

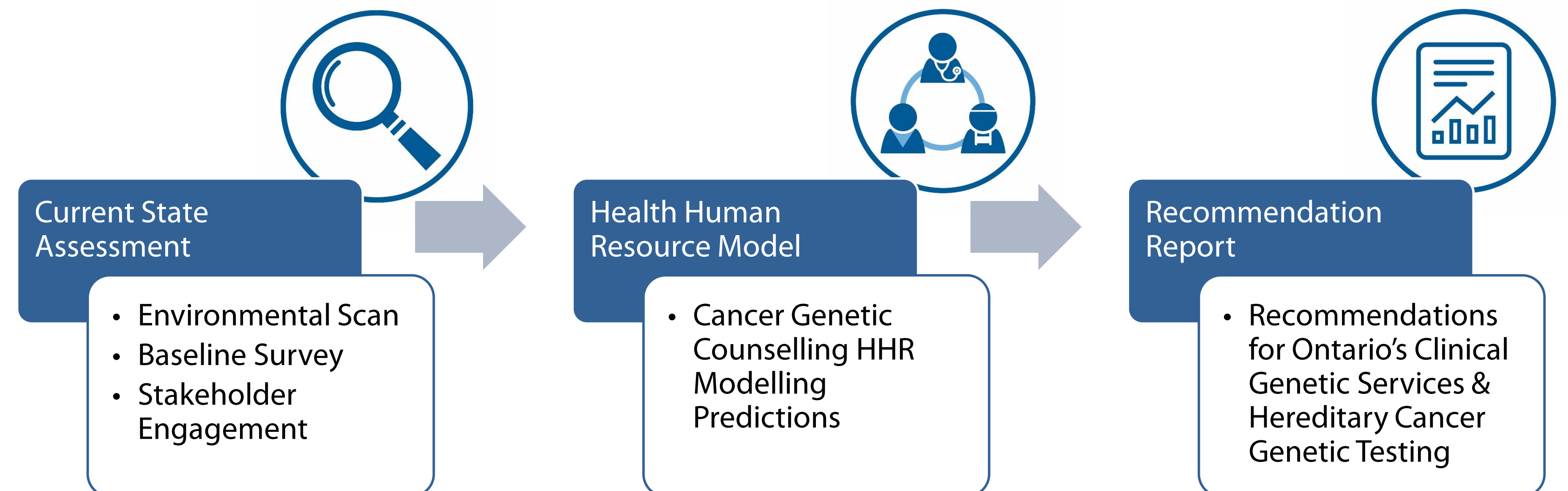
Background

CCO's engagement with the genetics community helped identify issues related to patient access to genetic services in the province, including:

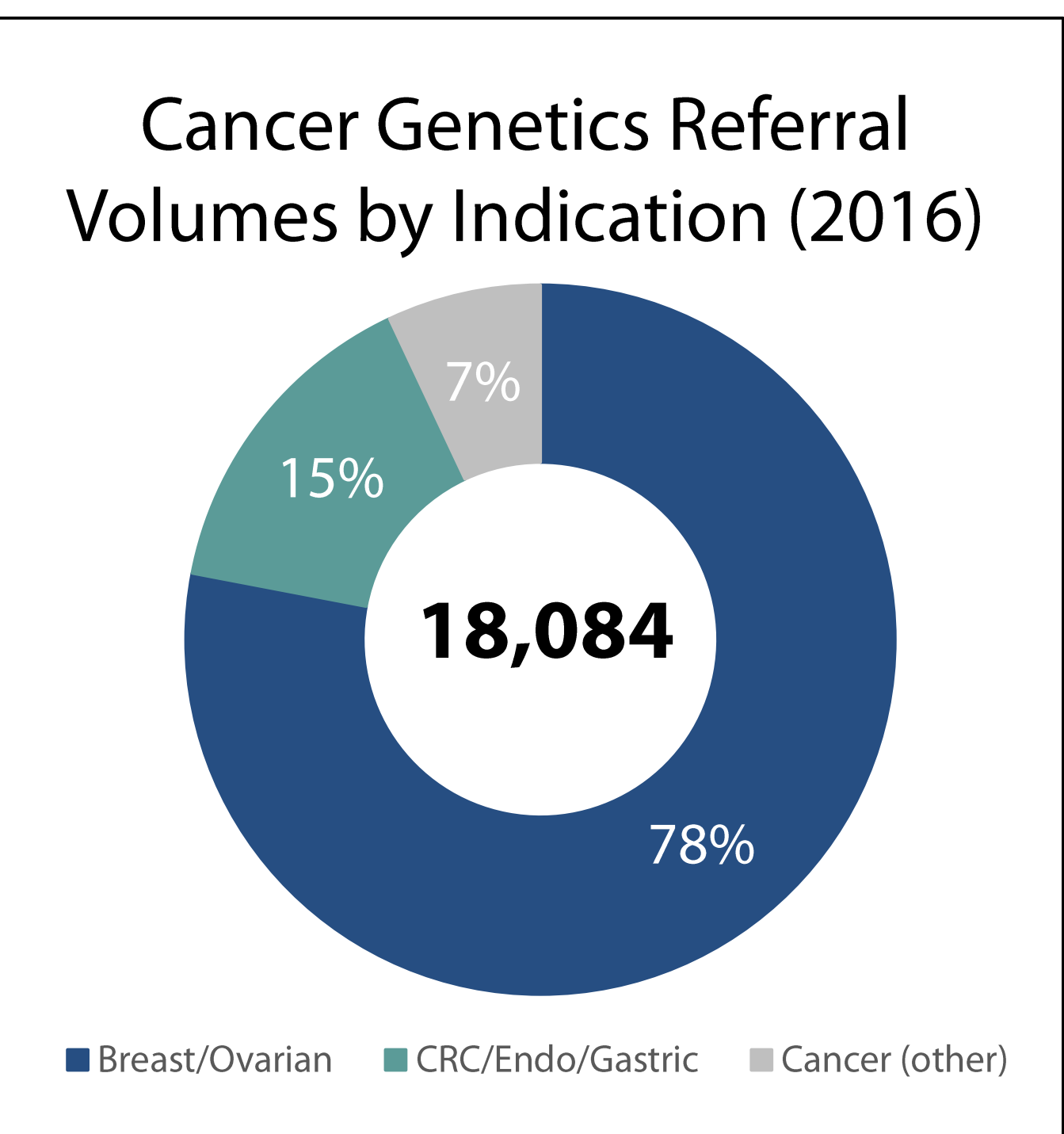
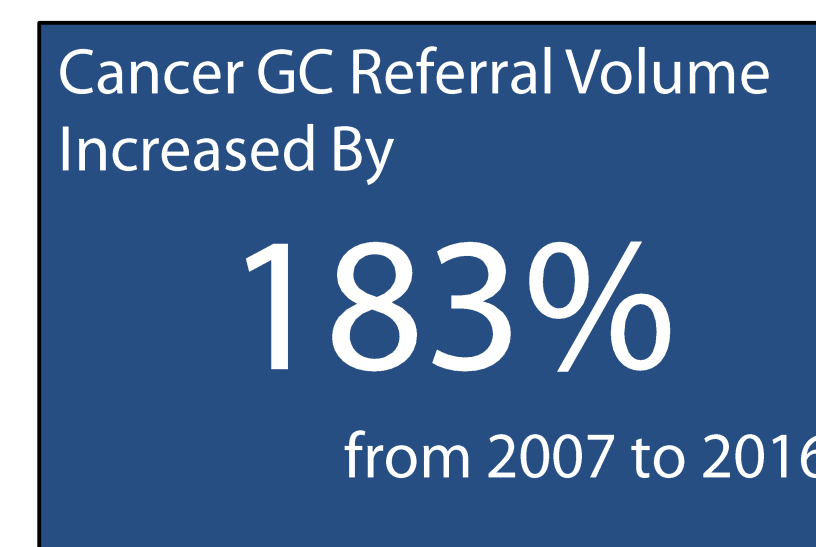
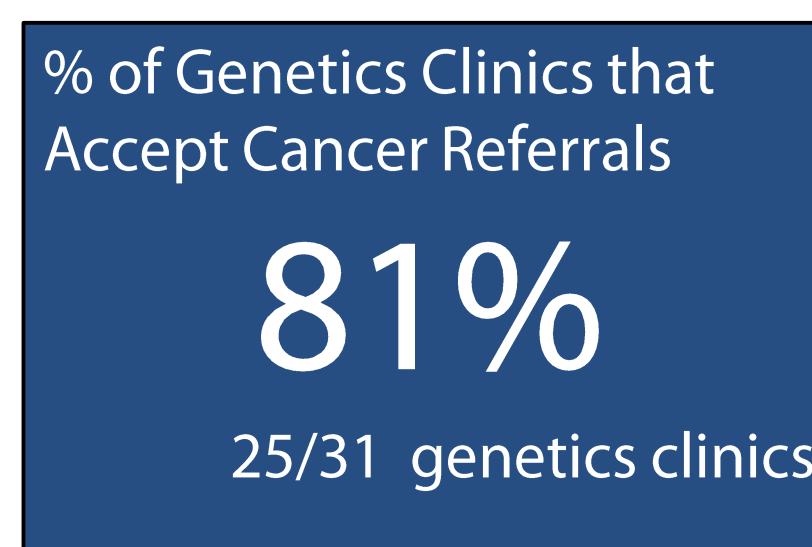
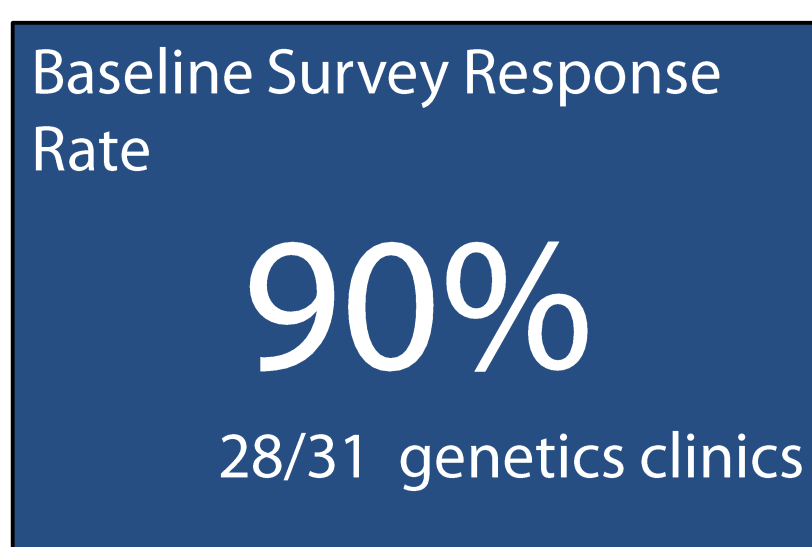
- Lack of a provincial system
- Increasing demand for genetic counselling and genetic testing
- Variation in care delivery and wait times across the province

Methods

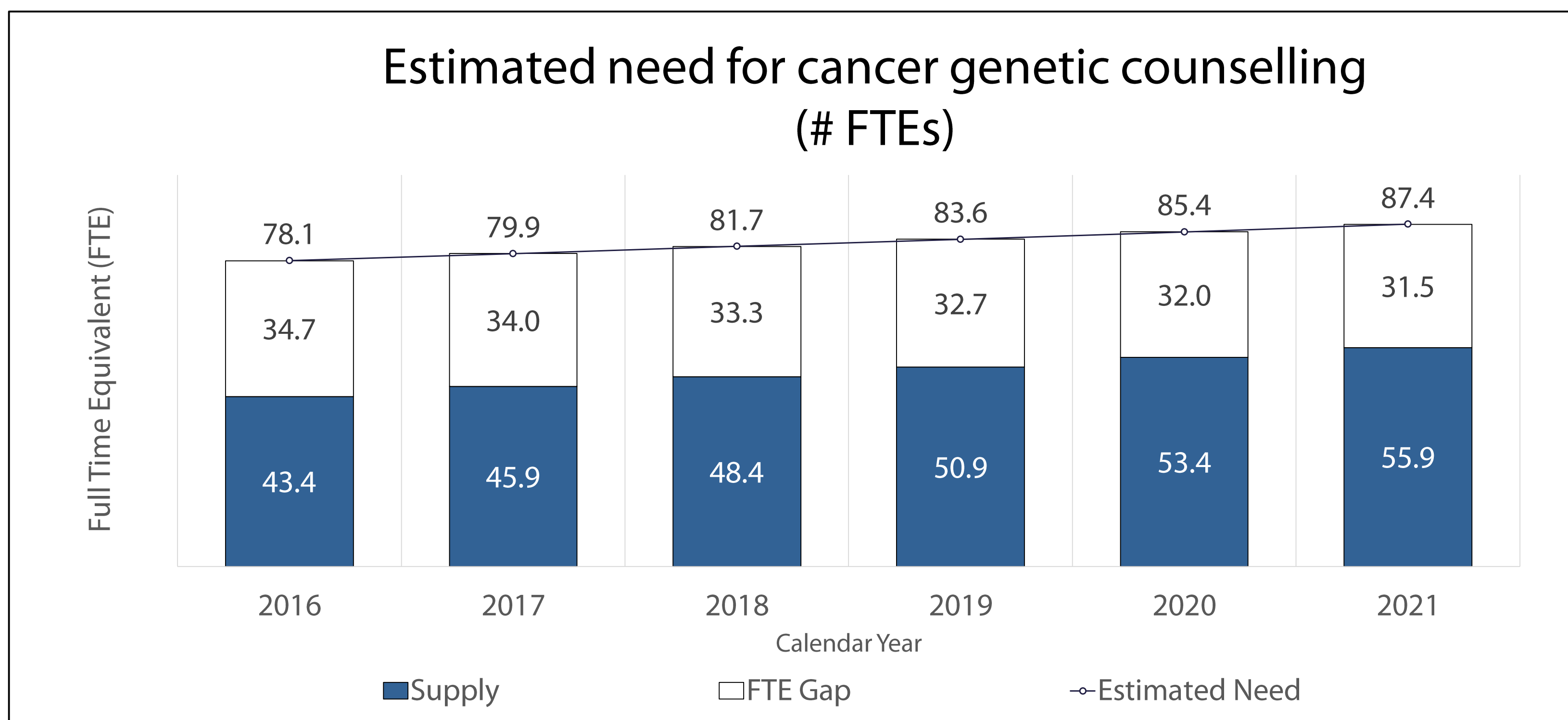
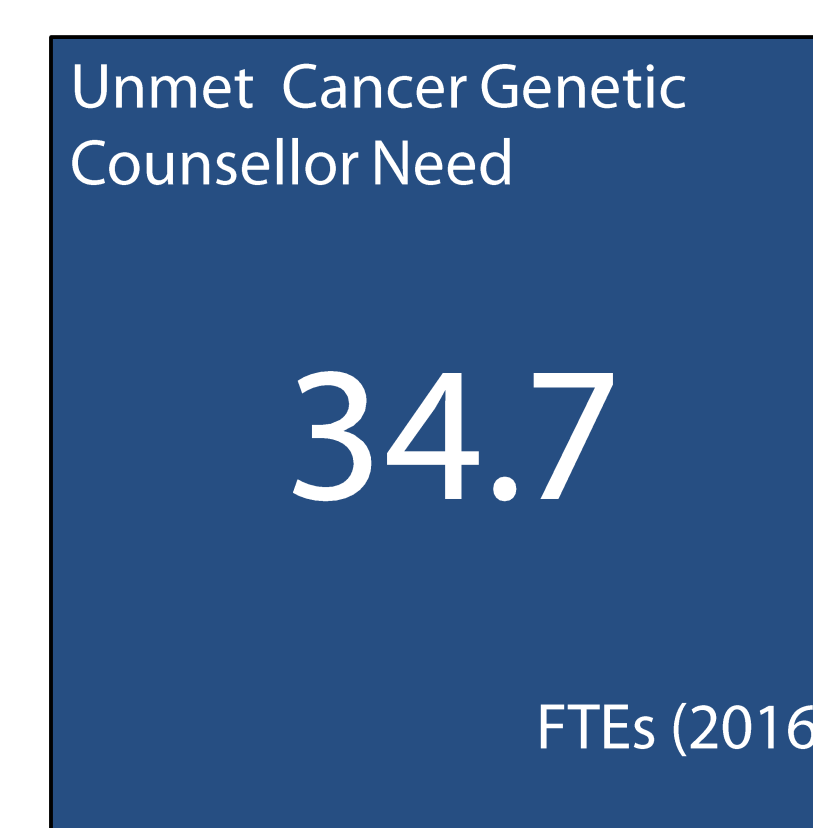
- Prioritized through CCO's Personalized Medicine Steering Committee
- Multidisciplinary Working Group convened to lead work
- Contacted all Genetics Clinics in Ontario
- Collaborative approach that engaged genetics clinics and those that interact with their services including: genetic counsellors, medical geneticists, primary care providers, oncologists, molecular geneticists and lab representatives, researchers, screening programs, and patients



Results



	2007	2016		
Cancer genetics referral volumes:	6,378	18,084	↑	+11,706
Cancer genetic counsellor FTE count:	34.5	43.4	↑	+8.9 FTE
Medical geneticist FTE count (cancer):	5.5	3.9	↓	-1.6 FTE
Oncologist FTE count (genetics clinic):	3.9	2.5	↓	-1.4 FTE



Wait times in calendar days from referral to first appointment (self-reported data)

Referral Type	Average*	Average (by clinic)		Range	
		High	Low	High	Low
Routine/Non-urgent cases					
Cancer	183	590	30	730	30
OBSP Eligible	122	590	30	730	30
Non-Cancer prenatal Referrals (excluding prenatal)	232	510	45	700	40
Urgent cases					
Cancer	24	91	5	90	0
OBSP Eligible	16	48.5	5	90	0
Non-Cancer prenatal Referrals (excluding prenatal)	22	75	3	90	1
Prenatal Only (all cases urgent)	7	7	7	14	1

Summary of Recommendations

1. Establish provincial governance and oversight

- Develop and oversee strategic planning and funding
- Develop standards and guidelines to ensure quality
- Educate providers and patients
- Reduce practice variation, increase capacity and timely access to services.

2. Improve patient access to genetic services through strategic planning

- Conduct comprehensive strategic planning to assess/address capacity and service gaps in clinical and laboratory cancer genetic services
- Develop policies to close those gaps to improve patient access to services

3. Standardize practice to reduce variation and ensure high quality services for patients across the province

- Develop and implement evidence based tools, advice, and clear guidelines (for referral, testing, and care) to standardize practice while ensuring equitable and timely access to genetic services for patients across the province

Conclusion

This work illustrates the increased demand for genetic services, the magnitude of the unmet need for genetic counselling, and the variation in practice that exists throughout the province. The recommendations propose a multifaceted approach for improved patient access to services; built on guidelines and practice standards, and monitored through performance measurement.

Ontario has a dedicated and engaged genetics community, including several national and international leaders in the area of cancer genetics. With the implementation of these recommendations, Ontario has the potential to position itself as a world leader in the field of Hereditary Cancer Genetics.

Acknowledgements

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