



Scaling Up Diabetic Retinal Screening in Ontario:
A Pan-Ontario Plan to Close the Screening Gap

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1. Summary

Evidence-informed care can prevent many chronic disease complications, but not all those who could benefit receive these services. This is the case for diabetic retinopathy, the leading cause of blindness among working age adults. Results from introducing a proactive, structured screening program in England and Wales show that it does not have to be.

Ontario could do the same, building on the Ontario Diabetes Strategy goal of ensuring that 80% of adult Ontarians with diabetes have three key diabetes tests within recommended timeframes, including a retinal eye exam. About 150,000 additional people would need to be screened over a two-year period to achieve this rate.

We propose a cross-LHIN approach to reduce the risk of vision loss among people with diabetes that balances the advantages of collective effort towards a shared province-wide goal and responsiveness to the unique circumstances of each LHIN. The Ontario Telehealth Network and Diabetes Action Canada – CIHR Strategic Patient Oriented Research Network in Diabetes (OTN-DAC) will work with each LHIN to develop a tailored and feasible plan and budget that leverages existing investments in CHCs, FHTs, diabetes education programs, and other services including:

- **Proactive outreach** to those who have not been screened, facilitating access to community-based and/or telehealth services;
- **Launch/expansion of telehealth retinal screening to reach vulnerable/underserved groups**, with 2-4 nodes required per LHIN at a cost of up to \$635,000 per node over 3 years to screen 4000 patients which translates to about \$159 per person screened or \$265 per person with diabetic retinopathy or other pathology identified;
- **Use of a learning health system model**, using and generating lessons learned and evidence to inform planning and implementation of patient-centered care; and,
- **Partnerships** with local, regional, and national groups that have a shared commitment to reduce vision loss for people with diabetes, as well as an interest in working together to reduce barriers to screening and follow-up, and/or to develop shared services to optimize economies of scale.

2. The Challenge

Serious complications of chronic diseases affect the lives of hundreds of thousands of Ontarians. They tend to have high needs for health services and to be amongst those with the highest healthcare costs. Evidence-informed care can prevent many complications, but not all those who could benefit receive these services.

This is the case for diabetic retinopathy, the leading cause of blindness among working age adults. [Results from England and Wales](#) show that it does not have to be. These countries introduced a proactive, structured screening program that includes multi-faceted interventions such as telehealth and effective recall of patients. Following its introduction, diabetic retinopathy ceased to be the leading cause of blindness in this age group for the first time in at least 5

decades. In Wales, a [recent study](#) found that there was a more than 40% reduction in certifications of sight impairment related to diabetic retinopathy following the introduction of an organized screening program.

Figure 1: What People who have Diabetes Say

Respondents to an online survey of adults Canadians with diabetes and adult caregivers of people with diabetes conducted for Diabetes Action Canada placed priority on research on ways to prevent and treat kidney, eye, nerve, and heart complications

My late mother had diabetes in her late 70's. Towards the end of her life, she could hardly see. It was heartbreaking for everyone in the family. My brother was diagnosed with type 2 diabetes about 5 years ago and takes insulin 4 times a day. He sees two different ophthalmologists; one is a diabetes specialist. He has had several eye laser treatments due to his diabetes. I am very concerned for him so YES of course this is very important for people who have this problem.

- 50-year-old woman living with type 2 diabetes

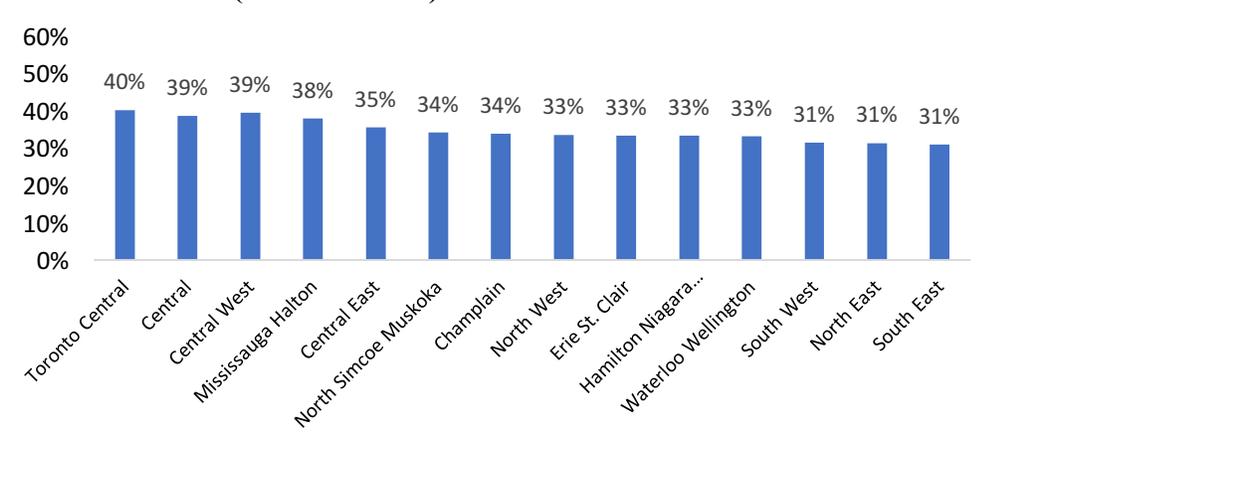
Very important, my mother didn't have an opportunity to get eye exams and became blind before she died.

- 52-year-old woman living with type 2 diabetes

Ontario could do the same. The provincial [Diabetes Strategy](#) aims to ensure that 80% of adult Ontarians with diabetes have all three key diabetes tests (an HbA1C blood sugar test, an LDL-C cholesterol test and a retinal eye exam) within recommended timeframes. About 150,000 additional people would need to be screened over a two-year period to achieve this rate since ICES reports that [about 400,000 Ontarians with diabetes](#) have not had an eye exam in the last two years. Guidelines recommend screening for retinopathy every 1-2 years.¹ Younger adults with type 1 diabetes, [Indigenous peoples](#), [recent immigrants](#), and [residents of inner cities and remote areas](#) have lower screening rates. [Almost all people with Type 1 diabetes and more than 60% of those with Type 2 diabetes](#) develop some form of retinopathy in the first 2 decades after a diabetes diagnosis.

¹ Note: some people with diabetes may have received a retinal exam for which a billing was not submitted to OHIP, which would not be tracked through administrative data or be included as part of provincial statistics.

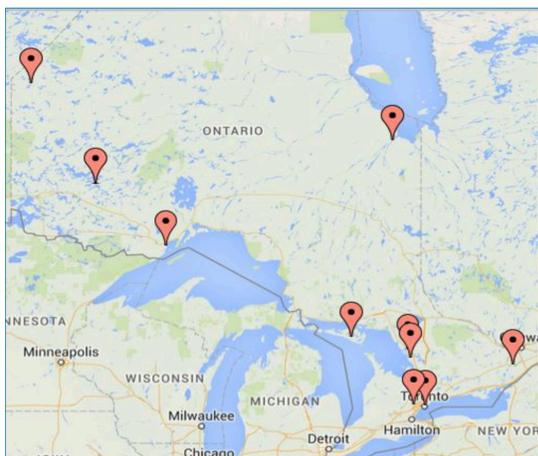
Figure 2: Percentage of Ontarians with Diabetes Who Have Not Had an Eye Exam in the Past Two Years (Source: ICES)



3. Where We Are Today: Alignment with Provincial and LHIN Priorities & Initiatives

Population-based, evidence-informed strategies can lead to [improved diabetes care](#). A goal of the [Ontario Diabetes Strategy](#) is for 80% of adults with diabetes to have retinal eye exams and two other key diabetes tests within recommended timeframes. Health Quality Ontario tracks screening rates in its annual [Measuring Up report](#). In collaboration with ICES, it also shares local results via [Primary Care Practice Reports](#). [Quality-based procedures](#) for prevention and treatment of diabetic retinopathy are also being explored.

Many LHINs have developed vision care plans that include a focus on screening for diabetic retinopathy, and there is an opportunity to scale up these efforts. There are also a variety of efforts underway that focus on preventing and managing complications of diabetes more broadly. In several cases, these initiatives stress the importance of equity considerations.



This is a key reason driving the use of telemedicine for retinal screening in some urban and rural pockets of the province. Nine organizations across Ontario – from inner city Toronto to Manitoulin Island – host teleophthalmology services. All programs are focused on outreach to underserved and vulnerable groups and/or regions. Several have won awards recognizing the innovative nature of their services and the contributions they have made to improving the equity of screening services and vision care.

Based on experience gained from these services across the province, teleophthalmology is ready to scale. OTN has recently refreshed its web-based software tools to streamline the service, as well as the documentation and communication of screening results. Several LHINs have indicated that they intend to leverage these new tools as they broaden the reach of telemedicine-enabled screening.

While screening volumes via telehealth services have been rising, they remain modest. About 4,600 people had retinal screening via telemedicine over the last 3 fiscal years. Retinal specialists review the scans and facilitate follow-up care. In South Riverdale, for example, 25% of patients screened had diabetic retinopathy, 5% had sight-threatening disease, and 35% had other pathology such as age-related macular degeneration (AMD), glaucoma, or cataracts. A recent economic analysis (by the Toronto Health Economic and Technology Assessment Group) found that telehealth for retinal screening in this context is cost effective relative to usual care.

These local initiatives have demonstrated that well-designed programs can reach groups who would otherwise be unlikely to receive screening/treatment. This includes situations in rural/remote areas where eye care is not otherwise accessible and those in urban areas where services tailored to the needs of marginalized groups may not otherwise be available. Success appears to be less about the technology and more about the business/clinical model. Payment and regulatory requirements affect who refers patients and who delivers services. There is a strong desire for integration with other chronic disease initiatives.

In addition, experience suggests that to scale and spread, programs need:

- An outreach model with local champions to locate hubs/mobile sites appropriately and ensure suitable referrals;
- Strong partnerships with ophthalmologists, optometrists, and primary care that ensure continuity of care;
- Sustainable funding models; and
- Equipment that is affordable and mobile.

4. The Opportunity: Reducing the Risk of Vision Loss for All Ontarians with Diabetes

To test new approaches to preventing diabetic retinopathy as a model for broader chronic disease management, we propose a systematic and replicable cross-LHIN initiative to **reduce the number of Ontarians with diabetes who have not received recommended retinal screening, thereby reducing the risk of vision loss**. It will aim to ensure timely screening results, appropriate specialist and follow-up care, and links with the patient's broader circle of care, including primary care. The initiative will have a focus on vulnerable/under-screened groups.

Key features of the proposal include:

- **Common goal, tailored approaches:** A cross-LHIN approach that balances the advantages of collective effort towards a shared province-wide goal and responsiveness to the unique circumstances of each LHIN;
- **Proactive outreach** to those who have not been screened, facilitating access to community-based and/or telehealth services;
- **Launch/expansion of telehealth retinal screening**, leveraging population-based data to identify local areas within each LHIN that have higher rates of the most vulnerable and of under-screening for diabetes complications;
- **A learning health system model**, using and generating evidence to inform program decisions in an iterative approach; and
- **Partnerships** with local, regional, and national groups that have complementary levers for change and a shared commitment to reduce vision loss for people with diabetes.

5. A Strategic Partnership for Change

Delivering province-wide improvements in vision care within a learning health system framework requires active engagement of many individuals and groups. This diverse strategic partnership brings together Ontarians and a number of organizations that serve them, each of which has unique strengths and capabilities. What brings them together is a shared commitment to a common overall goal.

Importantly, our proposed approach is informed by the voices of **individuals with diabetes and their families**, captured via a survey undertaken for Diabetes Action Canada and key informant interviews (see Figure 1).

The overall initiative is led by the province's 14 **Local Health Integration Networks (LHINs)**. They have responsibility for planning, integrating, and funding local health services so as to improve access to care and the patient experience. The LHINs will also work with **their region's health care providers** – including a regional retinal champion – in scaling-up diabetic retinopathy screening.

Throughout the process, the LHINs have been collaborating with:

- **Diabetes Action Canada (DAC)** is the Canadian Institutes of Health Research-funded Strategic Patient Oriented Research (SPOR) Network in Diabetes and its Related Complications. It aims to facilitate important and meaningful connections between patients, their primary healthcare providers, and specialists to improve health care with significant cost savings for the health system. DAC is also part of the broader SPOR program. Through links with the Ontario SPOR Support Unit, DAC will facilitate access to data on diabetic retinal screening held by the Institute for Clinical Evaluative Sciences
- **Ontario Telemedicine Network (OTN)** brings virtual care innovation to the healthcare system so that the people of Ontario can get the care they need when and where they need it most: at home, in their community or in hospital. For more than a decade, OTN has increased access to health care and education across the province with one of the world's most extensive telemedicine networks. Working with its many partners and leveraging its unique knowledge of health care and digital technology, OTN addresses challenges by introducing and spreading new ways of delivering care that benefit patients, care providers and the healthcare system. An independent, not-for-profit organization, OTN is funded by the Government of Ontario.

6. Common Goal, Tailored Approaches

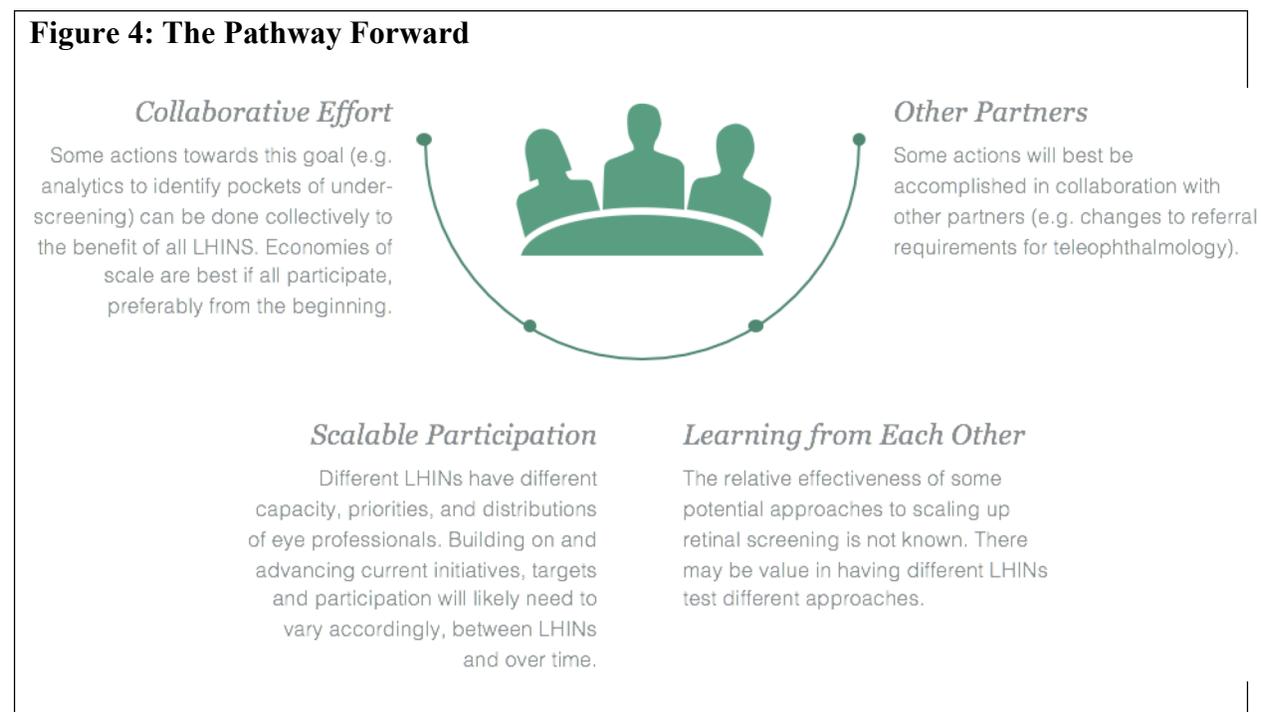
LHINs share the goal of reducing the risk of vision loss by closing gaps in retinal screening. The intent is to establish a cross-LHIN approach that balances the advantages of collective effort towards this common goal and responsiveness to the unique circumstances of each LHIN (see Figure 4). Use of Diabetes Canada clinical practice guidelines (as updated from time to time) to define screening protocols will help to ensure alignment with provincial and national efforts to improve diabetes care.

Given that capacity and readiness vary by LHIN, a progressive implementation with scalable participation is recommended. All LHINs and their partners would commit to the overall goal and to a core set of activities. Individual LHINs would choose an initial level of participation beyond this core and advance over time as their circumstances evolve.

To this end, OTN-DAC will work with each LHIN to develop a tailored and feasible plan and budget that leverages existing investments in Community Health Centres, Family Health Teams, Diabetes Education Programs, and other services. This will enable customized screening programs that fit each LHIN's unique capacities and circumstances, as well as help to ensure that services are complementary to and integrated with other regional chronic disease management efforts, including those offered by primary care.

While it is expected that there will be general consistency in the core components of the screening program, different care models – and different approaches to integration – may be appropriate in different contexts. For example, each LHIN would develop criteria to prioritize communities, organizations, and providers where screening sites would be established. This approach would take into account alignment with regional vision care plans and community needs and resources. Likewise, LHINs may choose to work in partnership (e.g. through Service Level Agreements) with selected health care providers for image capture services. The variation across, and in some cases within LHINs, will offer opportunities for natural experiments and shared learning.

Figure 4: The Pathway Forward



In addition, cross-LHIN services offer an opportunity to leverage economies of scale and shared learning. For instance, collaboration on data and analytics to identify local areas with large screening gaps and to monitor trends have been built into this proposal. Additional options, such

as a shared or pooled image reading centre and direct outreach to those not screened could also be undertaken, with the cost to each LHIN for these additional services dependent on the number of participating LHINs, the scale of shared services, and funding or in-kind contributions from other partners.

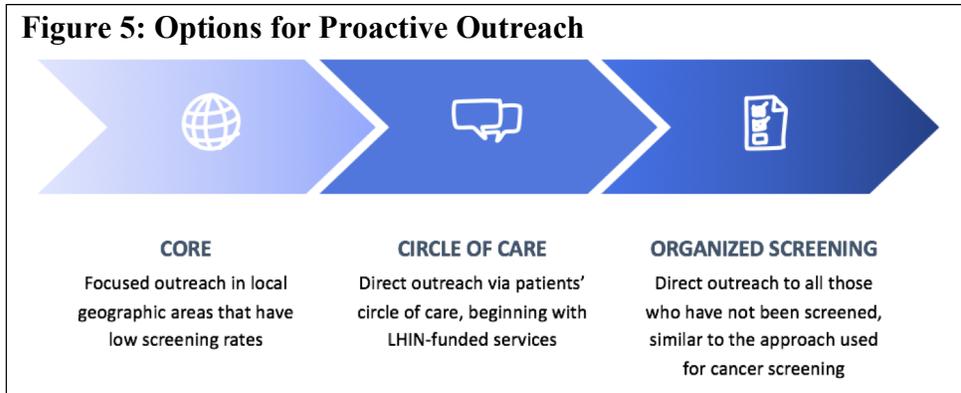
7. Proactive Outreach

Reminders and follow-up matter. Almost three in four Canadian adults say that if preventive or follow-up care is recommended because of their age or health problems, they should receive reminders about this care.² Experience from [organized cancer screening programs](#) also shows that proactive outreach to those who have not been screened in the recommended period improves patient outcomes.

OHIP data can identify who has diabetes but has not had an eye exam in the past two years. While Ontario does not currently use the results to refer patients to screening, the [English experience](#) shows the power of doing so. Accordingly, the aim is to proactively reach out to those who need screening and refer them to community-based and/or telehealth screening.

There are a variety of ways in which this could be done (see Figure 5). At the most basic level, outreach can be undertaken on a geographic (not person-specific) basis, targeting areas with low screening rates identified via analysis of OHIP data. It depends on actively undertaking local outreach via health/community services, partnerships, and venues. This approach builds on experiences and methods currently used in some parts of the province and is highly feasible. However, it can be resource intensive and may not reach all those who have not been screened.

A more sophisticated approach would be to use near real-time OHIP data to identify individuals who have not been screened and reach out to them directly.



Outreach could either be via their existing circle of care or via a central authority, similar to the approach that Cancer Care Ontario uses for cancer screening. The Ministry of Health and Long-Term Care collaborated with selected primary care providers to trial the former approach through the Baseline Diabetes Dataset Initiative. Detailed outreach strategies would be incorporated into LHIN-specific implementation plans. Initially, it may make sense to focus on patients for which LHIN-delivered services (e.g. home care and diabetes education programs) are already part of their circle of care.

² Source: Consumer Experiences Study of 3,162 Canadians aged 18+ conducted for Canada Health Infoway by Harris Decima (2012).

Longer-term, the intention would be to work with LHINs and other partners to enable direct outreach on a population basis, as is done by Cancer Care Ontario for services such as pap smears and mammography. This approach is likely to result in higher screening rates but requires enabling actions to be successful. For instance, there would be a need to confirm legal authority under privacy legislation for outreach, secure regular access to near real-time screening data from the Ministry of Health and Long-Term Care (discussions underway), establish relevant partnerships, and have appropriate infrastructure in place to enable outreach, access to screening services, and follow-up. In addition, consideration should be given to integrating screening information into clinicians' point-of-care systems, the connecting platforms, patient portals, and similar services. In both cases, the work could potentially be undertaken on a cross-LHIN basis, engaging appropriate partners.

8. Reaching Underserved Groups: Scaling Teleophthalmology

A core element of the proposed initiative is that each LHIN would launch or expand telehealth retinal screening to reach vulnerable/underserved groups. Planning for these services would consider patient outreach and referral, image capture, image review and clinical advice, timely screening results, appropriate specialist and follow-up care, and links with the patient's broader circle of care, including primary care.

OTN-DAC would work with each LHIN to develop a tailored and feasible plan for launching or expanding telehealth retinal screening that reflects their existing services,

capacity, and vision care plans. To facilitate this process, LHINs who have not already done so would identify regional retinal champions to serve as their clinical lead and to coordinate with colleagues across the province as needed.

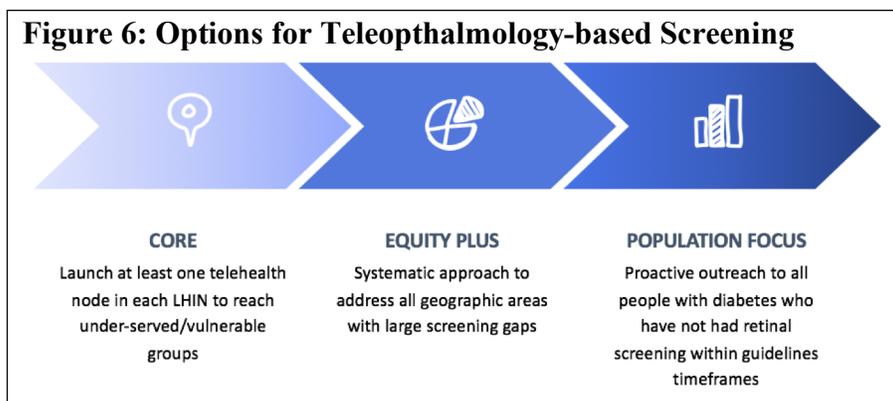
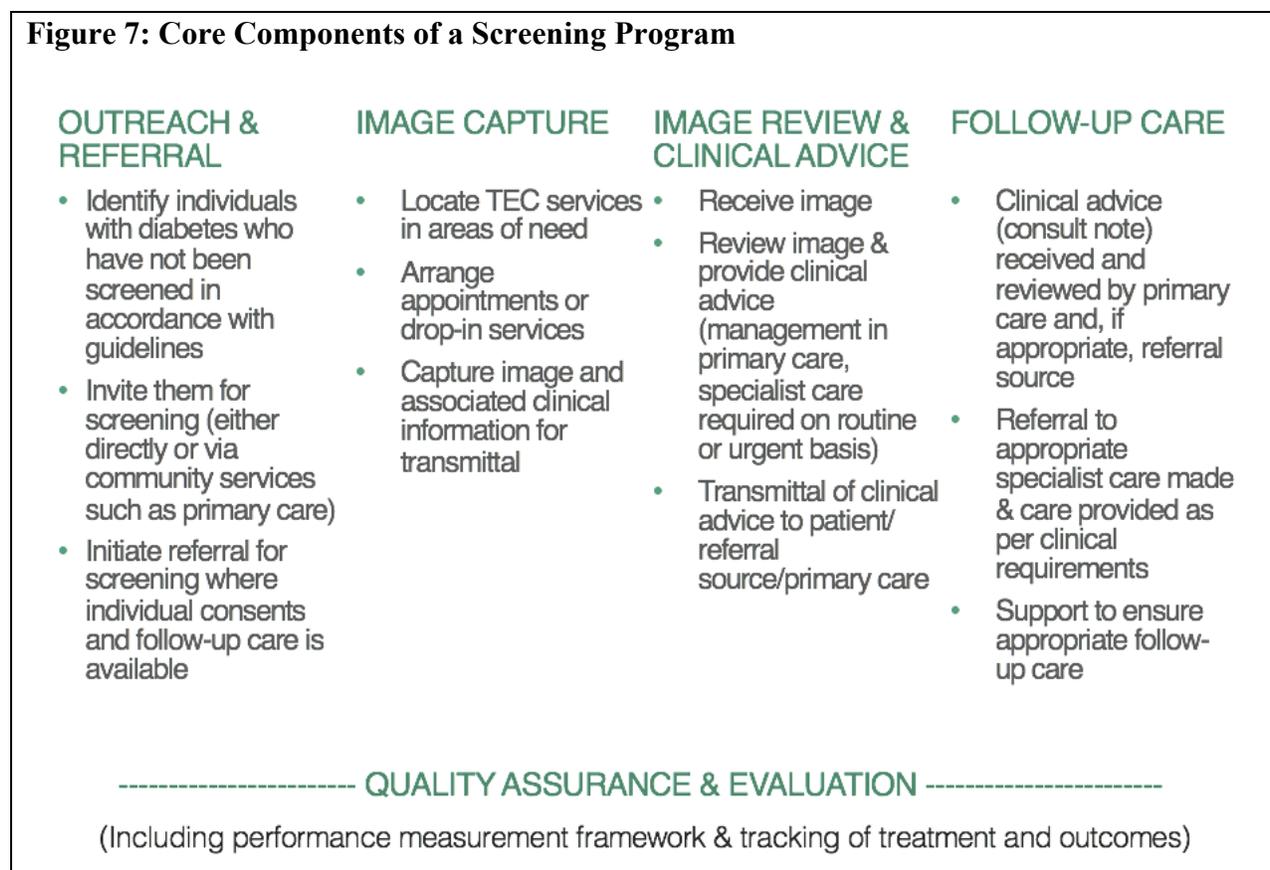


Figure 7: Core Components of a Screening Program

Plans would include the anticipated scope and timing of telehealth screening rollout/expansion. Service nodes would be located in areas of highest need by leveraging population-based data to identify local areas that have higher rates of the most vulnerable and of under-screening for diabetes complications. The number of telehealth nodes needed in each LHIN depends on geography, community screening capacity, and existing telehealth services. It is estimated that 2-4 nodes (some with mobile cameras) per LHIN would be required. OTN has estimated a cost per node of up to \$635,000 over 3 years to screen 4000 patients (see Figure 8). This translates to about \$159 per person screened or \$265 per person with diabetic retinopathy or other pathology identified.

Figure 8: Estimated Screening Volumes and Costs for a New Telehealth Node

	Year 1 (2 quarters)	Year 2	Year 3
Screening Target - # of clients (total)	200	1,536	2,304
Screening Target - # uninsured clients	40	307	461
Total Expenses	\$ 95,750	\$ 246,730	\$ 291,775

To optimize outcomes, it needs to be as simple as possible for patients who need screening and follow-up care to access the service. Ways of reducing barriers to screening and follow-up will be incorporated into the planning process. For instance, some LHINs have added retinal

screening to diabetes education program referral forms to facilitate the referral process. Likewise, family physician or nurse practitioner referral is currently required to access teleophthalmology services. If the need for screening is identified by another party, this extra step can affect screening uptake. LHINs and their partners – individually and collectively – could explore ways of addressing this issue. In addition, screening must be accompanied by a plan to ensure appropriate follow-up care, particularly for those with urgent health problems, and an accountability framework for doing so.

9. Continuous Learning and Adaptation to Drive Better Outcomes

A learning health system approach that takes into account and advances research and best practices on scaling and spreading health innovation is core to our plans. We would use evidence, including lessons learned from existing initiatives, to inform program decisions; generate new knowledge through research and evaluation; and facilitate sharing and exchange of best practices and solutions among LHINs and other partners.

A learning health system is “designed to generate and apply the best evidence for the collaborative healthcare choices of each patient and provider; to drive the process of discovery as a natural outgrowth of patient care; and to ensure innovation, quality, safety, and value in health care.”

- Institute of Medicine [Roundtable on Evidence-Based Medicine, 2015](#)

Previous efforts by ICES and HQO have confirmed that it is possible to track screening rates across the province using existing data. Through DAC and its partners, analytics at a local level will help identify geographic areas within LHINs that have low screening rates. This information can be used to improve the equity of services, e.g. by locating teleophthalmology sites based on the distribution of under-screened populations.

In addition, the intent is to partner with the Ministry of Health and Long-Term Care to offer LHINs regular updates on screening trends within their region. This information should assist with tracking progress relative to goals. It can also aid in understanding the extent to which various approaches to scale-up reduce the number of people who have not received recommended screening and improve outcomes.

There will also be the opportunity for LHINs or sites within LHINs to participate in [more detailed research projects](#) that assess effectiveness and acceptability of new models of care and other research questions. These more in-depth projects will be managed by DAC and its academic partners separately from the scale-up effort.

A Partnership for Transformative Change

Progress depends on working together. Led by the LHINs, this initiative would bring together the complementary strengths of local, regional, and national groups who share a commitment to reducing vision loss for people with diabetes.

Each LHIN would commit to the overall goal and develop an implementation plan that is responsive to their current unique circumstances. They will also work together and with partners to shape and leverage cross-LHIN services designed to facilitate province-wide progress towards the collective goal. Participating LHINs may choose an initial level of participation, advancing over time as their situation changes.

LHIN leadership commitments

- A shared target of reducing the number of Ontarians with diabetes who have not received recommended retinal screening, thereby reducing the risk of vision loss
- Implement core services and confirm the desired level of participation beyond the core, including collaborating on a regional plan consistent with this decision and with local capacity and programs
- Provide funding for program support, e.g. telehealth screening nodes and shared services
- Identify retinal specialist (ophthalmologist) as LHIN champion
- Partner in addressing policy/regulatory barriers to screening, such as direct outreach to individuals who have not been screened and removing barriers to screening and follow-up

Support provided by OTN, DAC, and other partners

- Diabetes Action Canada (DAC)/ICES to identify geographic areas within LHINs with screening gaps, track screening trends, and offer other evaluation support
- OTN/DAC to provide template for – and collaboration in development of – regional plan consistent with desired participation tier and local needs/capacity
- OTN to offer telehealth infrastructure and support for retinal screening
- MOHLTC to explore provision of data to enable direct outreach to persons who have not been screened via circle of care or population-based program (discussions in progress)
- MOHTLC via OHIP to pay professional fees for most screening and follow-up as per established fee schedules (see box below)
- DAC to coordinate shared/pooled image reading centre (if desired)
- DAC to serve as partner in trialing and evaluating new technologies and models of care

OHIP Coverage for Retinal Screening

The Ontario Health Insurance Plan (OHIP) covers complete eye exams by an optometrist or physician every 12 months, plus any required follow-up for Ontarians with diabetes between ages 20 and 64. It also pays for annual routine eye exams and required follow-up for seniors. In addition, there are e-consultation assessment codes specific to teleophthalmology that require referral from primary care physician or nurse practitioner. Referring clinicians can also bill for an e-consultation when they collect additional data (e.g. ophthalmology images not present in the primary care physician's records) to support a specialist's initial, repeat, follow-up or minor e-assessment.