Time for Transformative Change: CARP Submission to the Advisory Panel on Healthcare Innovation

Healthcare remains the highest priority for Canadians and a more immediate focus as we age. The mandate of the Advisory Panel on Healthcare Innovation to seek improvements in the quality and accessibility of care will resonate broadly as will the challenge to sustainably reduce the growth in healthcare spending which is directly funded through our taxes.

The time is ripe for transformative change in the healthcare system. At $215 billion and growing,[i] healthcare spending in Canada is potentially unsustainable, especially in face of growing demand and rising costs of technology and medications. At the same time, older Canadians and their families find the system inadequate to the task of meeting their post-acute and chronic care needs, very difficult to navigate, and incomplete.

A more fundamental problem is that the health care system is designed around the priorities of the service providers and not the people who they are supposed to serve. As a result, services are separated into discrete silos with a funding model that research shows is designed to continue increasing costs. It is time for a full system re-design.

A Social Contract for Healthcare

Healthcare is a social contract between citizens[ii] and their government. Our taxes pay for the services but this is more than a mercantile arrangement. Citizens should be able to expect certain values to govern the relationship – universality, quality, and access - values found in the *Canada Health Act*. These translate into expectations for national standards of quality care and timely access.

A social contract for healthcare therefore contemplates national standards of care and access to services that are responsive to our needs, comprehensive and available when and where we need them. Sustained funding ensures that such expectations can be met.

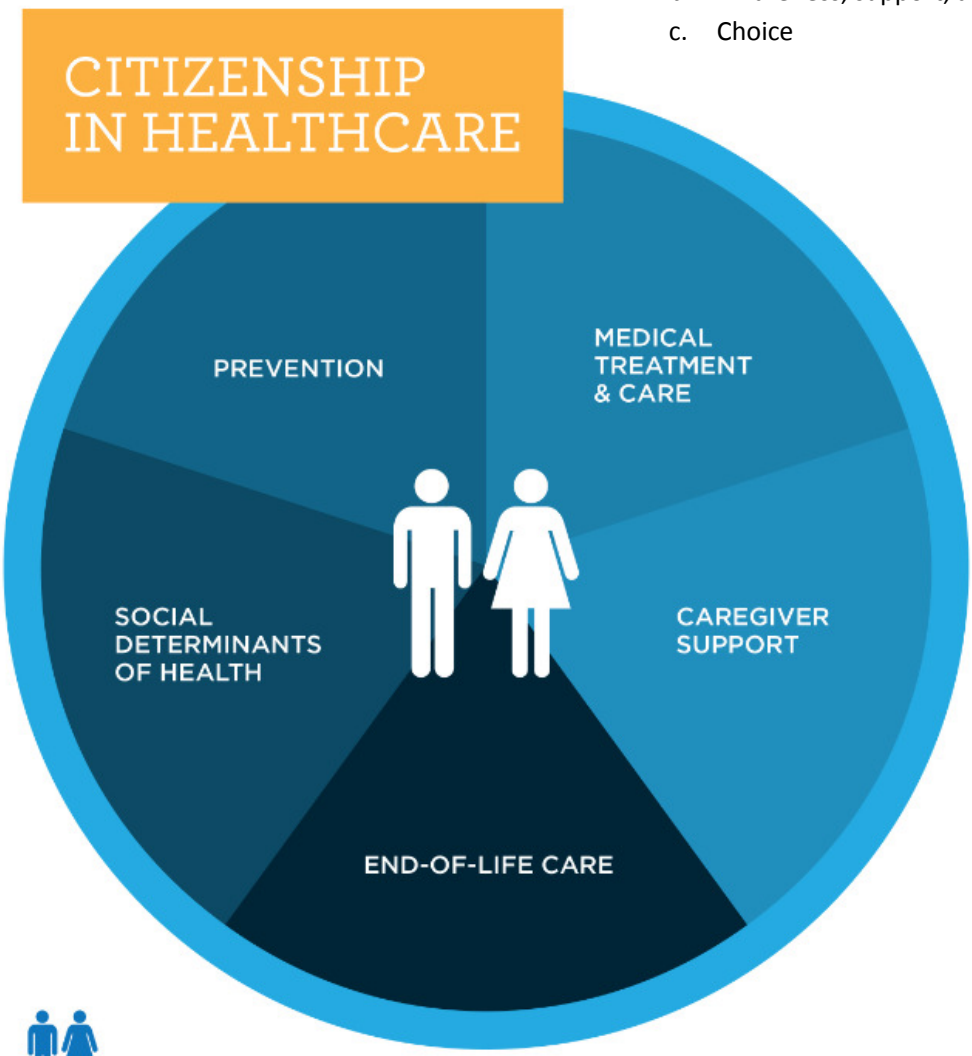
As funders of the system, it is also in our interest that the services are delivered in the most cost effective manner, getting value for our money, and it may be time for a system overhaul to reallocate resources to improve the quality and access to care.

The hospitals, nursing homes, and clinics as well as the nurses, doctors, social service workers and personal service workers who work in them are mandated to deliver the healthcare services but always within the broader social contract. They have a professional responsibility to those in their care, tantamount to a fiduciary duty, which is often also compromised by the current system design failures. Any system wide change requires the benefit of their specialized insights and direct engagement.

The common goal of the social contract is articulated in the preamble to the *Canada Health Act*: *to protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers*- thereby putting the healthcare citizen at the focus of the mandate.

A healthcare system that better serves the needs and expectations of all Canadians as we age would have five major, inter-related components:

1. Social determinants of health
    a. Anti-poverty
    b. Social engagement
    c. Independent living
2. Prevention of ill health
    a. Education and information
    b. Immunization
    c. Intervention – regular testing, activation
3. Medical care when and where needed
    a. Timely access
    b. Specialized training
    c. Home and community based care
4. Caregiver and Family support
    a. Financial support
    b. Training and respite
    c. Workplace protection and leave
5. End of life care
    a. Right to palliative care
    b. Awareness, support, access, and planning
    c. Choice



The Social Contract for Healthcare

The Healthcare Citizen's Values & Expectations

- National standards of care quality and timely access
- Care responsive to need
- Sustained funding
- Value for money
- System overhaul to reallocate resources

360 Degrees of Care

Each of the five components plays a vital role in *protecting, promoting and restoring the physical and mental well-being* of Canadians, as mandated in the *Canada Health Act* (CHA). But there must be a seamless continuum of care. Acute medical care alone is not sufficient. Addressing living conditions and providing tools for healthy living and disease prevention are as important to physical and mental well-being as receiving quality and timely care that responds to changing needs up to and including the last stages of life. The social contract with the citizens of the healthcare system goes beyond the medical physical needs but includes the whole person and is informed by the underlying values of national standards of care and access in providing comprehensive, responsive care as and when needed. To accomplish this, 360 degrees of care must deliver on all five components:

1) Social Determinants of Health

The 360 degrees of care starts with the social determinants of health - the social, economic and environmental factors that determine the health of individuals. Evidence overwhelmingly shows that poverty, social isolation, a poor physical environment, and lack of education leads to poor health outcomes.[iii] Significant improvements in health cannot be achieved without investments in providing better income, education, working conditions, and social environments that promote independent living.

Government has many opportunities to help Canadians stay healthy, engaged, and independent for as long as possible. For example, all communities should be age-friendly cities where universal design and barrier-free access governs the availability and design of public spaces and public transit systems. National funds should be committed to affordable housing options, including those with assisted living supports. Such examples would allow Canadians to maintain their independence and remain socially engaged in their own communities and live in a clean and safe home, with reduced respiratory disease and exposure to environmental health risks. Healthy social relationships have proven to have significant health effects, such as lowering premature deaths.[iv] Governments also play a role in ensuring people have income security to allow access to healthy food, good living conditions, and more control over their lives, which are associated with better health.[v] Particularly, government can help ensure that Canadians have adequate income in retirement, a vulnerable time for many, by cooperating to increase the CPP which will also reduce dependency on other government programs like OAS/GIS.

2) Prevention of ill health

Prevention plays an important role in the 360 degrees of care. Similar to the social determinants of health, prevention measures help people help themselves by giving them the appropriate tools and conditions to protect themselves against preventable illnesses and disease. The healthcare system must ensure that Canadians have access to health education and awareness as well as the necessary tools to take action. For example, healthcare system should make needed immunization accessible for all. Canadians also expect to access to regular exams and necessary interventions to detect and address health problems early on rather than waiting until the problems have grown, decreasing one's quality of life and costing the system more.

3) Medical care

Canadians need to be able to expect that medical care will be there for them when they need it - services that will be responsive to their needs, comprehensive and available when and where they need them – regardless of geography and pocketbook.

The current healthcare system is designed around the service providers and not the users. Healthcare providers decide how care is managed and delivered and how resources are allocated, which is done independently within each region, hospital, and department, and according to current studies, without any overall coordination or strategic leadership. Consequently, Canadians must advocate for themselves and navigate a fragmented and inefficient system of silos within silos, failing to receive the care they need. Too often Canadians are without care to manage their chronic conditions at home or they are stuck between institutions without any transition care options. For example, there should be a continuum of post-acute care that rehabilitates and transitions people back to full independence within their own home when possible but instead people are often placed on ALC (alternative level of care) beds, where their ability to regain their independence diminishes. The hospitals have no mandate to provide any post-acute care or to help people transition home or to other assisted living environments. The system fails to provide any solutions. Instead, the people stuck in 74,000 ALC hospitalizations across Canada[vi] are accused of wasting healthcare dollars.

The healthcare system must be redesigned around the citizens' need. Care must be responsive - the right kind of care they need and where and when they need it. Responsive care means replacing ALC beds with a restore and release model that provides rehabilitation and prevention to restore people to health and independence before they are released back home and provides preventive measures to reduce the risk of future hospitalizations. It might also mean shifting hospital budgets into community based care, to allow more people to remain in their own homes. For example, long-term care services can be packaged to be delivered at home, addressing a gap for people who need more than a few hours of home care per week but do not need to be in a long-term care facility – and potentially divert up to 25% of those in long waiting lists for nursing homes. Responsive care also means specialized training based on the needs of the population. With increasing need for dementia care, all frontline healthcare providers should be trained to properly diagnose and care for patients with dementia and their families.

System transformation needs leadership to overhaul the system by breaking down the silos, reallocating resources more strategically, and redesigning care so it is responsive to citizens' needs. For example, Finland's healthcare system includes a national quality framework for care of older people.[vii] While the regions deliver the care, the national government provides funding and a national framework that specifies quality of care standards and targets to reduce variation across the regions. The framework has a policy aimed at replacing institutional care with home care and other forms of housing, such as sheltered housing units with 24-hour assistance, as well as a National Curriculum for long-term care workers who undergo a three years of formal training. [viii]

4) Caregiver and Family Support

The needs of the healthcare citizen do not stop at good medical care provided inside hospitals but continue full circle outside in the community and in homes. Many Canadians receive ongoing support and care from informal caregivers, usually family members and friends. The current non-refundable Family Caregiver Tax Credit recognizes informal caregivers but the maximum credit of $300 provides little coverage for lost income and out-of-pocket expenses, especially for those providing heavy care.

The government should provide more meaningful financial supports and make the tax credit refundable while also providing respite and job protected leave with pay for informal caregivers who are crucial contributors to the health and wellbeing of Canadians. Some provinces have committed to providing better supports such as Nova Scotia, where $400/month is provided to an informal caregiver caring for a low income adult with a high level of disability or impairment.[ix] Many countries have policies for caregivers such

as an annual grant for respite care for up to four weeks in Austria and a comprehensive network for support institutions for caregivers that offer training courses across the country in Sweden.[x]

5) End of Life Care

End of life care completes the 360 degrees of care of the healthcare citizen. While most of the components of the healthcare system currently exist, albeit in desperate need of redesign, quality end of life care is not readily available for most Canadians. Canadians are uncertain about end of life care and what care choices are available to them, and many look to their doctors for answers but doctors feel unequipped to have these conversations. Currently, only 15% of Canadians have access to in-hospital [xi] palliative care and access depends on where they live.[xii]

End of life care needs to be prioritized as an essential health need. Indeed, as set out in Quebec's Bill 52, palliative care should be a legislated right. This will mean that regardless of geography all Canadians will be guaranteed palliative care when they need it and the consequences of failing to provide will give Canadians grounds to take legal action. Several countries, like Germany, France, Italy and Catalonia, have legally provided citizens the right to palliative care. [xiii] Italy's law gives its citizens the right to palliative care but also ensures customized care models for each patient, quality of life until the end, and it has defined national palliative care training requirements for physicians and other care professionals.[xiv]

End of life care must also extend to choice over how life ends. Although attempts have been made through Quebec's Bill 52 and MP Stephen Fletcher's Bill C-581 and C-582 (poised to be debated in the Senate) end of life care choices continue to be a large gap in the 360 degrees of care. Government leadership is needed to set standards of care and ensure that quality end of life choices are available. Canadians want assurance that they will have control over their end of life care decisions and that their dignity will be maintained until the end.

Innovation as System Redesign

System transformation is the innovation that the healthcare system needs. Canadians want to see system transformation that upholds the social contract to *protect, promote and restore the physical and mental well-being of residents of Canada and to facilitate reasonable access to health services without financial or other barriers*, as set out in the *Canada Health Act*. Canadians are frustrated with innovative pilot projects that add more elements and costs to the system with limited impact. Instead, they want to see a system-wide transformation with real impact on their health and well-being. Healthcare citizens are calling on government to look at the healthcare system as a whole and not as individual parts and silos, to focus on care and not where it is now delivered, and to design the system based on the needs of the healthcare citizens rather than the needs of the service providers. It is time that the system provides a comprehensive 360 degrees of care around the needs of the healthcare citizen.

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[i] http://www.cihi.ca/CIHI-ext-portal/internet/EN/SubTheme/spending+and+health+workforce/spending/cihi015954
[ii] "Citizens" in this context is not limited to those with Canadian citizenship status but refers those entitled to access the public healthcare system
[iii] http://www.who.int/social_determinants/themes/en/
[iv] http://www.phac-aspc.gc.ca/ph-sp/determinants/determinants-eng.php#social1
[v] http://www.phac-aspc.gc.ca/ph-sp/determinants/determinants-eng.php#income
[vi] According to 2007-2008 data from CIHI. https://secure.cihi.ca/free_products/ALC_AIB_FINAL.pdf
[vii] http://www.rcc.gov.pt/SiteCollectionDocuments/NationalFrameworkforHighQualityServicesforOlder%20.pdf
[viii] http://www.oecd.org/els/health-systems/Finland-OECD-EC-Good-Time-in-Old-Age.pdf
[ix] http://novascotia.ca/dhw/ccs/caregiver-benefit.asp
[x] http://www.oecd.org/els/health-systems/47884889.pdf
[xi] No statistics are available for community based palliative care
[xii] http://actionplan.gc.ca/en/initiative/palliative-and-end-life-care
[xiii] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3720186/
[xiv] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3680835/