

Health System Use Working Group Report

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EXECUTIVE SUMMARY

This report describes the work of the Health System Use Working Group (HSUWG); sponsored by the Ontario Health Data Council (OHDC) to identify the data uses and purposes that will help enable the transformation of Ontario's future health data ecosystem. It describes the current health data ecosystem challenges through the perspectives of different health system stakeholders (patients and their families, caregivers, providers, health system leaders, government decision-makers, etc.), the key drivers of the health system transformation, and proposed key recommendations for achieving the desired future state. A real-life clinical scenario articulates the needs, challenges, and data requirements at all levels of the health system and captures the Ontario health system transformations expected to be achieved through the application of the recommendations. A set of implementation considerations aligned with each recommendation are provided to outline actionable steps which may be taken as a product of this work.

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INTRODUCTION

Ontario Health Data Council (OHDC) Overview

The Ministry of Health (MOH) is committed to transforming Ontario's health system into one that is world-leading, consumer-driven, data informed and digitally integrated. In March 2021, the MOH struck an advisory body called the Ontario Health Data Council (OHDC). Part of OHDC's mandate is to advise on a data management strategy that fosters a Rapid Learning Health System (RLHS) within a person-centered integrated population-based management approach. The OHDC advises on the management of Ontarians' health data to generate analytics, insights, and innovations desired by patients and their families, health care providers, health system delivery organizations, and government decision-makers.

Health System Use Working Group (HSUWG) Overview and Timelines

The Health System Use Working Group (HSUWG) was established to outline the future health system vision and identify the requirements Ontario's future health data ecosystem. This is driven by how health data can or should be used to drive improved experiences and performance across the health system. The HSUWG consists of 11 members, including OHDC members, and other invited health system subject matter experts (see Appendix A for full membership list). The work of the HSUWG is chaired by Dr. Robert Reid and supported by the Secretariat from the MOH. The mandate of the HSUWG is to develop a future facing data and digital strategic framework that enables a person-centered rapid learning health system for the entire population of Ontario.

The HSUWG inaugural meeting was on September 2, 2021, and to date there have been a total of 12 weekly sessions. Findings from the meeting discussions as well as insights and perspectives of HSUWG members are represented in this report.

Key Concepts: Challenges, Three Drivers and Recommendations

There are several data-related barriers that exist in Ontario's health system today. Through public policy consultations with patients and caregivers (typically family members), and health system stakeholders, the MOH has identified current and future health system data challenges faced in the delivery and receipt of healthcare in Ontario. "Health system data" are defined as data originating from clinical care organizations, public health units, and community agencies. These discussions have conveyed a highly disconnected, poorly integrated, and siloed health data ecosystem that hinders patients/caregivers, healthcare providers and regional/provincial planners from accessing and using data efficiently for care or health system management purposes. In addition, the COVID-19 pandemic also highlighted the negative consequences of having barriers to data access and lack of interoperability in our existing health data ecosystem. The current challenges significantly affected our COVID-19 response and prompted officials to transform this system.

The HSUWG identified three relevant, and desirable drivers for the future of health care in the province: Population Health Management (PHM), Integrated and Accountable Care (IAC) and the Rapid Learning Health System. Using these three drivers, the group developed a framework to determine the data-related requirements for a spectrum of health data uses ranging from those needed by individual Ontarians and their health care providers, through to those needed by

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provincial planners and decision makers. To address the data challenges of the health system and transform the key drivers into actionable outputs across these uses, the HSUWG consolidated their work into three key recommendations, and for each identified a variety of detailed implementation considerations. These recommendations will contribute to the work done by the three other working groups of the OHDC: Data Governance, Data Stewardship and Digital Citizen.

Key Recommendations

Based on the three major drivers identified and the comprehensive use-case analysis, the group proposes the following key recommendations to help enable Ontario's desired future health data ecosystem:

- **Recommendation #1:** Provide patients and caregivers with access to their own data from across care settings, and to contribute and manage as single integrated patient record.
- **Recommendation #2:** Implement data stewardship with duty to share across the care system to enable real-time linkage and use of integrated data for various purposes [at micro, meso and macro levels].
- **Recommendation #3:** Implement approaches and tools to support integrated population health management and a rapid learning health system with a focus on equity considerations.

PATIENT AND CAREGIVER PERSPECTIVES

The future vision of the Ministry is a data-driven, digitally enabled integrated health system which serves the needs of all individuals living in Ontario. The Dialogue on Data initiative is a phased public policy consultation sponsored by the OHDC to identify the current health data challenges of different health system users, ranging from individual patients to government decision makers, and to determine key requirements for this future health data ecosystem. Patient and caregiver consultations can render sociopolitical processes more visible, reduce bias favoring clinician priorities, acknowledge multiple perspectives and inform system transformation. Highlights of the consultation discussions informed the work of the HSUWG:

- Key challenges included disjointed health care experiences, the burden of fragmented health records and tools to access health records, risk mitigation policies that inhibit data sharing, lack of near real-time integrated information, and concerns regarding the harms that transpire to individual Ontarians because of siloed and largely inaccessible data in the health system of today.
- A key limitation of the current health data infrastructure includes the lack of integration of data from hospitals, community and social service organizations and other institutes needed to address social determinants of health and equity considerations.
- Key needs and aspirations included ability for patients, families, and caregivers to access and contribute to their integrated health records to drive empowerment and self-efficacy in decision making and management of care. As well as the ability for real-time data sharing across providers to facilitate personalized care plans and experiences and improved clinical and social outcomes.

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The rapid shift to virtually delivered services arising from the COVID-19 pandemic has highlighted the disparate nature of health journeys and the inequities experienced by individuals living in Ontario and across its geographies. Furthermore, it has laid bare the data constraints, capacity challenges, and delays that health system stakeholders, such as patients, front-line care providers, health system administrators and researchers, encounter in accessing and utilizing health information within the current data ecosystem.

The burden of multimorbidity is rapidly growing in Ontario, requiring person-centred care for physical, mental, and social conditions. As a result, there will be an increased need for built-in supports for patient, family and caregiver enablement and self-management. These forces combined speak to the urgent need for action to support health system transformation that is anchored in the needs and aspirations of Ontarians, and to build a data ecosystem that enables the future vision of person-centered, integrated population-based care with shared accountabilities across sectors, driven by a Rapid Learning Health System.

DRIVERS OF THE HEALTHCARE SYSTEM

Population Health Management (PHM)

PHM focuses on proactively delivering high-quality person-centered care tailored to a group of individuals with unique and shared needs. It requires identifying defined population segments and their key health and social needs to provide the appropriate corresponding services and consistently positive care experiences. Population segmentation and patient engagement is key to a PHM approach as it improves clinical health outcomes for a particular group of people. Health and sociodemographic data are needed to identify population segments used to tailor care that meets each segment's unique health and social needs and to design outreach services for each group and community. PHM is a data-driven function that enumerates all people in a defined population, dynamically identifies their unique health and social needs, and monitors how these needs are met and evolve over time.

Equity

Meaningful population segments should have clinical face validity and apply an equity lens to ensure the needs of underserved populations are met and existing health disparities are addressed. Detailed data are required for diverse communities and population segments to identify gaps that exist and monitors how they are managed population-based health and wellness data and insights from across all lived experiences and settings can be leveraged to address gaps and ensure equitable access, treatment, and outcomes for all Ontarians. Data should be collected in culturally safe and appropriate ways, with careful governance to ensure that it is not interpreted or used to harm or discriminate against communities or groups. To promote equity in the health system, it's essential to routinely collect Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs). PROMs assess the lived experiences of patient/caregivers by capturing their perspectives on their health status, goal attainment, quality of life and social inclusion. PREMs assess their experiences of using health services, including communication, responsiveness, and recovery orientation.

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Indigenous Data Collection

More accurate and complete First Nations, Inuit and Métis health data can help to support understanding of Indigenous health and care needs and address existing health inequalities. Due to the unique data governance needs of First Nations, Inuit and Métis data, the data requirements and systems will be separately proposed with leadership from First Nations, Inuit and Métis communities, in accordance with their data strategies and their rights as declared in United Nations Declaration on the Rights of Indigenous Peoples. Please refer to the Digital Citizen Working Group Report for further details.

Integrated and Accountable Care (IAC)

IAC systems are created when providers across different care settings come together to deliver coordinated value-based, high-quality person-centered care to a defined population. Care organizations also agree to be held jointly accountable for quadruple aim outcomes, population health, patient experience, provider experience, for an efficient per-capita cost. The IAC approach is grounded by the Quadruple Aim principles and is currently being applied by Ontario Health Teams across Ontario. Data can be used to integrate care planning and facilitate the delivery of timely and efficient care across these teams. Increasing information sharing among care teams will enable providers to collect data once and use it for multiple purposes, reducing administrative burden while improving the experiences of each person's care journey.

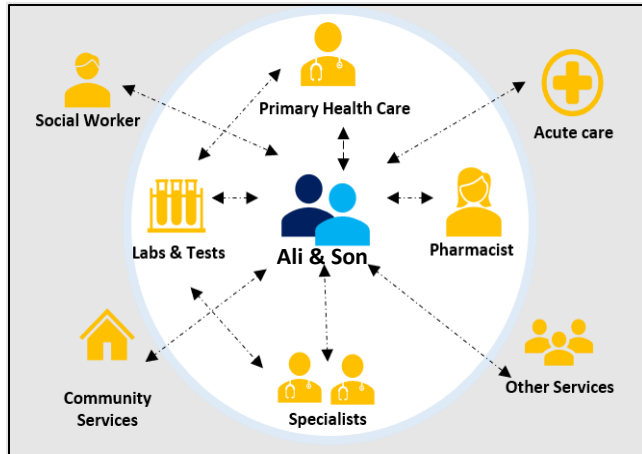
Rapid Learning Health System (RLHS)

A RLHS combines health and research systems to support rapid learning and continuous improvement at all levels including self-management, clinical encounter, program organization and data governance. This system is anchored on patient and caregiver needs, perspectives, and aspirations, is driven by timely data and evidence, and supported by a culture of learning and improvement. RLHSs can be applied at a micro (patients/providers), meso (integrated care services) and macro (provincial planners) level. For instance, the system should facilitate policy, planning and regulations at the macro level, support local and regional operations at the meso level and promote health and wellness delivery at the micro level. The data system should drive the use of real-time data and intelligent data for various purposes including, but not limited to; patient care delivery, informed decision making, precision medicine, health system planning and financing, system transparency and accountability, quality improvement, research and innovation, analytics and performance evaluation purposes. In other words, an ideal RLHS should have the potential to adapt, innovate and improve services through continual harnessing of data and analyses informing continuous discussion among key stakeholders.

ENABLING THE FUTURE HEALTH DATA ECOSYSTEM IN A REAL-LIFE CLINICAL SETTING

The HSUWG created a clinical case example of a typical patient with complex health needs to ground the discussion. Archetypes at micro, meso, macro, and continual learning and evidence generation levels were created to identify data use barriers and implementation considerations of required changes at each level. (Please see Appendix B for more information on purposes, barriers and changes needed at each archetype level).

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- **Ali**, 80-year-old male, lives alone in rural Ontario, heavy drinker
- Has recurrent depression and Type 2 diabetes
- Only son is primary caregiver
- Irregular contact with primary healthcare provider
- Frequent ER and hospital admissions
- Interacts with multiple care providers
- Receives community services 2-3 days /week
- Prescribed multiple medications

Micro Level – Patients and Caregivers

The purpose of health data use at the micro level for patients and caregivers includes informing patient-provider goal setting and care planning and supporting patient self-management. Patients and caregivers must have access to the patient's own complete medical records, track referrals, and be able to contribute to their medical information. A major barrier of effective data use at this level is the absence of an integrated patient record in Ontario, where patients and caregivers can access comprehensive health information that is shared across multiple agencies (hospitals, primary care, home and community care and long-term care).

Micro Level – Clinicians and Care Managers

The HSUWG established that clinicians and care managers use health data to inform care decisions and coordinate services for patients. At the individual level, this data needs to be available in real time and processed in a usable manner so that clinical decisions and care delivery can be personalized each person's unique characteristics. This includes automated data and prompts that are derived from validated prognostic tools. Clinicians and care managers also need the ability to proactively reach out to patients and communities to enable clinical population health management for patients with similar needs. Data barriers that may be encountered by clinicians and care managers include lack of clear population segmentation definitions and interoperability across data systems for other users accessing and sharing health records. There is also confusion and fear among clinicians related to existing privacy frameworks around privacy and consent for the use and sharing of data for clinical, administrative and outreach purposes.

Meso Level – Integrated Care Service and Regional Planners

The purpose of data use at the meso level is to facilitate population level needs and segmentation and support integrated and equitable service planning and delivery. Data uses include quality improvement, adapting and evolving models of care and adjusting funding and resource allocation. Barriers for integration of care services and regional planning include missing data from community, social, and other institutional sectors, as well as lack of real-time linkage and longitudinal integration of data across services. Data for performance monitoring and management is also needed at the meso level.

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Macro Level – Ontario Health (OH)/MOH Planners and Analysts

The HSUWG determined that health data at the macro level facilitates provincial service planning, program designing and delivery, funding allocation, and setting quality standards and expectations for integrated care delivery. Ontario Health and MOH system planners and analysts need data at this level for public and clinician level reporting (performance management, regulatory, accountability and financial) and for health human resource and capital planning. Data barriers at the provincial level include lack of clearly defined data interoperability standards and a common data infrastructure, poor linkage across multiple data repositories, and ongoing data governance and privacy issues.

Continual Learning and Evidence Generation

Health system learning and evidence generation requires information to flow across all levels of the health system (micro, macro and meso) and allows for the identification of population trends, gaps in quality of care being delivered and overall performance (statistical analysis, mathematically modelling). Research and analysis can also support rapid cycle evaluation with comparator groups, report generation and monitoring outcomes to inform future changes to care delivery and planning. Data barriers related to continuing learning and evidence generation include capacity issues related to analytics support, and data literacy and uptake among clinicians, decision makers, planners, and knowledge users. Lack of key data sources, such as PREMs and PROMs and lack of linkage to sociodemographic and social service data in Ontario's existing health data system are also barriers to continual learning and evidence generation.

JURISDICTIONAL SCAN

The HSUWG secretariat also conducted a jurisdictional scan (including a literature review and interviews with relevant individuals) on successful data systems in other jurisdictions. The purpose was to learn more about the data governance structure, strategies, data models and challenges of other systems and how those lessons can potentially be leveraged to develop Ontario's data system (Please see Appendix C for further information).

KEY RECOMMENDATIONS AND IMPLEMENTATION CONSIDERATIONS

The use case analysis focusing on health data uses within and across the different levels of the health system signifies the importance of implementing the recommendations made by HSUWG. The following section elaborates on different policy/governance, technical, and operational implementation considerations required for the recommendations.

Recommendation #1: Provide patients and caregivers with access to their data from across care settings, and to contribute and manage as single integrated patient record.

Essential elements:

- Establish policies and technologies to enable patients and caregivers to read, review, contribute, and manage their health information as a complete integrated and interoperable patient record (including PREMs and PROMs data).
- Establish and implement data standards to enable purpose and use-driven collection of core data elements across the care settings in a consistent way.

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- Standardize and incentivize collection and use of PREMs and PROMs across all care settings and integrate with clinical data for purposes and use at micro, meso and macro levels; minimize patient/caregiver collection burden and address language barriers.

<i>Policy, Standards, Legislation</i>	<i>Technology</i>	<i>Operational (including cultural and organizational)</i>
<ul style="list-style-type: none"> Implement policy and related legislation to enable patient and caregiver access to integrated care records, starting with existing provincial assets. Implement minimum provincial patient record standard (e.g., International Patient Summary). Establish provincial standards for PREMs and PROMs for all care settings. 	<ul style="list-style-type: none"> Leverage and build on existing assets (e.g., electronic health records) to provide an integrated patient record with an integrated view (e.g., single portal). Implement a provincial approach to digital identity (inclusive of patients and caregivers) for accessing integrated patient records. Implement user friendly technologies to ease the collection and quality of data directly from patients and caregivers. attention to enabling use by vulnerable groups. 	<ul style="list-style-type: none"> Establish governance (regional/local leadership and champions) to implement a minimal provincial patient record standard including collection of PREMs/PROMs. Establish and execute infrastructures and user-friendly processes to facilitate patients entering data, with attention to equity-deserving groups. Establish support for patients and caregivers in use, contribution, and management of their records.

Recommendation #2: Implement data stewardship with duty to share across the care system to enable real-time linkage and use of integrated data for various purposes [at micro, meso and macro levels].

Essential elements:

- Enable any data policy and legislation to implement duty to sharing of data within and across care settings and its linkage with provincial datasets.
- Remove data silos by modernizing the current infrastructure to create a common data infrastructures and health information exchange to enable collection once and use of integrated data for multiple micro, meso and macro purposes.
- Develop and implement provincial role-based access controls for micro, meso and macro uses [to remove use-based data silos].
- Establish approaches for ethical governance of data interpretation and use, with attention to underrepresented and equity-deserving groups.

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<i>Policy, Standards, Legislation</i>	<i>Technology</i>	<i>Operational (including cultural and organizational)</i>
<ul style="list-style-type: none"> ○ Launch a review of policy and related legislation to standardize data collection and streamline the requirement to share data including enabling collect once (from multiple care settings) and use integrated data at all care settings. ○ Establish provisions for managing/controlling larger volumes of health data. 	<ul style="list-style-type: none"> ○ Implement a health information exchange: leverage existing data infrastructure to enable integrated standardized data (with centralized and federated data processing) for varied purposes outlined. ○ Use automation technologies for real-time processing and cleaning. ○ Implement access controls for various uses, and ensure data are protected and safeguarded. 	<ul style="list-style-type: none"> ○ Remove barriers to data sharing including clarifying the scope of data sharing agreements requirements (e.g., providing guidelines, educational to sector). ○ Build capacity in the system for purpose driven capture and use of data. ○ Train and monitor data users on the appropriate access, interpretation and use of data.

Recommendation #3: Implement approaches and tools to support integrated population health management and a rapid learning health system including equity considerations.

Essential elements:

- Expand definition of health care data to include community and social care including social determinants of health, patient-generated data, patient/provider experience and outcome measures.
- Create standardized, integrated population segmentation and analytical tool(s) with real-time linkage (health, social and administrative) of data across various care settings.
- Enable purpose driven access to integrated population segmentation data (including individual patient level where appropriate) for clinical, operations, management, and planning.
- Anchor the data system on patient and caregiver needs, perspectives, and goals, driven by timely data and evidence and supported by a culture of learning and improvement.

<i>Policy, Standards, Legislation</i>	<i>Technology</i>	<i>Operational (including cultural and organizational)</i>
<ul style="list-style-type: none"> ○ Establish policy and incentives for sociodemographic data collection and use. ○ Expand the current policy and related legislation to 	<ul style="list-style-type: none"> ○ Review existing provincial data and analytic tools (across Ontario Health, Ministry of Health, others) and expand to implement population 	<ul style="list-style-type: none"> ○ Support the system in the use of integrated population data to develop and deliver evidence-based integrated care pathways

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<p>enable integrated population segmentation data to be made available at individual care setting.</p> <ul style="list-style-type: none"> ○ Establish a standard for integrated population segmentation data. 	<p>segmentation data tool(s).</p>	<p>and monitor through performance, quality, and value measures.</p>
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SUMMARY: IMPROVEMENTS ACROSS DATA USE LEVELS

The key recommendations proposed by HSUWG will enable the transformation of Ontario’s health system by creating a common data infrastructure that integrates health-related data across all data use levels. This transformed health data ecosystem will better equip patients and caregivers, and enable providers, regional/system planners, and other relevant stakeholders to access the health data and tools needed to deliver timely, effective, comprehensive, and equitable care. If the suggested recommendations can be implemented, Ontarians could see and benefit from improvements across all data use levels, including patient-level experiences to system-level enhancements. The recommended approach also aims to remove health related disparities and ensure all Ontarians receive timely, evidence-driven care, in the appropriate setting. In the case of Ali, improvements across all data use levels would continually drive positive changes in his care experiences and health outcomes, thus improving his individual patient journey.

Improvements for Ali Across Each Data Use Level:

- **Micro Level:** Ali’s health and experience improve, and he is better able to self-manage his care from the comfort of his home. Ali and others like him have better experiences and more productive interactions with their providers. As well, there are benefits for the clinician at the micro level, including more efficient care and improved provider experiences.
- **Meso Level:** Ali's data is added to appropriate population segments to identify priority groups and perform population-level needs analysis. People like Ali across his community receive more equitable care that is aligned to resident population goals.
- **Macro Level:** PREM and PROM data from populations where Ali resides can be used to inform and adjust provincial health policies and services. Integrated data system across micro, meso and macro levels improves Quadruple Aim outcomes across Ontario.
- **Continual Learning and Evidence Generation:** Comprehensive data collection will determine user priorities for care model development and advance disease treatments that will ultimately improve delivery practices for patients like Ali. Useful evidence is generated to implement and evaluate new programs and support continuous quality improvement.

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APPENDIX A: Working Group Membership

Each HSUWG member brings their unique knowledge, expertise, and perspectives to make recommendations for the future health data ecosystem. The members do not represent the interests of the organization or constituencies they are affiliated with.

- **Dr. Robert Reid** (facilitator), Hazel McCallion Research Chair in Learning Health Systems, Chief Scientist at the Institute for Better Health (IBH) and Senior Vice President of Science, Trillium Health Partners
- **Ms. Ashnoor Rahim**, Vice President, Community Care Unit, WoodGreen Community Services
- **Dr. Peter Tanuseputro**, Scientist, Ottawa Hospital Research Institute and Bruyere Research Institute; Assistant Professor, Division of Palliative Care, University of Ottawa
- **Dr. Kevin Smith**, President and CEO, University Health Network
- **Dr. Paul Kurdyak**, Director, Health Outcomes and Performance Evaluation, Institute for Mental Health Policy Research, Senior Advisor, Centre for Addiction and Mental Health (CAMH) and Vice President, Mental Health & Addictions-Clinical, Ontario Health
- **Dr. Sacha Bhatia**, Executive Lead, Population Health and Value Based Health Systems, Ontario Health
- **Mr. Dov Klein**, Vice President, Population Health and Value Based Health Systems, Ontario Health*
- **Dr. Jennifer Rayner**, Director, Research & Evaluation, Alliance for Healthier Communities
- **Ms. Colleen Neil**, Executive Lead, All Nations Health Partners Ontario Health Team; Executive Director, Sunset Country Family Health Team
- **Dr. Linda Rabeneck**, Vice-President, Prevention & Cancer Control, Cancer Care Ontario, Ontario Health; Professor, University of Toronto, faculty of Medicine and the Dalla Lana School of Public Health
- **Dr. Gail Dobell**, Director, Evaluation, Health Quality Ontario, Ontario Health
- **Dr. Walter Wodchis**, Professor, Institute of Health Policy, Management and Evaluation, University of Toronto; Research Chair, Implementation and Evaluation, Institute for Better Health

**Attended as a delegate for Dr Sacha Bhatia*

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APPENDIX B: Data Use Levels

Micro Level: Patients and Caregivers

DATA PURPOSE / USE	DATA BARRIERS	CHANGES NEEDED
<ul style="list-style-type: none"> <input type="checkbox"/> Promote patient/caregiver activation <input type="checkbox"/> Patient/provider goal setting and care planning <input type="checkbox"/> Patient/caregiver self-management support <input type="checkbox"/> Care providers have updated information across care delivery sectors <input type="checkbox"/> Track referrals <input type="checkbox"/> Access and contribute to accurate and comprehensive information on medical record 	<ul style="list-style-type: none"> <input type="checkbox"/> No unified patient record - patients can't access comprehensive information shared across multiple agencies/practices <input type="checkbox"/> No standardized approach to sharing care plans or patient goals <input type="checkbox"/> Patients not able to: <ul style="list-style-type: none"> <input type="checkbox"/> Track referrals across sectors <input type="checkbox"/> Contribute to own health records (incl. updating outdated/inaccurate information) <input type="checkbox"/> Not able to track patient self-management systematically <input type="checkbox"/> Data not linked to self-management supports 	<p><u>Policy and legislative changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Continuous data linkage and sharing across care entities, including patient level clinical data <input type="checkbox"/> Patients and caregivers able to meaningfully contribute to their own data <p><u>Technical changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Creation of Common Data Infrastructures such as a Health Information Exchange <input type="checkbox"/> Adoption of technologies to allow patients/caregivers to read, review, and contribute to their health information <input type="checkbox"/> Patients have easy direct access to personal info and health records across system <p><u>Operational changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Value collection and integration of clinical and patient reported data to be used for multiple purposes <input type="checkbox"/> Patient-generated data (e.g., flash-glucose monitor data), leveraged by care team to gain greater insight into disease management; integrated into existing EMR solutions

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Micro Level: Clinicians and Care Managers

DATA PURPOSE / USE	DATA BARRIERS	CHANGES NEEDED
<ul style="list-style-type: none"> <input type="checkbox"/> Inform care decisions and coordinate care <input type="checkbox"/> Tailor services to unique patient and caregiver needs <input type="checkbox"/> Patient self-management <input type="checkbox"/> Proactive outreach to facilitate population health management <input type="checkbox"/> Patient safety and quality improvement <input type="checkbox"/> Care planning, tracking and goal setting 	<ul style="list-style-type: none"> <input type="checkbox"/> No unified or interoperable record that that can be shared <input type="checkbox"/> Lack of clear population definitions <input type="checkbox"/> Not collecting and integrating key patient indicators (demographics, outcomes and experiences, social services) <input type="checkbox"/> Confusion and fear among clinicians related to privacy framework, consent and sharing data for outreach <input type="checkbox"/> Data often de-identified with inability to support patient-level care decisions <input type="checkbox"/> Routine reporting tools not available or used and many different reporting tools are used by different agencies 	<p><u>Policy and legislative changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Prioritize policy work to enable ‘duty to share’ of data assets and access for all purposes including population health (e.g., hospital reports, diagnostic imagine repositories, home care data) across care setting without need for agreements <input type="checkbox"/> Create data standards for the collection of core data elements (e.g., demographics, experiences, outcomes) across care settings <p><u>Technical changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Interoperable data infrastructure based on international standards <input type="checkbox"/> Data linkage across sectors and sharing of ‘local’ data in real time (i.e., push data directly from EMRs without admin time culminating reports) <p><u>Operational changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Value collection and integration of clinical and patient reported data to be used for multiple purposes across care settings <input type="checkbox"/> Systematic data collection with data from all interactions are meaningful to patient/caregiver <input type="checkbox"/> Create data sharing standards among institutions to facilitate near real-time exchange

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Meso Level: Integrated Care Service and Regional Planners

DATA PURPOSE / USE	DATA BARRIERS	CHANGES NEEDED
<ul style="list-style-type: none"> <input type="checkbox"/> Population level needs and service analysis <input type="checkbox"/> Population segmentation <input type="checkbox"/> Equity and integration of social services <input type="checkbox"/> Integrated service planning and delivery <input type="checkbox"/> Quality improvement and evolving models of care <input type="checkbox"/> Care team performance management and assessment <input type="checkbox"/> Funding and resource allocation 	<ul style="list-style-type: none"> <input type="checkbox"/> Data stewardship and standards for data sharing are unclear/inconsistent <input type="checkbox"/> Patient level social determinants of health data not available to identify disparities between groups <input type="checkbox"/> Missing data from community and social sectors <input type="checkbox"/> Lack of consistent data standards for collection and use <input type="checkbox"/> Lack of real-time linkage and longitudinal integration <input type="checkbox"/> Multiple data repositories with no single source of data <input type="checkbox"/> Missing common infrastructure and interoperability 	<p><u>Policy and legislative changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Modernize data sharing and privacy frameworks to eliminate barriers to integrated care and population health management <input type="checkbox"/> Allow purpose driven access to integrated data resources from across care setting for clinical, operations, management, and policy purposes <p><u>Technical changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Creation of population rosters and adoption of standardized segmentation tools to promote population health management across care settings <p><u>Operational changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Integrated data validity and quality through common data rules and definitions across providers <input type="checkbox"/> Access to process and outcome data across care settings to implement and monitor relevant & actionable indicators (quadruple aim) <input type="checkbox"/> Building capacity of suitable data analysts to create and update queries

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Macro Level: OH/MOH Planners and Analysts

DATA PURPOSE / USE	DATA BARRIERS	CHANGES NEEDED
<ul style="list-style-type: none"> <input type="checkbox"/> Provincial planning and program design <input type="checkbox"/> Funding and resource allocation <input type="checkbox"/> Setting quality standards and expectations for integrated care delivery <input type="checkbox"/> Develop indicators, monitor performance and reporting <input type="checkbox"/> Improve data sharing abilities between providers <input type="checkbox"/> Public and clinician level reporting (legislative/regulatory reporting, accountability, financial reporting) <input type="checkbox"/> Health human resource and capital planning 	<ul style="list-style-type: none"> <input type="checkbox"/> Data governance and privacy issues (real and perceived) <input type="checkbox"/> Multiple data repositories with no 'single source of truth' <input type="checkbox"/> Critical primary care data not linked with other health care data <input type="checkbox"/> Lack of linkage to social service providers <input type="checkbox"/> Barriers to being able to link all these data to create a unified interoperable record for a person/citizen <input type="checkbox"/> Data needed to measure performance against standards may not be available/collected <input type="checkbox"/> Lack of consistent data standards around the collection of data across care settings 	<p><u>Policy and legislative changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Create standards and incentives for the collection and use of demographic data, standardized patient-reported outcomes, and experiences measures. <input type="checkbox"/> Expand definition of health data to include data relevant to the determinants of health (e.g., data from community and social sectors) <p><u>Technical changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Matrixed, easy-to-navigate data repository/exchange that enable micro, meso, and macro data uses <input type="checkbox"/> Promote automation as much as possible with the principle of collect once and use for multiple purposes. <p><u>Operational changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Develop data access controls, permission schema and data flow design that is purpose /use driven <input type="checkbox"/> Development of common data rules and definitions across providers and care settings

HEALTH SYSTEM USE WORKING GROUP SUMMARY REPORT

Continual Learning and Evidence Generation

DATA PURPOSE / USE	DATA BARRIERS	CHANGES NEEDED
<ul style="list-style-type: none"> <input type="checkbox"/> Analyse population data to examine patterns/trends & determine gaps in quality (statistical analysis, mathematical modelling, etc.) <input type="checkbox"/> Merging qualitative data that incorporates patients and provider perspectives <input type="checkbox"/> User priorities for care model development <input type="checkbox"/> Rapid cycle evaluation with comparator groups / counter-factuals <input type="checkbox"/> Report generation including data visualization for evidence-based decision making <input type="checkbox"/> Monitoring outcomes for future needed changes 	<ul style="list-style-type: none"> <input type="checkbox"/> Multiple data lakes with no singular source of data <input type="checkbox"/> Inconsistent and/or inaccurate data over time <input type="checkbox"/> Capacity issues re: analytics support, and data uptake among planners, decision makers, KUs and clinicians <input type="checkbox"/> Limited PREMs and PROMs data <input type="checkbox"/> Lacking information about model implementation and fidelity <input type="checkbox"/> Lack of consistent standards for data collection and use <input type="checkbox"/> Lack of linkage to SES and social service data 	<p><u>Policy and legislative changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Remove barriers to enable continuous data linkage and sharing across care entities, including clinical data <input type="checkbox"/> Capture PREMs and PROMs data in a consistent and sharable format <p><u>Technical changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Data available in a timely manner for different purposes across all uses <input type="checkbox"/> Enabled real-time data analysis and visualization <input type="checkbox"/> Ease of simple queries to identify patients according to sociodemographic, clinical and provider data <p><u>Operational changes:</u></p> <ul style="list-style-type: none"> <input type="checkbox"/> Culture of generating evidence when rolling out interventions <input type="checkbox"/> Stronger connection between researchers and knowledge users (including MOH)

HEALTH SYSTEM USE WORKING GROUP SUMMARY REPORT

APPENDIX C: Jurisdictional Scan Summary

	NCCARE360 (NORTH CAROLINA)	IHEI (INDIANA)	KAISER PERMENANTE (USA)	ESTONIA	NUKA SYSTEM OF CARE (ALASKA)
Year of establishment	2019	2004	2005	2008	1998
Serving population	10 million	18 million	12.2 million	1.3 million	65,000
Geographic Scope	Activated in 100 counties, 2200+ organizations onboarded, network system, multiple EMRs	123 hospitals connections, 18,738 provider practices are on board	One unified organization, single EHR	Nation-wide (99% of Estonian patients have countrywide digital record)	TBD
Data Model	Data network that unites healthcare and human services organizations. Presents Unified approach to delivering whole health care and connecting patients with social services	Inter-organizational clinical data repository. Provide data and tools to improve payment reform as well as patient, population, and government care	Comprehensive, integrated EHR platform that provides unified data. Provide affordable, quality health care services to improve patient and community health	Centralized, National database. Gathers data from all providers (using different systems) and presents in a standard format. Provides data to providers at the point of care. Generates statistics for the government	Centralized data model which allows linkages between multiple operating systems and a web-based reporting tool that displays up-to-date data to physicians and care teams. Population-focused and person-centric data.
Healthcare Model Type	Public-private partnership	Private ACO	Unified integrated delivery system	Universal Run by an NGO for the Estonian government	TBD