VON Canada Ontario:
Managing Privacy within a Central Data Repository
February 2011

Key Results:

- Engaged 45 agencies in the South East and Mississauga Halton Local Health Integration Networks on the RAI-CHA and GoldCare in 15 months.

- Implemented a central data repository based on a 'hub and spoke' information model to manage thousands of client health records.

- Instituted a streamlined client consent process that complied with PHIPA and PIPEDA privacy regulations.

- Assumed the role of a Health Information Network Provider, and fulfilled the responsibilities and expectations of that role in 12 months.

- Emerged as an early adopter of the RAI-CHA, and will begin compiling outcome results and feedback to help inform implementation best practices for CSS sector.

- Recognized the contributions of a project team member with the 'Gold Award for Excellence in Innovation', a VON Canada national award.

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Centralized approach to streamlined information management.

OVERVIEW

In January 2009, the South East (SE) and Mississauga Halton (MH) Local Health Integration Networks (LHINs) decided to implement an electronic version of the interRAI Community Health Assessment (RAI-CHA). It is used to help identify seniors at risk of progressive frailty and functional decline in activities of daily living – a key objective of each LHIN's respective Aging at Home program.

VON Canada Ontario manages the SMILE program in the SE LHIN, which provides frail and elderly seniors with services to assist with daily living activities such as meal preparation, housekeeping, shopping, and transportation. The Mississauga Halton (MH) LHIN's Supports for Daily Living (SDL) programs have a similar mandate and objectives, providing 24-hour daily living activity assistance to those with permanent physical limitations or impairments and frail seniors. These programs were identified as good places to start the implementation of the interRAI CHA in each LHIN in addition to all CSS agencies in the SE LHIN.

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In a project managed by VON (Victorian Order of Nurses) Canada Ontario, a healthcare information management solution was selected that would not only enable wide-scale deployment of the RAI-CHA, but would also provide meaningful data to support resource allocation and decision-making for the community support services (CSS) sector's Aging at Home initiatives. That solution is GoldCare.

As Lori Cooper, District Executive Director - Community Support, VON Canada Ontario explains, the breadth and depth of GoldCare distinguished it from other solutions. "We thoroughly reviewed several solutions, and GoldCare was the clear choice. It was strong on every one of our requirements, and in many cases, exceeded our expectations for the RAI-CHA, where their installation results in the CSS sector were miles ahead of other vendors."

GOLDCARE: A THREE-FOLD PURPOSE

GoldCare's RAI-CHA instrument uses a standardized set of tools and templates to simplify assessment completion and submission. Developed in consultation

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with the Canadian interRAI team based out of the University of Waterloo, GoldCare's RAI-CHA fully complies with interRAI standards. Assessment data is accessed through an intuitive interface that provides an up-to-date view of the client's past and current assessment activity.

Outputs such as assessment protocols and outcome scores are automatically calculated and displayed, providing the basis for creating comprehensive clinical documentation and care plans. This centralized approach to information management increases data accuracy and workflow efficiency, leading to enhanced service planning and delivery, as well as quality of care.

In the case of the SE and MH LHINs' implementation, GoldCare serves a three-fold purpose: it manages an electronic version of the Community Health Assessment; it provides an efficient process for managing client consent; and, it acts as a centralized data repository (database) of interRAI CHA-related client records. The centralized data repository was the key component of the implementation, as it provides the foundation for shared assessment and security protocols related to privacy regulations.

AN IMPORTANT NEW ROLE FOR VON CANADA

With so many agencies and service providers needing access to client RAI-CHA records, privacy was an essential (if not the most important) component of implementing the central data repository and developing the consent process. The latter actually came out of a rigorous investigation to determine and assess the roles, responsibilities and risk of the parties that would access client data, specifically as it pertained to PHIPA (Personal Health Information Privacy Act) and PIPEDA (Personal Information Protection and Electronic Documents Act) regulations.

This investigation initially focused on completing a Privacy Impact Assessment and Threat Risk Assessment through a third-party privacy consultant. A CSS sector local steering committee was also formed with the intent of reviewing and carrying out the recommendations of those assessments. The steering committee would also review privacy practices, auditing procedures and breach processes at an agency level, as well as IT policies and safeguards for laptop use.

In fact, it was during the investigation that the privacy consultant determined that VON's role in managing the central data repository was far greater in scope and significance than originally perceived. Under the PHIPA regulation, VON is considered a Health Information Network Provider (HINP), as the organization provides services to two or more health information custodians (in this case, the SE and MH LHIN agencies) for the purpose of enabling the custodians to use electronic means to share personal health information to one

another. In other words, VON is facilitating access to software and a secure database so that client information can be accessed via an electronic method (the GoldCare database) by the participating agencies.

Rather than let the revelation delay implementation, Cooper says VON embraced their new role. "As new partnerships and technologies continue to shape the CSS sector, and vice versa, every organization is seeing their role and responsibilities to clients change. The HINP is one such role that has emerged and continues to evolve. With client privacy and confidentiality such a hot topic, the HINP role has actually allowed us to be on the leading edge of establishing data security and risk management policies and procedures, and integrating those requirements directly into our care model. In many ways, being identified as a HINP early on was an advantage, as retrofitting those requirements after the implementation had gone live might have been challenging."

RISING TO THE CHALLENGE

Although the responsibility for fulfilling the requirements of the HINP role resided mostly with VON, it was not alone in its undertaking. As Cooper affirms, the GoldCare team was with them every step of the way. "We had a lot of questions about the procedures for breach management and auditing. In addition to answering our questions, and documenting privacy procedure information, the GoldCare team conducted a thorough review of those procedures from the perspective of a HINP. In some cases they even modified their policies to better meet our needs. They put themselves in our shoes, so to speak. GoldCare proved beyond a doubt why we consider them a partner, and not just another vendor."

In all, VON's transition to the HINP role, and its completion of the following responsibilities, occurred in 12 months:

- Investigating unauthorized access/use/disclosure (breach) of personal health information

- Issuing plain language descriptions of services and safeguards (about data security)

- Issuing public description of services, safeguards, guidelines and policies

- Maintaining audit logs of system activity and access to personal health information

- Conducting privacy impact and threat risk assessments

- Ensuring proper restrictions of access to personal health information

- Documenting accountabilities of parties that access personal health information

However, as this is an ongoing role, VON will next complete an assessment to determine how successful it was in meeting the HINP requirements. VON will also recommend strategies for improving information sharing with the SE and MH LHINs. The latter will support the Ontario LHINs Privacy Project (OLPP), which is developing tools and resources to facilitate an inter-organizational approach to privacy planning, and setting deliverables for instituting LHIN-wide privacy standards. Its involvement in privacy-related initiatives has established VON as a trailblazer in the sector, and its success as a HINP serves a guidepost to other agencies adopting that role.

HUB AND SPOKE INFORMATION MANAGEMENT MODEL

The HINP requirements were incorporated into the development of the central data repository, which contains client records resulting from the RAI-CHA assessment and care planning process: outcome scores, client assessment protocols (CAPs), program admission details, progress notes, and more, from multiple agencies. However, each agency needed to maintains its records separately, yet still have access to the records of referring agencies and those providing joint services to the client. The key was ensuring data remained secure, while still allowing agencies to efficiently support clients across the sector.

The solution was a hosted GoldCare database supporting a 'hub and spoke' model in which client records are accessible (with appropriate permissions) to all agencies. Under this model, VON acts as the 'hub' on behalf of participating agencies, who are considered the 'spokes', with a centralized single point of access to client RAI-CHA data via the GoldCare web interface.
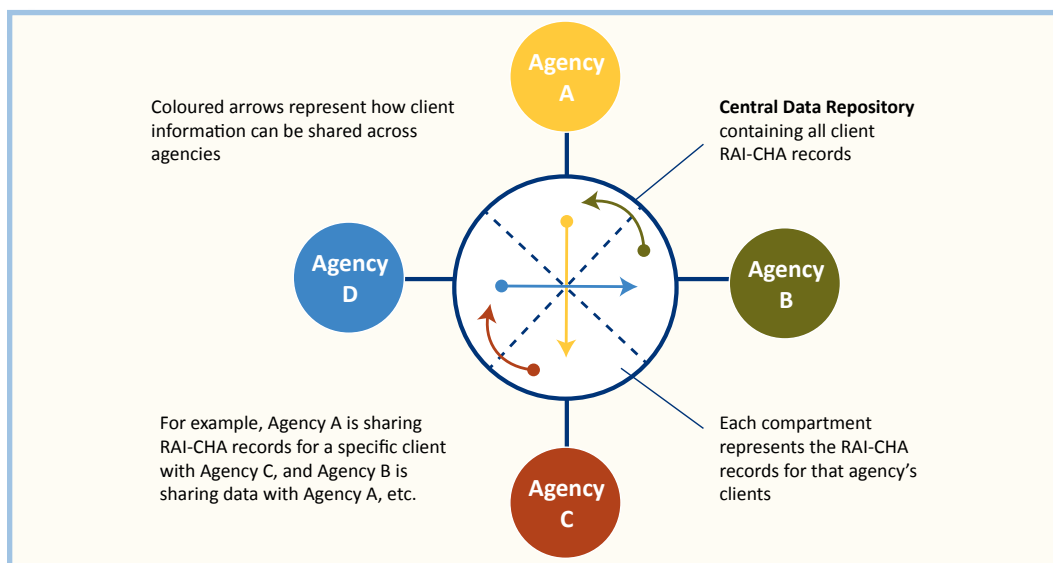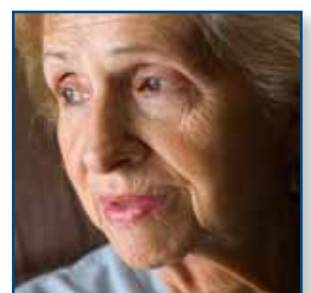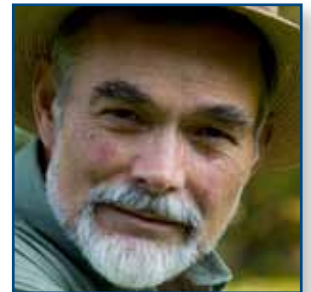

Coloured arrows represent how client information can be shared across agencies

Central Data Repository containing all client RAI-CHA records

For example, Agency A is sharing RAI-CHA records for a specific client with Agency C, and Agency B is sharing data with Agency A, etc.

Each compartment represents the RAI-CHA records for that agency's clients

Figure 1: Hub and Spoke Information Management Model

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The setup of the GoldCare database ensures there is only one version of the client record that is collectively maintained by care team members across all agencies, instead of multiple versions/copies that may be duplicated, superseded, outdated or incomplete. As a result, data accuracy and expediency is increased. What's more, because the time and effort needed to complete and file paperwork is reduced, referrals to services have a much quicker turnaround – an important goal of the agencies.

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As Janeil Neilsen, Project Manager – interRAI CHA, VON Canada Ontario, explains, this information management model and setup helps more than just the agencies. "Streamlining access to information means the entire assessment, care planning and service delivery process is streamlined, to the benefit of clients. Any time you can improve the accessibility and timeliness to critical information, the client reaps the rewards, which is improved quality of care. In every sense of the word, this information management model is our success – VON Canada, the agencies, the clients, and the LHINs; we all share in its success."

In addition, by maintaining data through a centralized database, the client consent process is more tightly controlled. "Managing and hosting data through GoldCare allows us to capitalize on its table-driven and highly configurable infrastructure, which facilitates straightforward setup and administration of data. GoldCare user accounts are also role- and permission-based, allowing us to put the proper restrictions in place to control system access and ensure data security and integrity," says Neilsen.

STREAMLINING THE CLIENT CONSENT PROCESS

By managing the client records in one database, the implementation project team was able to devise a consent process that seamlessly provided access to agencies, while still meeting privacy requirements. In this implementation, referrals, and thus the initial client consent, are maintained in the GoldCare Master Client Index. Service providers can search for clients in the index, and with the proper consent, view the client's record.

However, if consent to view that client's record is not present, GoldCare will automatically generate a consent form for the service provider to complete. Once completed, consent is granted, and the client's record becomes accessible. However, if the consent is not completed, access to the client's record is denied.

Clients assigned to the service provider are displayed in a GoldCare Workspace, a customizable 'home page' that provides a consolidated view of client assessments, care plans, outcomes and other relevant data. New (i.e. consented) clients are automatically added to the Workspace, giving the service provider a comprehensive overview of their clients, and the status of their care – including assessments and care plans completed by other agencies for that client.

As shown in the diagram below, Workspaces display client RAI-CHA records pulled from the central data repository, as based on client consent. For example, Clients A and B are assigned to Agency 1, and are displayed in that agency's Workspace. Client B is then referred to Agency 2. So now Agencies 1 and 2 will see the same client RAI-CHA records for Client B in their respective Workspaces.

Until the proper consent is granted, Agency 1 cannot view data for Client C, just as Agency 2 cannot view data for Client A. Finally, Client D has not been referred to either agency, and is therefore displayed in neither agency's Workspace.
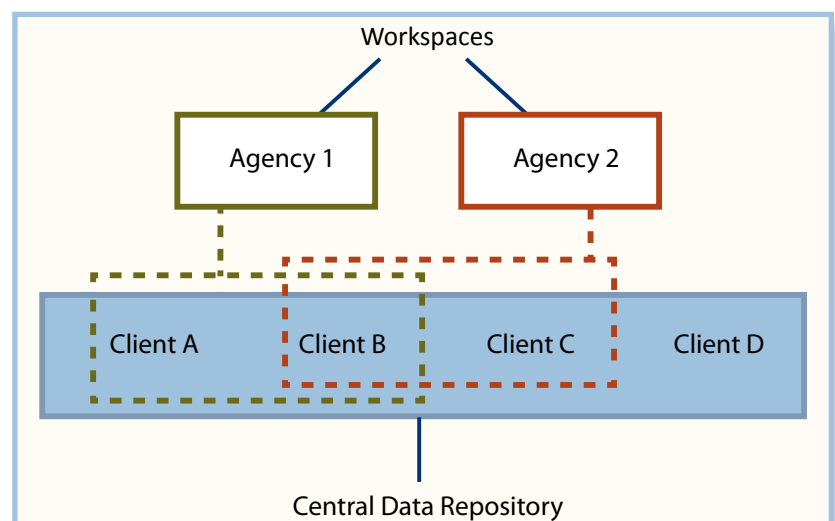

Figure 2: Client Records Displayed in Workspaces

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To date, about 35 service providers and assessors are accessing approximately 2,441 client records. Another 10 agencies are receiving electronic referrals in the system. With the SE and MH LHIN agencies admitting more clients into their CSS programs, SMILE and Supports for Daily Living programs, the number of records will increase significantly over the next five years. Neilsen says GoldCare is more than capable of handling that growth rate. "The entire GoldCare system is designed to optimize the integration, accessibility and efficient management of information. Workspaces and other tools can be tailored to the role and permissions of the user. And the scalable and flexible nature of GoldCare means we'll be ready and well-equipped to implement any new requirements down the road."

STRONG RELATIONSHIPS THROUGH KNOWLEDGE SHARING

VON's transition to the HINP role in such a short timeframe, as well as the development of the central data repository and consent process, was made possible through the collaborative team effort of VON, the LHINs, Community Support agencies and GoldCare. This cooperative and supportive culture was apparent throughout the implementation process, and more specifically, during training and system rollout.

"Removing barriers to information, and maintaining open communication between all stakeholders has strengthened our relationships at every level. A true team environment has emerged, in which we're all committed and working together to provide the best value to clients, and improve quality of care."

Knowledge sharing and education are facilitated and endorsed through the Action Advisory Committee, which is comprised of leaders from Community

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Support agencies, VON, the Community Care Access Center and the LHIN. Education was the single greatest contributor to this success. "Far from being a one-time thing, education and knowledge sharing has become an integral part of our processes, and philosophy in general. It has permeated every aspect of how the service providers and agencies support both one another, and clients," states Cooper. An example is a buddy system that puts training in the hands of the most experienced GoldCare and RAI-CHA users.

"Removing barriers to information, and maintaining open communication between all stakeholders has strengthened our relationships at every level. We have come to respect the unique qualities and experiences of each party – the technical expertise of the GoldCare staff, the leadership of the LHINs, the invaluable feedback provided by the agencies. A true team environment has emerged, in which we're all committed and working together to provide the best value to clients, and improve quality of care."

An ongoing Assessor User Group gives assessors a forum for asking questions, receiving answers and open discussion, and providing a receptive and supportive environment to learn, share and expand knowledge and skills. The user group also hosts guest speakers, maintains an intranet site, and publishes a monthly newsletter, further examples of how it is providing continuous learning opportunities to agency members.

Cooper says this collaborative and cooperative spirit has extended to the interactions between VON, GoldCare, the LHINs and the agencies. "Removing barriers to information, and maintaining open communication between all stakeholders has strengthened our relationships at every level. We have come to respect the unique qualities and experiences of each party – the technical expertise of the GoldCare staff, the leadership of the LHINs, the invaluable feedback provided by the agencies. A true team environment has emerged, in which we're all committed and working together to provide the best value to clients, and improve quality of care."

FUTURE GOALS AND EXPECTATIONS

With the central data repository and privacy standards well in hand, VON turned its focus to the next phase of the electronic RAI-CHA project – establishing best practices. In May 2010, the Community Care Information Management Project Team (CCIM) formally selected on behalf of the provincial government the RAI-CHA as the standard instrument for intake,

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assessment and care planning for the CSS sector in Ontario. In the months since that announcement, the CCIM has been consulting with the LHINs and their CSS sector agencies to pilot and evaluate RAI-CHA implementation approaches.

As an early adopter, by October 2010, the SE and MH LHINs already had 45 agencies using the RAI-CHA through GoldCare: 35 agencies actively completing assessments, with another 10 receiving the electronic referrals. The implementation team is now starting to compile outcome results and feedback for the SE and MH LHINs and CCIM Project Team. In acknowledgment of their work, the CCIM Project Team has worked with the SE and MH LHIN agencies to help them enhance their assessment processes, and ensure alignment with provincial priorities and goals. In short, establish best practices to guide other LHINs as they adopt the RAI-CHA.

The implementation team's success caught more than just the CCIM Project Team's eye; Janeil Neilsen was recognized for her work on the project with the VON Canada Gold Award of Excellence for Innovation, a national award. It is one of the few times this award has been given in the Innovation category, a testament to Neilsen's expertise, dedication, and incredible results on this project.

Looking ahead, VON and its partners will continue to roll out GoldCare interRAI CHA software across the SE and MH LHINs, and coordinate with the user group to expand the overall knowledge, skills and outcomes of using the RAI-CHA among service providers and assessors.

As Cooper concludes, the results they have achieved with GoldCare have put the agencies and the LHINs on the path to continued success. "As a collaborative group of agencies we're in the unique position of being able to address a number of pertinent issues facing the CSS sector: electronically managing client records, complying with PHIPA and PIPEDA standards, and implementing the RAI-CHA. We have laid the groundwork, and in some cases, set new precedents for improving the processes and outcomes of Community Support programs including SMILE and Supports for Daily Living. Service planning and delivery is enhanced which has resulted in better quality of care for clients. And when it's all said and done, that's what matters most. GoldCare played a crucial role in making all of that happen."

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The Victorian Order of Nurses (VON) is Canada's largest, national, not-for-profit, charitable home and community care organization, providing 75 home care, personal support, and community services to enhance each client's quality of life. VON's model of care and service shapes the actions of thousands of VON staff and volunteers touching the lives of millions of Canadians. The model of care and services places the client, caregiver, and family at the centre of care and decision making supported by the interdisciplinary team. Whether in the home or community, with individuals, families or groups, members of the VON team take a leadership role in forming partnerships with clients and other stakeholders to promote optimal health, increase capacity and impact public policy.

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GoldCare gives care providers versatile healthcare management software to efficiently manage and support the full continuum of community, residential and long-term care. Clinical, operational and administrative applications are fully integrated through an intuitive interface that provides staff with a consistent and up-to-date view of client information. This centralized access to information helps organizations to streamline workflow, reduce paperwork, increase data accuracy and improve operational efficiencies. Our multidisciplinary and integrated approach to client management, plus a dedication to industry-advancing solutions are just some of the reasons why GoldCare is used by hundreds of care sites across Canada, Australia and New Zealand.

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Phone: 1.800.463.2688
sales@mygoldcare.com
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