing access to justice for communities with unmet needs, as outlined in Chapter V of the Discussion Paper. Integrating a HEIA analysis into the work of institutions and service providers involved in the LSL could significantly advance access to justice, by increasing understanding of potential differential health impacts of services and programs on marginalized population groups, and ensuring mitigation strategies are developed to lessen the potential of widening health disparities.

HEIA is an important tool for policy-makers and program planners to proactively apply a health equity lens to their decision-making processes, with a primary focus on assessing new initiatives. For already-established systems of policies or programs, a Health Equity Audit<sup>30</sup> offers an approach that identifies unmet needs, sets clear priorities for service planning and delivery, and assesses opportunities for more equitable resource allocation. HEIA can be incorporating into decision-making going forward, while a Health Equity Audit can be used to review existing LSL laws, services and supports.

***Recommendation 2: Wellesley Institute recommends that the Ministry of Health and Long-Term Care direct institutions and service providers to use health equity tools such as Health Equity Impact Assessments and health equity audits for assessing and adapting programs, policies and services that support people during their last stages of life. These institutions include, but are not limited to, the Ontario Palliative Care Network and regional networks, Cancer Care Ontario, hospices, and long-term care facilities.***

### **3.2 Coordinating Policy and Legislation**

The cross-sectoral principle is particularly salient given our focus on the SDOH. Individuals' health trajectories are often impacted by barriers that operate outside of the health care system, such as housing, employment, and discrimination. It is critically important to link different policy sectors together, embedding LSL as a priority across them, aligning their actions with LSL principles, and ensuring that they share responsibility for supporting individuals in their LSL as well as their caregivers and communities.

It is critical to consider how SDOH, such as income, safe and stable housing, and access to food, impact the access to care, experiences and outcomes of individuals in the LSL and their families. For example, HQO has identified that individuals with low incomes are less likely to receive palliative home care than

wealthier Ontarians.<sup>31</sup> Income is a demonstrated SDOH, which impacts access to important conditions for health such as safe housing, nutritious food and medications. Public coverage of palliative care, medications, and medical equipment costs, for example, vary by care setting and LHIN and these costs often need to be supplemented by individuals in the LSL and their families, either out of pocket or through private insurance. We can expect that covering these costs will be more challenging for individuals and families with less income. These challenges may be compounded by that reality that low-wage workers in Ontario rarely receive comprehensive health benefits from their employers.<sup>32</sup> As Ontario's LSL system increasingly moves care delivery outside hospitals, cross-sectoral and cross-governmental action is needed to ensure that *all* Ontarians, regardless of their income, care setting, or social support network, are able to have their needs met in the LSL.

Similarly, as identified in the LCO's Discussion Paper, caregivers are an affected group with significant unmet needs related to SDOH, such as employment protections and income security. Supports for caregivers are guided by legislation that crosses policy sectors and levels of government. These include the provincial *Employment Standards Act*,<sup>33</sup> which governs Family Medical Leave and Personal Emergency Leave, the federal Employment Insurance program which offers Compassionate Care benefits, and the provincial *Ontario Disability Support Program Act*,<sup>34</sup> which allows caregivers to access social assistance without employment or job training conditions. These disparate pieces of legislation provide basic supports for caregivers, yet they remain largely uncoordinated. Cross-governmental efforts to expand and harmonize caregiver supports, such as extending supports during bereavement, are needed to support caregivers and reduce caregiving distress which is expected to lead to health inequities. Efforts to expand these supports would likely benefit from more consistency and harmonization across ministries and jurisdictions.

These examples illustrate the challenge, and the necessity, of approaching LSL as a shared responsibility: improving the experiences of communities with unmet needs means addressing a range of interrelated issues in separate but intersecting areas of policy. The LCO poses the question: "what gaps [in legislation that intersects with LSL] exist that would benefit from greater certainty or clarity?" We suggest that this critical question is best answered through a systematic process of legislative review, with ongoing involvement from the diverse policy sectors that impact individuals in the LSL and their caregivers. To achieve this, there is a need to create a governance structure that is accountable for reviewing legislation.

***Recommendation 3: Wellesley Institute recommends that the Ministry of Health and Long-Term Care establish a cross-government working group to identify system gaps and strengthen existing legislation and policies that intersect with the last stages of life using a health equity approach. This working group can provide expertise on system level issues in the last stages of life and promote collaboration across sectors.***

***Recommendation 4: Wellesley Institute recommends that the Ontario Palliative Care Network play a coordinating role among institutions to identify gaps, support collaboration and strengthen institutional policies and practices in order to reduce unmet needs and health inequities in the last stages of life.***

### 3.3 Facilitating Connections Between Services

Embracing the principles of person-driven services and cross-sectoral action requires that we recognize that people have multiple overlapping needs in their last stages of life, and that they engage with the LSL system through diverse points of entry. While many people in their LSL are already engaged in the health care system, it is also important to recognize that people interact with other services throughout their day-to-day lives. Some of these may be well-positioned to facilitate service provision and knowledge exchange, particularly for individuals who face barriers accessing the health care system. To this end, just as policy sectors must establish strong working relationships, service providers also must be able to collaborate to help individuals access the supports that they need during their LSL, whether their first point of contact is within or outside the health care system.

The experience of people experiencing homelessness, identified as a community with unmet needs in the LCO's Discussion Paper, illustrates the importance of expanding the pathways by which people access supports and services in the LSL. The LCO identifies the role that the shelter system plays in facilitating health services for individuals experiencing homeless. Initiatives like PEACH and Mission Hospice aim to provide care to people who are engaged in the shelter system. However, this highly targeted approach has limited capacity to reach the many people who are "invisibly" homeless, staying with friends, relatives, or strangers because they have no permanent place to live.<sup>35</sup> These individuals cannot be reached through the shelter system, and face many of the same barriers to health care. Instead they may seek community services like libraries, food banks, and mental health services. Each of these service encounters is an opportunity to refer people in their last stages of life to relevant health services, simplifying the navigation process and ensuring that they receive the care that they need.

These connections can also operate from within the health care system by supporting individuals throughout their hospital stay and during their transitions to other care settings. For example, the Health Justice Initiative at St. Michael's Hospital offers patients access to legal advice and advocacy for a range of issues that may impact their health and well-being, including housing, family law, and discrimination.<sup>36</sup> By addressing these SDOH, initiatives like this can improve the quality of life of individuals with unmet needs in the LSL. These collaborative initiatives are worth exploring as a model for meeting individuals' diverse needs in their LSL.

We suggest that this is an opportunity to explore promising models, such as PEACH, Mission Hospice, and the Health Justice Initiative and consider how such models might be scaled up across the health system.

***Recommendation 5: Wellesley Institute recommends that Local Health Integration Networks, as the lead agencies for health equity planning in Ontario:***

- a. develop strategies to identify and address the ways in which the social determinants of health may facilitate or inhibit access to care for those in the last stages of life;***
- b. convene service providers from across sectors to collaborate to address the full needs of individuals in the last stages of life.***

### 3.4 Strengthening Monitoring and Data Collection

In addressing the proposed principle of “for everyone,” it is important to recognize that communities and the barriers they face are not static; some inequities will diminish over time, while new equity concerns will emerge. To be person-driven, it is important that legislation, programs, and services for LSL be responsive to the changing needs of the population.

Health care systems cannot adequately respond to needs that are not well understood. To ensure that we are accurately able to identify inequities in the health care system and monitor how they are changing, we must track the access to and quality of services for diverse communities. To this end, strengthening monitoring and evaluation practices in the health system through more robust data collection is an important step in advancing equity in the LSL.

For example, the LCO recognizes that those for whom English is not a primary language may have unmet needs in the last stages of life. Research demonstrates that this group experiences poorer health care than the general population, and recent work by Wellesley Institute highlights the limited availability of medical interpretation services across Ontario.<sup>37</sup> Despite these demonstrated inequities in access to care based on language, there is limited data available about how this growing population is accessing and using health care services in the last stages of life. While some LHINs collect data on patients’ preferred language as part of a broader effort to increase socio-demographic data collection led by HQO, this is not uniformly applied throughout the province. Moreover, the data that is collected focuses on patients’ needs (“What language do you prefer to use?”) and does not necessarily capture whether such needs are being met (“Were you able to communicate clearly with your health care provider?”). The lack of data is a persistent challenge to implementing new services and improving existing services for ensuring linguistically accessible care.

Additionally, it is important to note that Ontario is home to an estimated 500,000 people who are living without health insurance,<sup>38</sup> a group that is not currently identified in the LCO’s discussion about communities with unmet needs. There are a host of reasons why an individual may be uninsured: some may be new permanent residents who are waiting to become eligible for OHIP, some may have arrived as refugees and not yet had their claims processed, some may not have legal status in Canada. This population further exemplifies the challenge of inadequate data collection. It is unclear whether and how uninsured people are accessing health care (both in hospitals and in the community sector), what their other needs might be in their last stages of life, and even how many such individuals are living in Ontario. Wellesley Institute has identified that individuals without OHIP experience major barriers in receiving health care and may delay or forgo necessary treatment.<sup>39, 40</sup> More comprehensive data could support policy-makers to adequately address the health care disparities that this group faces.

The data we collect must be comprehensive enough to ensure that system planners can understand the needs of individuals in the LSL, evaluate the health equity impacts of interventions, and identify emerging inequities. Therefore, we must collect socio-demographic data as well as comprehensive data on access, quality of supports and services, and outcomes in the last stages of life. Such data must also be sufficiently granular to allow for disaggregation. This approach allows service planners to better understand the intersecting barriers that many individuals face, in keeping with the principle of

being person-driven. Moreover, this data collection strengthens the principle of responsibility and accountability by providing policy-makers in the health care sector with clearer benchmarks and goals to inform action.

There is currently considerable discussion related to the collection and use of patient data in Ontario, particularly socio-demographic data and how it may be strengthened. There are a number of institutions and individuals involved in important data collection programs and initiatives. There is an opportunity, as work on data collection evolves, to consider how such data can be used to improve the health system experiences of persons in the LSL.

***Recommendation 6: Wellesley Institute recommends that steps be taken to strengthen the collection of patient data related to the last stages of life, in order to improve access and quality of services:***

- a. as data collection and governance in the context of health evolves, the Ministry of Health and Long-Term Care consider in its work data and monitoring needs related to the last stages of life;***
- b. Health Quality Ontario consider how its roles related to standards for quality care and for quality improvement plans may be used to strengthen data collection and monitoring related to the last stages of life;***
- c. in advancing their health equity mandates, Local Health Integration Networks monitor and evaluate access to and quality of services for persons in the last stages of life.***

## **4 Conclusion**

The last stages of life can be a complex and challenging time for people and their families. In this submission, we have outlined a health equity approach to the LSL that aims to address inequities present in the system as it currently operates. Our health equity approach is grounded in four key principles that provide a valuable structure and framework for considering policies, programs and practices related to the last stages of life.

Given the close connection between the LCO's work in this area and our mandate, we look forward to continuing to support this important project as it evolves towards final recommendations. We have a number of ongoing research projects whose outcomes may inform your work, and would be pleased to share our relevant expertise. Our work on this issue has been led by researcher Rebecca Cheff: she may be contacted directly at [rebecca@wellesleyinstitute.com](mailto:rebecca@wellesleyinstitute.com) or by telephone at (416) 972-1010, x. 274.



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## Endnotes

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- <sup>1</sup> Law Commission of Ontario. (2017). Improving the Last Stages of Life: Discussion Paper. Retrieved from: <http://www.lco-cdo.org/en/our-current-projects/improving-the-last-stages-of-life/>
- <sup>2</sup> See note 1
- <sup>3</sup> World Health Organization. (1986). The Ottawa Charter for Health Promotion. Retrieved from: <http://www.who.int/healthpromotion/conferences/previous/ottawa/en/>
- <sup>4</sup> Excellent Care for All Act, 2010, S.O. 2010, c.14. Retrieved from: <https://www.ontario.ca/laws/statute/10e14>
- <sup>5</sup> Government of Ontario. Bill 41, Patients First Act, 2016. Retrieved from: [http://www.ontla.on.ca/web/bills/bills\\_detail.do?locale=en&BillID=4215](http://www.ontla.on.ca/web/bills/bills_detail.do?locale=en&BillID=4215)
- <sup>6</sup> Health Quality Ontario. Health Quality and Equity. Retrieved from: <http://www.hqontario.ca/What-is-Health-Quality/Health-Equity-and-Quality>
- <sup>7</sup> Mandate Letter, Ministry of Health and Long-Term Care to Toronto Central LHIN, May 1, 2017. Retrieved from: <http://www.lhins.on.ca/Pan-LHIN%20Content/LHINs%20Accountability.aspx>
- <sup>8</sup> Wellesley Institute. (2017). Submission on Ontario's Draft Revised Public Health Standards. Retrieved from: <http://www.wellesleyinstitute.com/wp-content/uploads/2017/06/Wellesley-PHS-Submission-June-2017.pdf>
- <sup>9</sup> See note 1
- <sup>10</sup> Preamble to the Constitution of WHO as adopted by the International Health Conference, New York, 19 June - 22 July 1946; signed on 22 July 1946 by the representatives of 61 States (Official Records of WHO, no. 2, p. 100) and entered into force on 7 April 1948. Retrieved from: <http://www.who.int/about/mission/en/>
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