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Data-Driven Decision Support Tool Co-Development with a Primary Health Care Practice Based Learning Network

Jacqueline K. Kueper
Western University, jkueper@uwo.ca

Jennifer Rayner
Alliance for Healthier Communities, jennifer.rayner@allianceon.org

Sara Bhatti
Alliance for Healthier Communities, sara.bhatti@allianceon.org

Kelly Angevaare
Compass Community Health, kangevaare@compassch.org

Sandra Fitzpatrick
South Riverdale Community Health Centre, sfitzpatrick@srchc.com

See next page for additional authors

Authors

Jacqueline K. Kueper, Jennifer Rayner, Sara Bhatti, Kelly Angevaare, Sandra Fitzpatrick, Paulino Lucamba, Eric Sutherland, and Daniel J. Lizotte

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Jacqueline K Kueper*
Department of Computer Science, Faculty of Science, Western University, London, Ontario, Canada
Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, Western University, London, Ontario, Canada

Jennifer Rayner
Department of Research and Evaluation, Alliance for Healthier Communities, Toronto, Ontario, Canada
Centre for Studies in Family Medicine, Department of Family Medicine, Schulich School of Medicine and Dentistry, Western University, London, Ontario, Canada

Sara Bhatti
Department of Research and Evaluation, Alliance for Healthier Communities, Toronto, Ontario, Canada

Kelly Angevaare
Health Information Systems Department, Compass Community Health, Hamilton, Ontario, Canada

Sandra Fitzpatrick
Toronto Diabetes Care Connect
South Riverdale Community Health Centre, Toronto, Ontario, Canada

Paulino Lucamba
Chatham-Kent Community Health Centres, Chatham, Ontario, Canada

Eric Sutherland
Expert in Digitalisation of Health Systems, Paris, France

Daniel J Lizotte
Department of Computer Science, Faculty of Science, Western University, London, Ontario, Canada
Department of Epidemiology and Biostatistics, Schulich School of Medicine and Dentistry, Western University, London, Ontario, Canada

*Corresponding author
Email: jkueper@uwo.ca

Abstract

Background: The Alliance for Healthier Communities is a learning health system that supports 72 Community Health Centres (CHCs) across Ontario, Canada to provide team-based primary health care to people who otherwise experience barriers to care. Foundations have been laid for research and innovations that harness value from CHC electronic health record (EHR) data to support quality, equitable care delivery. The objective of this report is to describe the ongoing process and lessons learned from the first Alliance for Healthier Communities' Practice Based Learning Network (PBLN) EHR data-driven decision support tool co-development project.

Methods: We are using an iterative approach to decision support tool problem identification and methods development, moving between discussion sessions and case studies with CHC EHR data. We describe this process in terms of six major stages completed so far: population-level descriptive-exploratory study, PBLN team engagement, decision support tool problem selection, sandbox case study 1: individual-level risk predictions, sandbox case study 2: population-level planning predictions, and project recap and next steps decision.

Results: The population-level study provided an initial point of engagement to consider how clients are (not) represented in EHR data and to inform problem selection and methodological decisions thereafter. Three types of decision support, with initial application areas, were identified as meaningful target areas: risk prediction/screening, triaging specialized program entry, and identifying care access needs. Based on feasibility and expected impact, we started with the goal to support earlier identification of mental health decline after diabetes diagnosis. As discussions deepened around clinical use cases associated with example prediction task set ups, the target problem evolved towards supporting the upstream task of organizational planning and advocacy for adequate mental health care service capacity to meet incoming needs.

Conclusions: Our co-development project contributes towards a tool to support diabetes and mental health care, as well as lays groundwork for future CHC decision support tool initiatives. We share lessons learned and reflections from our process that other primary health care organizations may use to inform their own co-development initiatives.

Data-Driven Decision Support Tool Co-Development with a Primary Health Care Practice Based Learning Network

INTRODUCTION

Background

Increasing amounts of everyday data coupled with advancements in technology and artificial intelligence (AI) are transforming healthcare.[1–5] Multiple types of expertise are needed to be able to identify meaningful challenges and develop tools that will harness value from data to help solve those challenges.[6–10] Primary health care settings have received less attention than other sectors, and there is a need for increased engagement of end-users in development of AI-enabled decision support tools.[11,12] The **objective** of this report is to describe the process and lessons learned thus far in co-developing a decision support tool with and for a primary health care organization in Ontario, Canada.

Setting

The Alliance for Healthier Communities (Alliance) is a learning health system that supports team-based primary health care through 72 Community Health Centres (CHCs) across Ontario, Canada to people who otherwise experience barriers to care.[13–15] All providers record client and care information in a central, structured electronic health record (EHR) system that includes fields for sociodemographic characteristics (e.g., sex, gender, education) as well as dynamic tables to record temporal care encounter information (e.g., ENCODE-FM[16] codes to indicate diagnoses and procedures). All CHCs moved towards this common EHR with standardized data requirements in 2000, and each client's EHR has information from their entire care team.

For this project, Alliance staff partnered with academic researchers to identify and work towards opportunities to use the rich EHR data in novel ways that extend beyond care documentation to provide data-driven insights that will further support care delivery. All CHCs follow a standardized opt-out consent process for the use of de-identified data in research that reports aggregate results, which the analyses in this report fall under. The project was approved by the Western University Review Ethics Board (ID 111353).

Report Structure

We took an iterative co-development approach, moving between data analysis and group discussions to select and refine the target problem and methodology over time. Below we present our work to date in terms of six major stages, describing for each the goal(s), the activities completed to achieve the goal(s), and the tangible outputs. In the discussion section we summarize lessons learned and reflections from our overall process as well as around the specific project and data analysis tasks.

STAGES OF WORK

While the Alliance has been heavily involved in setting quality EHR standards (including the collection and use of sociodemographic and race-based data) and in research studies, and while AI-enabled decision support tools have been developed by other organizations, this was the first EHR data-driven decision support tool co-development project at the Alliance. As a precursor to being able to brainstorm meaningful clinical challenges amenable to support with EHR-based data analysis tools, a strategy was needed to introduce these types of secondary uses of EHR data and to support better understanding of how client characteristics and care patterns are represented in EHR data.

Stage 1: Population-Level Descriptive-Exploratory Study

Goals

1. To summarize sociodemographic, clinical, and health care use characteristics of ongoing primary care clients served through CHCs across Ontario from 2009 through 2019.
2. To serve as a foundation for community engagement and to inform decision support tool problem selection and methodological decisions.

Activities

Conduct study: This was a stand-alone research study using EHR data with complete methods and results published elsewhere.[17] Briefly, the base cohort included adult clients who indicated a CHC as their primary care provider ("ongoing primary care clients") and had at least one encounter in 2009-2019. We applied both the methods of traditional descriptive epidemiology (e.g., period prevalence of chronic conditions) and unsupervised machine learning techniques to explore more complex patterns (e.g., non-negative matrix factorization to examine care provider teams). While a range of novel methodology was used, the principles of descriptive epidemiology were applied throughout the study.

Disseminate findings: In addition to the research publication, findings were shared with the Alliance community through a Lunch 'n' Learn Webinar (regularly scheduled webinars advertised broadly to the Alliance community; see Stage 2) on October 7, 2022, with the recording made available for those who could not attend live.[18]

Output

Detailed information about the population and dataset of interest, serving as a reference to inform problem selection and methodological decisions throughout later stages of the project.

Stage 2: PBLN Team Engagement

Goals

1. To engage the broader Alliance community in critical thinking and discussion around secondary uses of EHR data.
2. To invite participation in the decision support tool co-development project.

Activities

Population data assessment: The Lunch 'n' Learn included an introduction to AI and decision support tools in addition to a summary of Stage 1 study findings. Embedded throughout the latter portion were polls and discussion points asking whether findings were consistent with expectations (i.e., do the EHR-based population-level summaries of sociodemographic, clinical, and care characteristics deviate from perceptions based on the audience's care delivery related experiences). Areas of inconsistency motivate further exploration to discern if the mismatch is an artifact due to data quality issues or methodological decisions, or if the mismatch is clinically relevant. For the latter, areas of potential concern (e.g., accurately high prevalence estimate) could be a good target for a decision support tool.

PBLN team formation: The Lunch 'n' Learn was a launching point to invite participation in the decision support tool project, with additional invitations distributed through the general Alliance community e-mail list and the recently formed PBLN member e-mail list.

Output

Core team of people involved in remaining stages of work, described by general roles:

1) Alliance research leaders (Director of Research, Research and Evaluation Project Lead): Provide input towards project process and all content/decisions, as well as coordinate engagement with the PBLN.
2) PBLN members (care providers, clinical staff, IS staff): Engage in critical discussion around problem selection and refinement, provide input towards methodological decisions, and review analysis findings.
3) External researchers (professor, postdoctoral associate): Facilitate discussion sessions, lead analyses, and summarize findings.
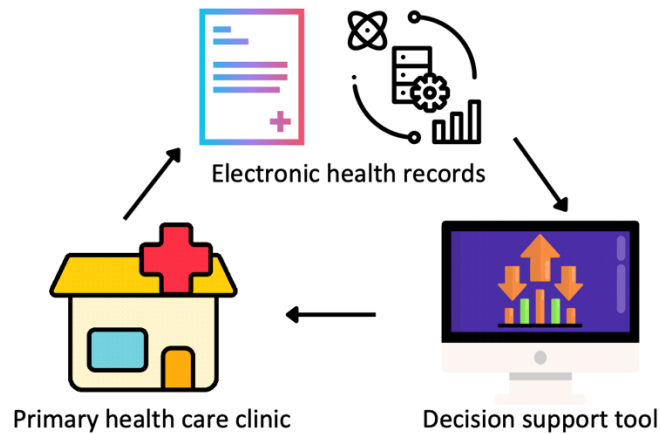
Stage 3: Decision Support Tool Problem Selection

Goal

1. To identify a meaningful challenge within CHCs that could be addressed using a data-driven decision support tool.
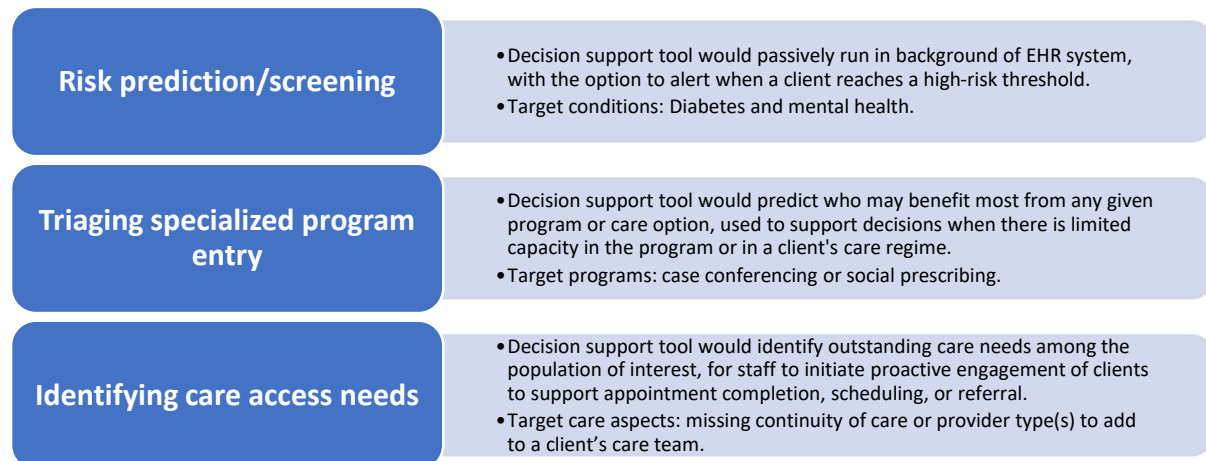
Activities

PBLN meeting: In October 2022, the first PBLN meeting was held. We briefly reviewed findings from the population-level overview study and discussed whether any outstanding descriptive

questions needed to be answered to guide future steps. We then discussed data-driven decision support tools within a learning health system paradigm (**Figure 1**) and brainstormed potential directions to pursue in the CHC context.

Electronic health records

Primary health care clinic

Decision support tool

Figure 1. Brainstorming paradigm for decision support tool problem selection.

Discussion synthesis: Ideas from the PBLN meeting discussion were summarized into three "types" of decision support—risk prediction or screening, triaging specialized program entry, and identifying care access needs—with target conditions or application areas within each type (**Figure 2**).

Risk prediction/screening	• Decision support tool would passively run in background of EHR system, with the option to alert when a client reaches a high-risk threshold. • Target conditions: Diabetes and mental health.
Triaging specialized program entry	• Decision support tool would predict who may benefit most from any given program or care option, used to support decisions when there is limited capacity in the program or in a client's care regime. • Target programs: case conferencing or social prescribing.
Identifying care access needs	• Decision support tool would identify outstanding care needs among the population of interest, for staff to initiate proactive engagement of clients to support appointment completion, scheduling, or referral. • Target care aspects: missing continuity of care or provider type(s) to add to a client's care team.

Figure 2. Candidate project directions presented by type of decision support (left bubbles) with envisioned use and target application areas.

PBLN meeting: In December 2022, we reviewed the three candidate project directions and decided to start with risk prediction for mental health decline after diabetes diagnosis. Rationale included i) *expected impact* (e.g., high prevalence of diabetes with known mental health comorbidities, coupled with the challenge of needing to select from a subset of many possible care options for someone with a new diabetes diagnosis); ii) *actionable* (e.g., all CHCs provide mental health care resources that could help prevent mental health decline for people living with diabetes); and iii) *feasibility* (e.g., relevant care captured in the EHR, and heavy focus on risk prediction in machine learning methods advancements).

Importantly, all three candidate directions (and more!) were seen as potentially valuable. We chose to focus on one area while simultaneously exploring feasibility and processes around this type of project; however, our vision is for this project to be the start of a larger and longer-term CHC decision support tool initiative, wherein multiple types of tools supporting diverse challenges are seamlessly integrated into the EHR system (see Discussion).

External consultation: We connected with Diabetes Action Canada[19] to learn more about related work and potential collaborators. Given the early nature and CHC-specific focus of our project, we decided to proceed with risk prediction model development using an existing 11-year retrospective extract of CHC EHR data, with the intention to consider expansion or tighter external collaboration after more internal feasibility and impact assessments.

Output

Initial problem selection: Support early identification of clients at high risk of mental health decline after diabetes diagnosis.

Stage 4: Sandbox Case Study 1 – Individual-level risk predictions

Goal

1. To gauge feasibility and deepen discussion around developing a decision support tool that predicts early mental health decline within a year of incident diabetes indication.

Activities

Preliminary analysis: Candidate cohort summary characteristics, and an outline of potential predictor and outcome definitions and data sources.

PBLN meeting: In February 2023, we met to review the preliminary analysis, make initial decisions on the cohort and how to operationalize the outcome and associated predictor variables. This was done interchangeably with further problem refinement by discussing the types of clinical actions that could follow identification of a client with high risk of the outcome (early mental health decline). Example clinical actions: incorporating into the current appointment a brief educational discussion about mental health and diabetes, noting down mental health to discuss in future appointments, referral to a specialized mental health provider, or referral to a CHC group program focused on mental health and/or on diabetes.

Model development: The eligible cohort included 1,250 adult ongoing primary care clients receiving care at an East Toronto CHC, who had at least one diabetes ICD-10 code[20] in 2011-2018, at least one year of follow-up care, and no mental health care or decline indication in the two years prior to their incident diabetes indication. The outcome was at least one ENCODE-FM code indicating mental health decline within one year of the incident diabetes indication. Five candidate models ranging in complexity from simple linear (Logistic Regression[21]) to complex machine learning techniques (CatBoost[22]) were trained and compared using a five-fold nested cross validation procedure. Hyperparameters were selected on the inner loop using a grid search for the highest Area Under the Receiver Operating Characteristic Curve (AUROC). **Table 1** presents summary performance metrics, with additional results available upon request.

	Logistic Regression	Lasso Logistic Regression	CatBoost - Features	CatBoost - Encodes	Hybrid Model
AUROC	0.60	0.65	0.68	0.67	0.63
AUPRC	0.14	0.15	0.15	0.15	0.15

Table 1. Numbers represent average performance across the five outer test folds. Legend: AUROC = Area Under Receiver Operating Characteristics Curve (measure of 'discrimination', the ability to assign a higher risk score to someone randomly selected with the outcome than someone randomly selected without the outcome; higher is better), AUPRC = Area Under the Precision Recall Curve (measure of the tradeoff between precision and recall performance; higher is better), CatBoost-Features includes sociodemographic and preprocessed clinical features (e.g., count of chronic conditions), CatBoost-Encodes includes sociodemographic features and clinical information as more granular ENCODE-FM codes, Hybrid model = Hybrid feature and similarity based model[23] with sociodemographic features and kernel-based similarity of ENCODE-FM codes.

PBLN meeting: In April 2023, we met to review and revise the initial model development analyses. To engage multiple types of contribution, meeting materials included case study summary slides to facilitate discussion between people with different backgrounds and roles, and an associated technical appendix (available upon request) tailored to those with methods or medical coding expertise. Overall, we decided the predictive performance of the sandbox model was not clinically useful (Table 1); however, the associated discussion surfaced ideas around how to better harness information from the data and around problem refinement. Example insights included broadening the eligibility criteria from incident to prevalent cases of diabetes, changing how to define active diabetes care in the data, and identifying the need to engage more people to better understand how different provider types code mental health care in the EHR so that the ENCODE-FM codes used to represent the outcome could be modified accordingly (e.g., do "feeling anxious" vs "anxiety" codes reliably distinguish stages of symptom progression towards diagnosis, or is code choice more so a result of different provider type scopes). In terms of features, medication and lab value data were hypothesized to be

useful for more accurate individual-level predictions; these data are planned for integration with the BIRT system, but not yet readily available.

Further consultations: Further input on the case study and suggested next steps was sought out in three ways: a PBLN member lead a focus group at their CHC, a poster presentation was given at a primary care research gathering, and an email call out for further input was circulated through the Alliance email listserv.

Problem refinement: A strong theme that emerged when critically analyzing the problem and candidate clinical actions was that while all CHCs provide mental health services, these are already at or near capacity and implementation of the decision support tool may increase demand past a point that could be maintained. Thus, we discussed the possible value of instead developing a system-level decision support tool to address the upstream problem of how to plan or advocate for adequate capacity within CHCs to address future mental health care service needs.

Output

Sandbox individual-level risk prediction model with ideas on how to improve development and refine the problem.

**Stage 5: Sandbox Case Study 2 – Population-Level Planning Predictions**

Goal

1. To use what was learned in Stage 4 to develop a sandbox model to predict the number of ongoing primary care clients with prevalent diabetes indications who will have mental health care needs in the upcoming year.

Activities

Model development: The revised cohort included 20,329 ongoing primary care clients receiving care for diabetes from any CHC in 2016-2018. Example data-related changes based on Stage 4 included broadening the outcome definition to include additional ENOCDE-FM codes (categories: emotional symptoms, symptoms involving appearance, suicidal ideation, affective disorder, and anxiety), and collapsing categorical feature true missing values (client was never asked) with responses where a client was asked and did not know or preferred to not answer. Given the goal of capacity planning rather than individual client need identification, we further loosened the cohort eligibility criteria to include clients already receiving related mental health care; these clients were previously excluded as minimum added value is expected from alerting the primary care provider responsible for diabetes diagnosis of mental health decline risk when the client was already receiving mental health attention from someone in their care team. In contrast, to support accurate planning these clients do need to be included when estimating the total number of clients with diabetes who would require mental health care services in the future.

We performed a similar five-fold nested CV procedure but restricted to feature-based models due to discussions (further supported by case study 1 results) that preprocessed counts of chronic conditions should be more informative than granular codes. Of the 20,329 eligible clients with prevalent diabetes in 2016-2018, 22.2% had a mental health care outcome recorded in 2019. We used a naïve 0.5 probability cut-off from the best performing model (CatBoost) across all outer test folds to demonstrate the type of information that could be made available to support capacity-planning decisions or advocacy. The overall model accuracy was 86% with CHC-specific accuracy ranging from 64% to 97%, plus one CHC where there were no predicted or actual outcome cases (100% accuracy). The CHC-specific proportion of clients with diabetes predicted to have mental health care needs ranged from 46% (vs. actual 48%) to 1% (vs. actual 13%). Calibration performance is in **Figure 3**, and additional metrics are available upon request.
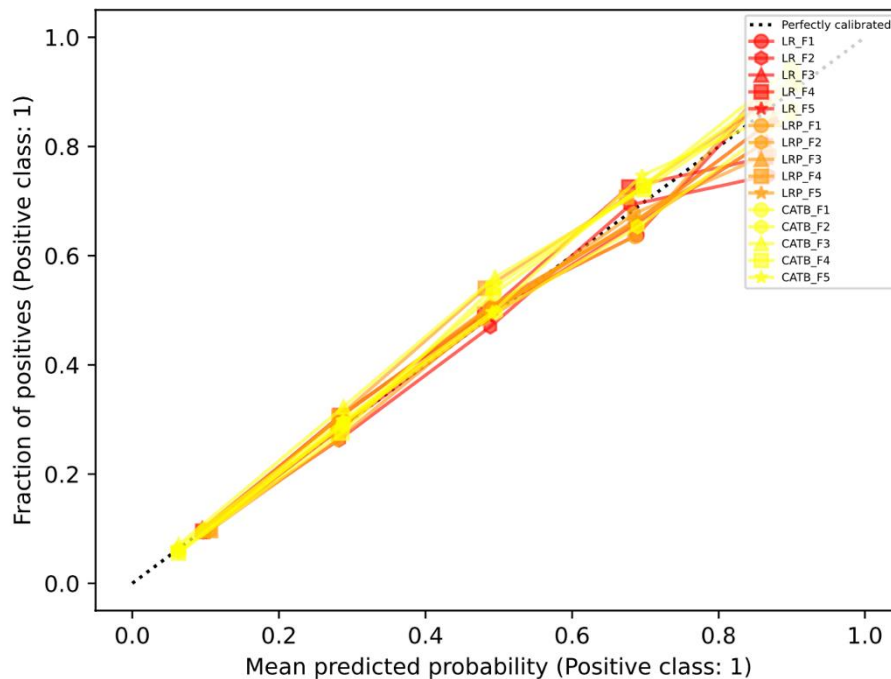
Figure 3. Calibration for population-level prediction results. Legend: LR = Logistic Regression, LRP = LR with L1 penalty, CATB = BatBoost, F# = Fold number in cross validation procedure.

Further discussion and reflection: We presented on all stages of the project at the Annual Alliance Conference,[24] and discussed the second case study at a PBLN meeting in July 2023. The performance of this sandbox case study showed promise for developing a revised model on more recent data that could achieve performance high enough to be useful for estimating the number of clients with diabetes that will have mental health care needs in the next year. Discussions further supported the idea that this type of advocacy and capacity planning tool would be a beneficial precursor to the individual-level tool in terms of actionability and associated clinical or system utility.

Sandbox population-level risk prediction model and ideas on how it may support system-level planning and/or advocacy for mental health service capacity.

Stage 6: Project Recap and Next Steps Decision

Goal

1. To review progress thus far and select which project direction to pursue next.

Activities

PBLN meeting: In addition to discussing case study 2 results, **t**he July 2023 PBLN meeting included a review of project progress, which was summarized into three points (**Figure 4A**)—project scoping and problem identification, case study 1, and case study 2—alongside potential next steps with expected resource needs (**Figure 4B**).
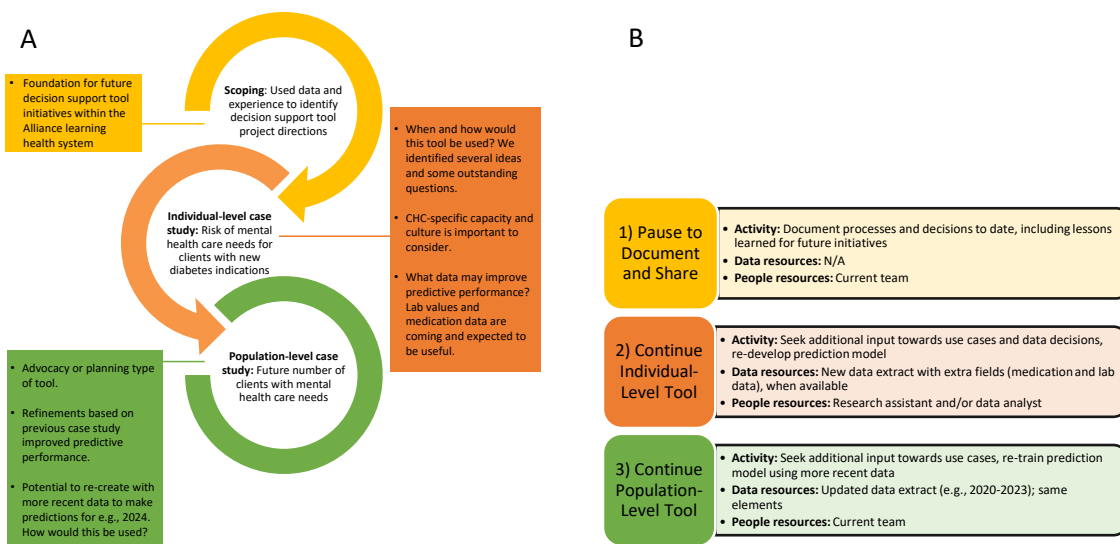
Figure 4. Summary of major completed work stages (A) and outline of next step options with expected resource needs (B).

Given the novelty of this project within the Alliance and the broader field of AI-enabled technologies for primary health care, the technical and process related progress made thus far towards a fully functional tool to support diabetes and mental health care additionally includes lessons that would benefit future projects of different focus. Therefore, we decided to pause to document our processes before revisiting the population-level planning tool direction.

Output

Decision to write the current report.

DISCUSSION

Summary

This report documents the processes and major decisions made thus far in the first EHR data-driven decision support tool co-development project with and for the Alliance for Healthier Communities. Our approach iterated between data analysis and group discussions. We started with a large-scale epidemiological study to learn about health and care patterns of the population of interest and about how clients are represented in CHC EHR data. We then selected the priority problem of supporting proactive mental health care for clients with diabetes, and conducted sandbox case studies and discussion sessions to further understand the problem, how a data-driven decision support tool could provide support, and the feasibility of achieving a high-quality technical solution given readily available EHR data. We decided to share our interim work, including overarching reflections and lessons learned below, as development of AI with and for primary health care organizations is an understudied area. We hope other organizations can use our example processes to inform or motivate their own work.

Reflections and Lessons Learned

- **Epidemiology as a foundation for innovation:** We used epidemiology as a launching point to supplement clinical and organizational expertise in brainstorming meaningful problem selection. Example beneficial uses included: 1) provided an overview of population health and care patterns (e.g., diabetes and mental health prevalence estimates informed expected impact assessment), 2) supported understanding around data quality and how clients are represented in aggregate EHR data (e.g., reliably recorded data elements informed feasibility assessment), and 3) informed methodological decisions during model development (e.g., the first year of care at a CHC has a distinct profile wherein incidence and prevalence are hard to parse). Furthermore, the single rigorous population-health overview can inform multiple initiatives, and it provides a baseline to inform longer-term evaluation or monitoring of the impact of EHR-based tools on the population over time and with continued use.

- **Importance of an interdisciplinary team:** While research and technical experts could help seed discussions with examples and guide feasibility-related decisions, clinical and organizational experts grounded discussions in terms of what was meaningful or realistic use of candidate tool ideas in practice and in the context of the organization—starting with direct envisioned uses (e.g., what would be clinical actions in response to X type of alert?) and extending into how to follow through on those actions in the context of competing demands and subsequent steps both at an individual client care level and at a system capacity and culture level. For example, our project started with the problem of how to support individual level mental health and diabetes care, and evolved into addressing a more pressing challenge of system-level advocacy to allow adequate resources to follow-through on best care options that would otherwise result from the original tool idea. A

second example was value of input from multiple provider types to refine the outcome and eligible cohort in line with the target problem(s), to align with the scope of practice of the intended tool end-user (e.g., primary care provider responsible for diabetes diagnosis) as well as other provider types that may or may not already be present in a client's care team (e.g., should someone seeing a therapist before diabetes diagnosis be included? Should it depend on the specifics of existing therapy appointment frequency, care characteristics, etc.?). Without proper understanding of the complete clinical context, a tool could be developed that even with excellent technical performance, does not result in added value. Input from leadership and IS experts further helped to scope our project in terms of what data are available and when, to connect with internal and external collaborators, and to support feasibility and continuity from a system-capacity perspective.

- **Sandbox case studies supported deeper discussion sessions**: The impact of using sandbox case studies in our project can be likened to how editing a manuscript often matures or builds on ideas relative to when writing the first draft. They were particularly valuable given the novelty of this type of project within the Alliance and the limited amount of research literature on co-development of AI-enabled decision support tools for team-based primary health care settings. Even when predictive performance of a sandbox model was poor, having a tangible example pushed discussions further than hypothetical scenarios or thought experiments could, which lead to changes in methodology and problem conceptualization. The opportunity to discuss why any given technical decision did or did not line up with realistic or impactful clinical support improved our current work, and resulting methodological decisions (e.g., active diabetes client identification, missingness strategy for sociodemographic variables) can be applied to future projects. Case studies also facilitated refinement of our target problem, as described above.

- **Problem scoping around data availability:** CHCs record rich EHR data that capture information about multiple domains of health through structured fields for sociodemographic characteristics (e.g., level of education, sex, gender) and through dynamic care encounter tables (e.g., ENCODE-FM codes to indicate diagnoses and procedures). The target problem and use case needed to consider data availability as completeness of static fields varies across CHCs, and not all data are readily available for decision support tool ingestion. For example, medication and lab value data were flagged as potentially valuable for both feature and outcome construction in our first sandbox case study, but at the time of our project these data were scheduled to become available for research and technology use about a year out. Part of the decision to focus on a population-level tool was that adequate performance is expected with readily available data whereas for improved individual level accuracy we decided it was "worth the wait" for additional data elements.

- **Multiple engagement strategies are needed:** We tried several engagement techniques throughout the project. The initial Lunch 'n' Learn session coupled with email list invitations was effective for forming the core project team. When trying to get further input towards

project-specific decisions, a PBLN member led focus group at their CHC was more effective than research poster presentations or further e-mail-based recruitment.

- **Working towards a broader decision support tool initiative:** This project focused on identifying one challenge to target with a decision support tool, showing value in A) individual identification of clients newly receiving diabetes care that are at high-risk of mental health decline, and B) population-level estimation of anticipated future mental health care needs given the existing population of clients with diabetes. Importantly, early discussions highlighted the desire to situate this specific project within a broader decision support tool initiative. As experience is gained and processes are streamlined there will be lower start-up cost to tool development or implementation. While there are hundreds of potential targets for decision support tools within the broad scope of primary health care, it will not be sustainable or beneficial to create or implement these independently; a fragmented approach to tool integration poses risks such as exacerbating alert fatigue or disrupting instead of augmenting team-based, whole-person care. Rather, our broader vision is to support more seamless integration of multiple types of tools to benefit people (e.g., better health outcomes), providers (e.g., improved workflow and decisions support), and communities (e.g., sufficient resources to meet demands). An additional consideration for expansion will be when to maintain a tool consistently across all CHCs versus adapt it to the local CHC context and available data.

This project more generally furthers the Alliance's learning health system work at three levels: data analysis capacity, stakeholder engagement, and process refinement.[14,15,25–27] First, demonstrating the use of AI to make data more meaningful through large-scale descriptive and real-time, clinically relevant predictive insights that will ultimately improve care delivery. Second, providing new avenues for clinician and provider engagement in data-driven learning initiatives; future work will additionally be able to engage the newly formed Client and Community Research Partners Program. Third, by providing a baseline process for tool development that future projects can learn from and build upon (i.e., what stages of work to keep, modify, or replace). Each future decision support tool initiative will provide additional opportunities for bidirectional learning whereby data are harnessed through AI to tackle a specific clinical problem and improve care delivery, while simultaneously learning how to improve and adapt the processes to achieve that clinical goal for different types of decision support and application areas.

Conclusions

This report describes the ongoing process and example lessons learned thus far in the first co-development project with and for CHCs in Ontario, Canada. Our approach of alternating between data analysis and discussion sessions started from an understanding of population-level sociodemographic, clinical, and care use characteristics and moved towards sandbox model development and problem refinement to narrow in on how to support system level

planning and advocacy for adequate mental health care service capacity for clients with diabetes. This project is a starting point towards a larger decision support tool initiative that would integrate multiple types of tools with the CHC EHR system. Our processes and reflections may further inform or motivate other primary health care organizations at a similar stage of learning how to best harness value from EHR data.

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