

EVOLUTION OF THE NIDUS PERSONAL PLANNING REGISTRY

'Connecting your information to the right people at the right time.'

The idea of a registry service for personal planning (advance care planning) documents has a long history in British Columbia.

There has been an evolution in:

- The understanding of the purpose of a registry for personal planning documents.
It enables real-time communication for time sensitive matters (i.e. for while we are alive; not after death).
- The knowledge and experience of the use and potential of a registry service.
It allows third parties to better serve the needs and wishes of their customers/members/clients/patients and provide a safeguard.
- The development of features and online function to store and make available a wide array of information and documents for the benefit of the individual and others who need to know.
It creates a sophisticated yet elegant system that is accessible, economical, versatile, private and secure.

1993 to 2000 — What is the purpose of a Registry?

The Representation Agreement Act was passed in 1993 and included provision for a mandatory registry service.

During implementation of the legislation, there were two schools of thought about the purpose and function of a government operated registry.

1. To facilitate communication – use an online notice-filing model.

This perspective was put forward by the Community Coalition for the Implementation of Adult Guardianship Legislation through the Legislative Sub-Committee report of the Representation Agreement Task Group (RATG) based on research conducted with the public and on existing registry services.

Research indicated that a well-run registry with online capacity charging a modest registration fee can return money to government.

The public wanted a registry that is accessible, private, and economical for communication purposes.

2. To safeguard against abuse – require submission of original documents to the Office of the Public Trustee for sealing.

This view was proposed by the Office of the Public Trustee and the Ministry of Attorney General.

The Community Coalition pointed out that the only way to provide a safeguard would be full examination of the documents. This level of surveillance would be costly, take considerable time, and require significant privacy protection measures.

In addition, the Community Coalition posited that there is no reason to believe that a registry of any kind can prevent abuse. It may, in fact, promote abuse because third parties might rely on a registry to screen documents instead of exercising their own duty of care.

In Sept. 2014, the Public Guardian and Trustee, Catherine Romanko, was a key presenter at the Nidus public event to launch the new online system of the Personal Planning Registry.

The Public Guardian and Trustee is an authorized Access User of the Nidus Registry. Finding out someone has made their own arrangements means the PGT services are not needed. But if there is a problem or a gap in the plan, the Registry can provide helpful information for developing an appropriate response.

2000 to 2006 – Establishing the Nidus eRegistry (version 1.0)

The Representation Agreement Act was proclaimed in February 2000, however provisions related to the registry did not come into effect. The government indicated that it was too costly. In 2006, references in the Representation Agreement Act to enable a government-run registry were repealed (removed).

Despite government's decision not to establish a registry service, the public continued to ask for it. In 2001, the Representation Agreement Resource Centre (RARC), a non-profit, charitable organization set up in 1995 by citizens and community groups involved in the law reform, explored the feasibility of an online registry service.

The Nidus eRegistry was launched in September 2002 as a partnership of the Representation Agreement Resource Centre, software company Gateway File Systems and Juricert, a subsidiary of the Law Society of BC. It registered Representation Agreements, Enduring Powers of Attorney and revocations of such. (Nidus is a Latin term for nest – symbolizing a place where something originates, develops, or is located.)

The Nidus eRegistry attracted the interest and attention of respected and influential individuals and groups and was featured in articles published by:

- The Vancouver Sun, by Money Columnist Michael Kane, September 23, 2002.
- The Law Society of BC Benchers' Bulletin, March-April 2003.
- The BC Medical Association, News Release, Nov. 17, 2003.
- The Financialist, Rogers Group, by David Chalmers now with Nicola Wealth Management and well known volunteer for Advocis (association of financial advisors), October 2004.

Registering representation agreements and enduring power of attorney is voluntary, but it is strongly advised...Nidus is currently the only agreement registry service. It is available online 24 hours a day.

BCMA, 2003.

Jay Chalke, who became the Public Guardian and Trustee in 2000, supported the Nidus eRegistry. His staff were authorized to conduct searches. Mr. Chalke also encouraged the government to consider instituting a legal duty on health care providers to search for a Representation Agreement (not specific to the Nidus eRegistry). This has not been done, but such a duty exists for organ donation in the Human Tissue Gift Act Regulation.

2006 to 2014 – new and improved Registry (version 2.0)

In April 2006, the Nidus Registry service went off-line. Significant amendments to adult guardianship and personal planning legislation were expected (although delayed until September 1, 2011) that would introduce a new legal planning document and amend features of the existing ones. A number of changes would be required of the registry due to amendments and also due to changes in technology.

Gateway File Systems decided to end their involvement. The Representation Agreement Resource Centre also underwent a name change, becoming the Nidus Personal Planning Resource Centre and Registry.

Nidus contracted Gravit-e Technologies in 2011 to develop a new online system based on the Nidus eRegistry pilot and our hands-on experience with users during the off-line operations.

In 2013, Nidus met with Dr. Doris Barwich, palliative care physician in Fraser Health (now head of the BC Centre of Palliative Care) and Dr. Cathy Clelland, Executive Director of Society of General Practitioners of the BCMA to demonstrate the new registry system and get their input.

David Flaherty, BC's first Information and Privacy Commissioner, volunteered to be a resource to Nidus on privacy issues for the new online system.

The Nidus Registry database is not a cloud-based service; the data and servers are located in Canada (and therefore not subject to United States legislation or scrutiny).

2014 to present – the Personal Planning Registry at your service

The re-branded and new online registry system was launched on June 12, 2014 for professionals and organizations.

The public launch was held on September 15, 2014 at the Vancouver Public Library in partnership with Courthouse Libraries BC with at least 250 people in attendance.

Approximately 5,500 accounts (people) were transferred from the original online and offline registry systems to the new online system. Some accounts were then deleted as notification of the transfer served as a reminder to update the Registry where an adult is now deceased.

In its first year of operation, over 1,000 accounts have been created in the new system by lawyers and notaries public as Registration Agents and by individuals (as self-registrants). This has happened with very little promotion of the Registry as we have been fine-tuning the system and finalizing the shared access feature.

The new system meets today's needs and the future expectations of a self-determined and technically proficient public.

In addition, the Registry offers the health care system responsiveness to ensure patient-centred care at end-of-life, emergency situations, and other circumstances related to hospital, facility and community care.

As the health system shifts seniors' care services to the community and at home, the Registry will help ensure continuity and consistency of care. It will also help with practical issues such as the certainty of decision maker for financial affairs and health and personal care consent to avoid possible confusion or conflict among family members. It can provide a source of information and coordination for the service system when organizing or providing support.

The Registry fosters and supports independence and self-management—a must if the formal system is to be sustainable. And it is aligned with the sentiments of a better educated populous and their expectation of timely communication. For those providing support to someone else, the benefit is being connected and involved without being 'tied down.'

The Personal Planning Registry meets today's needs and the future expectations of a self-determined and technically proficient public.

It also offers responsiveness to the health system to ensure best practices in end-of-life care, emergencies and other health and personal care circumstances.

“ I would REALLY like to register with Nidus. I think it is a terrific solution to problems I have seen over and over again as an RN in long-term care facilities.

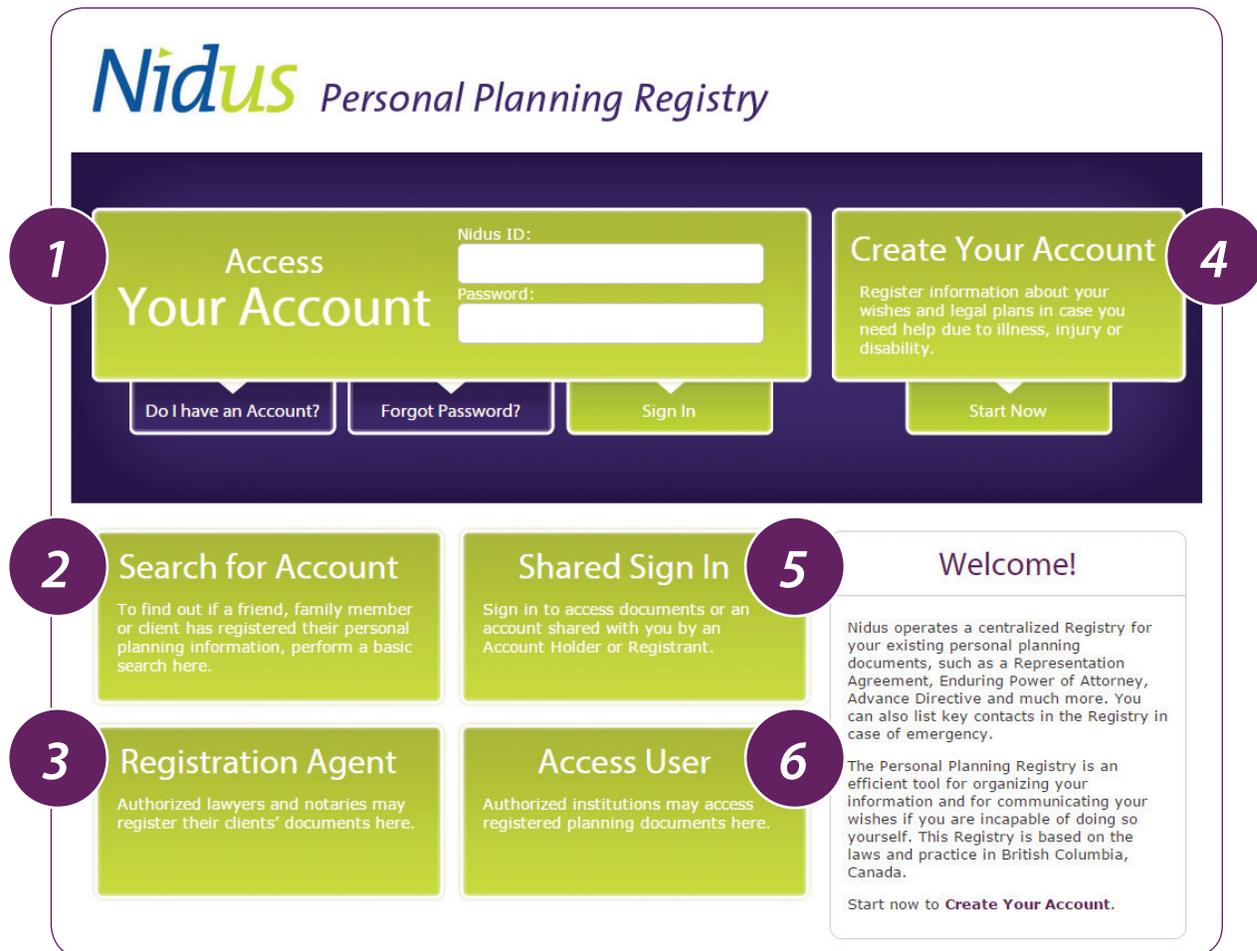
“ The Personal Planning Registry means family and friends don't have to rummage through drawers and bookcases hoping to find the legal documents they need! BC is lucky, Ontario needs this.

“ Thanks for this helpful information. I especially like the possibility to share my info with individuals (family or staff) I choose.

Chart of common voluntary registries in BC

| | PERSONAL PLANNING REGISTRY | ORGAN DONOR REGISTRY | WILLS REGISTRY |
|--|---|---|--|
| Store Information | ✓ | ✓ | ✓ |
| Type of information | Information about legal planning documents, care wishes and other details you want to keep track of or others may need to know if you are incapable or cannot communicate. Examples on page 6. | Decision to give or refuse organ/tissue donation. | Basic information that a Will was made and where original is kept. |
| Upload copy (image) of document(s) | ✓ | ? | No |
| View own record online | ✓ | No | No |
| Grant access to types of third parties to view | ✓ | Pre-determined | Pre-determined |
| Grant access to specific individuals to view | ✓ | No | No |
| Change permissions about who can view | ✓ | No | No |
| Update information | ✓ | Can modify consent by re-registering. | No – have to register a new notice. |
| Fees per person | To register – \$25.00 for the first document; \$10 for each additional. To search, view, update or print wallet card – free | Funded by government (taxpayers). | To register – \$17.00 per notice. To search – \$20.00 |
| Legislative requirements | No | Facility/health care provider has duty to search. | Duty of executor or administrator to search if estate is probated. |

www.nidus.ca/registry – Online Registry



1 Account Holders access their Registry Account to view, update, or add registrations.

4 Individuals (Account Holders) can create their own Registry Account as self-registrants (if they did not use a Registration Agent).

2 Not sure if mom or dad made any plans? Check to see if they might have a Registry Account.

5 Sign into Shared Access if an Account Holder gave you viewing access to their registered document. Account Holders can share a registration with others (e.g. representative, family physician, financial advisor, family member) using their email address.

3 Authorized Notaries Public and Lawyers can set up accounts and register documents for their clients. They can also view clients' existing registrations in order to advise on planning needs.

6 Third parties such as the Public Guardian and Trustee, financial institutions, health care institutions (e.g. BC Cancer Agency, hospitals, residential or community care programs) and government agencies can be authorized to view information and documents.

Welcome Account Holder

STORE IMPORTANT INFORMATION AND DOCUMENTS IN A CENTRAL LOCATION

Registrations appear on your account page. Click the name to view and edit. Grant permission for others to have read-only access. See diagram below.

Personal Information Record

Enter information such as 'emergency to do list,' name of doctor, financial institutions you use and further details to help your representative or others help you.

Personal Planning Documents

Register completed planning document(s). Type in date signed, where original is kept, enter names and contact information of appointees. Upload a copy after scanned in PDF format, permit access by third parties.

Other Documents

Upload a scanned copy of other important documents.

My Current Registrations

| | | | |
|---------------------------------------|------------------------------|------------------------|------------------------|
| My Personal Information Record | | | |
| View My Record | | Last Reviewed m/d/y | 09/23/14 |
| My Personal Planning Documents | | | |
| | Document # | Date Signed m/d/y | Last Reviewed m/d/y |
| <input type="checkbox"/> | Revocation Power of Attorney | 2942048-2 | 02/10/14 11/18/14 |
| <input type="checkbox"/> | Power of Attorney | 2942048-3 | 02/10/14 05/06/15 |
| <input type="checkbox"/> | Representation Agreement | 2942048-1 | 05/30/14 05/06/15 |
| My Other Documents | | | |
| Memorial Wishes | | | |
| Current Will | | | |

Choose Registration Options

Welcome Authorized Viewer

PERMIT THIRD PARTIES TO VIEW AND SHARE WITH SPECIFIC INDIVIDUALS

This is an example of information that others can see about a registered personal planning document. Account Holders may permit access by a third party—such as an authorized health care type of institution or a financial type of institution. Account Holders can also share their registration with specific individuals such as the representative, alternate, care provider.

See when the document was last updated or reviewed.

Your Registry search is current to May 14, 2015; 01:13 PM

Account Holder

Name: **Sylvia Star**
 Commonly known as: **Sylvie**
 Address: **555 Constellation Ave.
 Milky Way BC Canada
 V1V 1V1**
 Telephone: **555-666-7777**
 Phone/Address is for Contact Person: **No**

Appointee Information

Representative
 Name: **Brian Orion**
 Phone: **555-666-7777**
 Other Phone: **778-999-1234**
 Email: **info@nidus.ca**
 Address: **555 Constellation Ave.
 Milky Way British Columbia
 V1V 1V1
 Canada**

Alternate Representative
 Name: **Lyra Star**
 Phone: **888-999-1010**
 Address: **123 Draco St.
 Milky Way British Columbia
 V2V 2V2
 Canada**

Click to view a copy of an uploaded document. It can be printed and saved for a patient or client's record or future reference.

Document Information

Type: **Representation Agreement**
 Document Number: **2942048-1**
 Date Signed: **May 30, 2014**
 Last Updated: **May 6, 2015**

Document Location & Access

Location of Original Document: **Sylvia Star**
 Address 1: **555 Constellation Ave.**
 City: **Milky Way**
 Province: **British Columbia**
 Country: **Canada**
 Postal Code: **V1V 1V1**
 Phone: **555-666-7777**
 More Details: **fireproof safe in bedroom closet**
 Uploaded File: **View Document**
 Allow Financial & Legal: **No**
 Allow Health & Personal: **Yes**
 Permit allowed to access copy: **Yes**