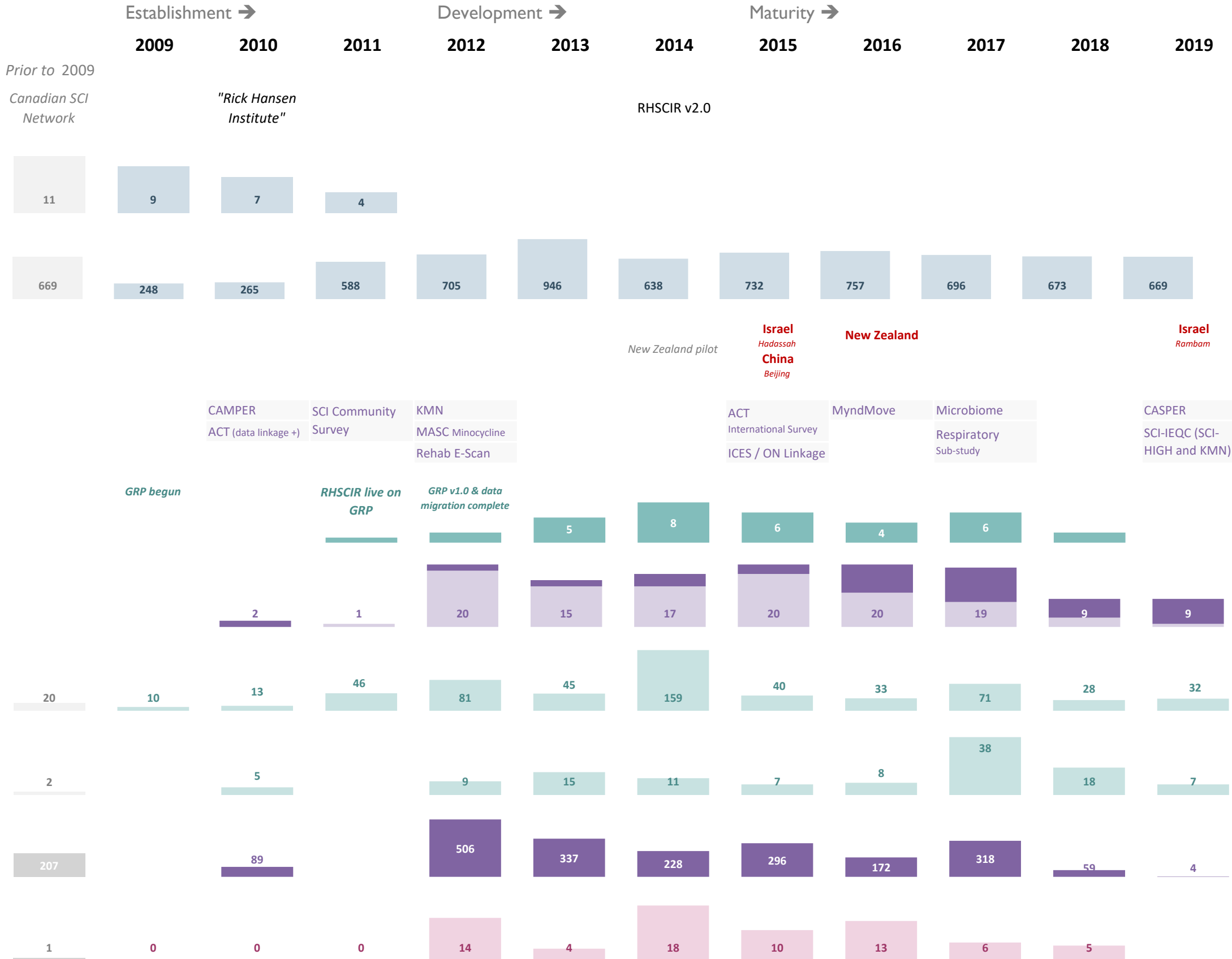


RETROSPECTIVE REVIEW OF THE RICK HANSEN SPINAL CORD INJURY REGISTRY (RHSCIR) PROJECT 2009 – 2019

EXECUTIVE SUMMARY (NOVEMBER 13, 2019)

Timeline

RHSCIR has accomplished much over the last 10 years



- Prior to 2004**
- The etiology of tSCI across Canada was limited.
 - Researchers had limited means to collaborate and limited community of practice.
 - Research cohorts were small and cohort heterogeneity limited the utility of research.
- Since 2009**
- RHI has provided sites with \$14M+ in research funding.

30 facilities in **18** sites, as of 2019

7,586 people enrolled

4 international collaborations in 3 countries

13 multi-site research studies supported by participation from at least **16** RHSCIR sites and at least 28 external sites

35 Global Research Platform clients reach into Canada (23), internationally (11), online (1)

132 data access requests increasingly external

578 KT activities (in addition to publications) 75% conference

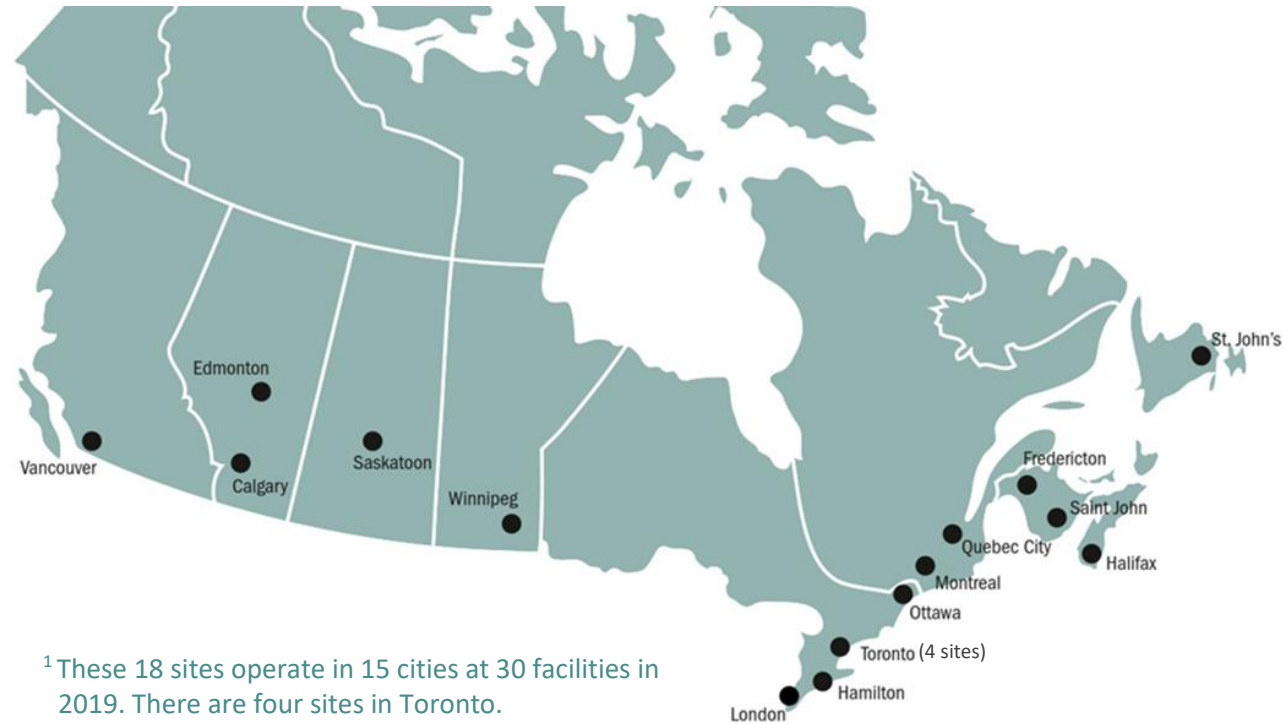
120 publications

2,153 citations as noted in Google Scholar

71 clinical activities, best practices & standards informed or implemented across 18 facilities

Goal Linking clinicians, researchers, and health care administrators with the goal of improving both research and clinical practice for individuals with SCI

RHSCIR has become a national network active at 18 sites¹ in 9 provinces²



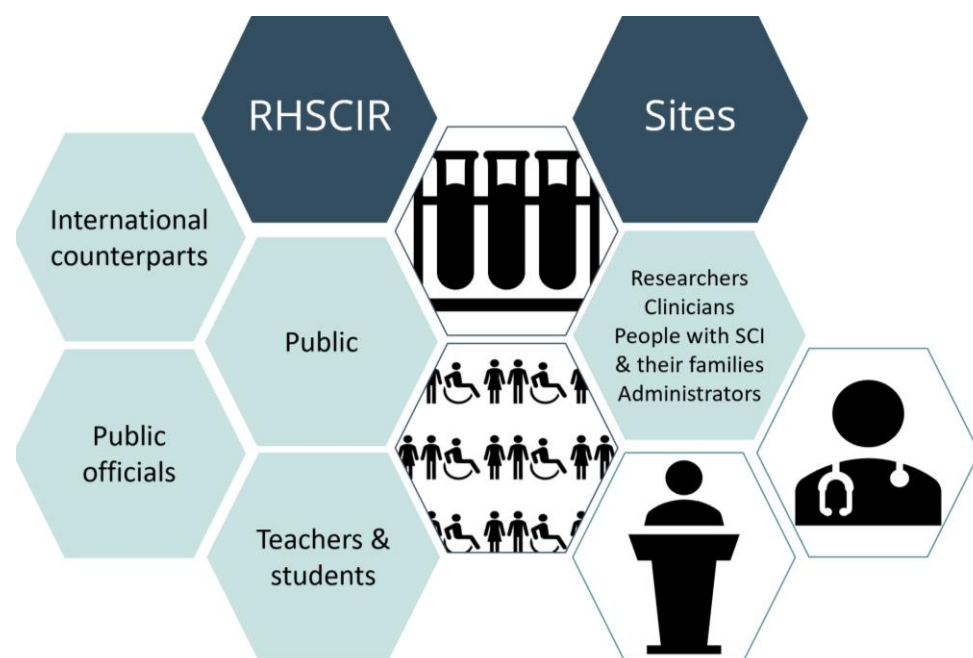
¹ These 18 sites operate in 15 cities at 30 facilities in 2019. There are four sites in Toronto.

Sites are engaged in multiple ways relating to research and care (beginning year)

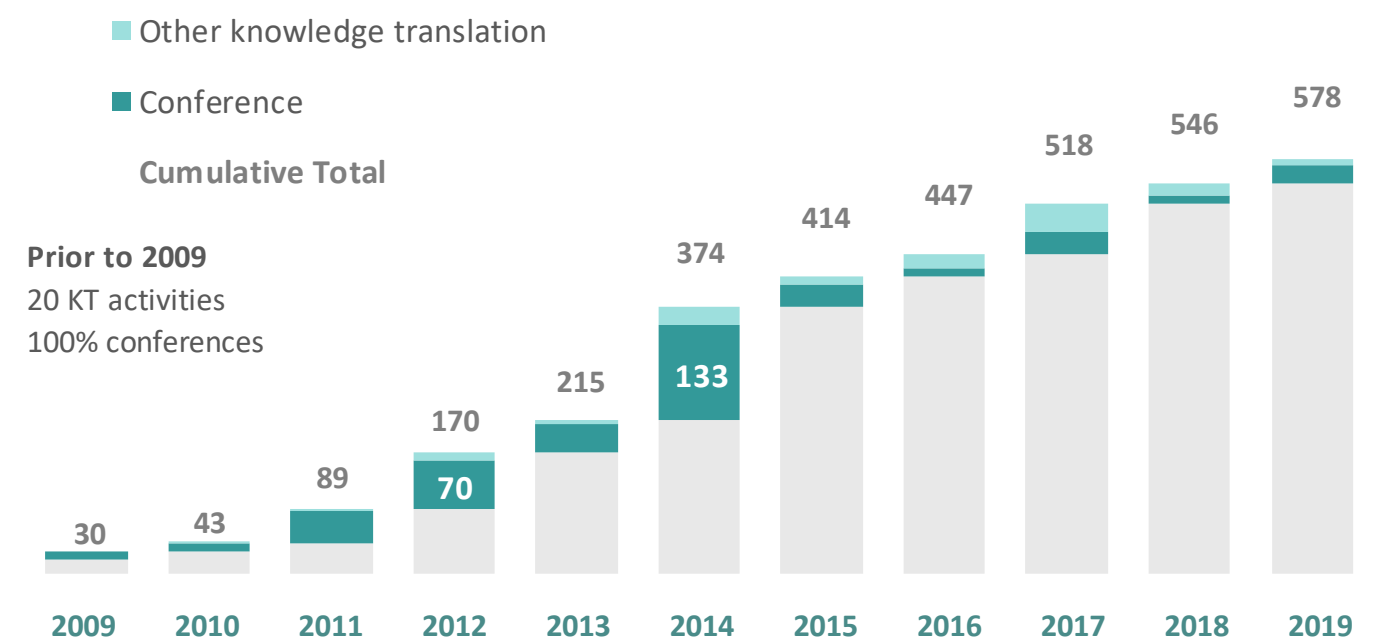
	Date added (2004)	Total enrollments (2004)	Multi-site research studies (2010)	Contributions to:			
				Data access requests (2011)	Scientific publications (2006)	Best practices implemented (2012)	Clinical improvements informed (2013)
Vancouver	2004	1522	7	34	82	4	11
Edmonton	2006	691	6	2	7	7	8
Calgary	2005	590	7	3	17	8	2
Saskatoon	2009	218	2	1	11	1	2
Winnipeg	2005	356	2	1	11	3	3
Toronto ³	2009	1333	14	10	38	6	2
Hamilton	2006	466	6	3	10	4	4
London	2009	312	5	1	15	6	2
Ottawa	2011	341	5	3	9	2	3
Montreal	2009	881	5	6	22	7	1
Quebec	2009	420	4		19	6	2
Halifax	2008	239	5		17	4	2
Saint John	2011	59			5		4
Fredericton	2011	59	6		3	1	1
St. John's	2010	99		2	1		
Atlantic			7	1			

³ Four sites are located in Toronto

RHSCIR has engaged with a wide range of stakeholders



Including through knowledge translation & outreach activities – especially conferences (75%)



Prior to 2009
20 KT activities
100% conferences

Goal Accelerating the discovery, validation and translation of relevant treatments and practices with the goal of improving outcomes and quality of life for people living with SCI

13 Multi-site research studies supported

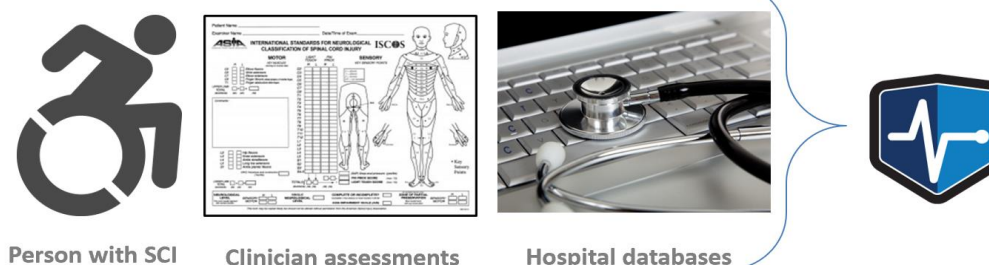
Participation from 16 RHSCIR and at least 28 external sites.

	RHSCIR	External
2010		
ACT data linkage & simulation model components	16	
CAMPER	7	one
2011		
SCI Community Survey	n/a	n/a
2012		
KMN	7	
MASC (Minocycline)	6	one
Rehab E-Scan	13	one
2015		
ACT International (survey)	2	at least 28
ICES / Ontario Linkage Project	3	
2016		
MyndMove	4	one
2017		
Microbiome	2	three
Respiratory Sub-study	6	
2019		
CASPER	2	two
SCI-IEQC (SCI-HIGH and KMN)	4	one

The Global Research Platform (GRP) developed for RHSCIR supports other research as well

- Development started in 2009
- RHSCIR went **live** on GRP in November 2011
- v1.0 features final May 2012
- RHSCIR data migration to GRP complete June 2012

Free data platform for SCI research: Moving from research into quality improvement/ knowledge translation

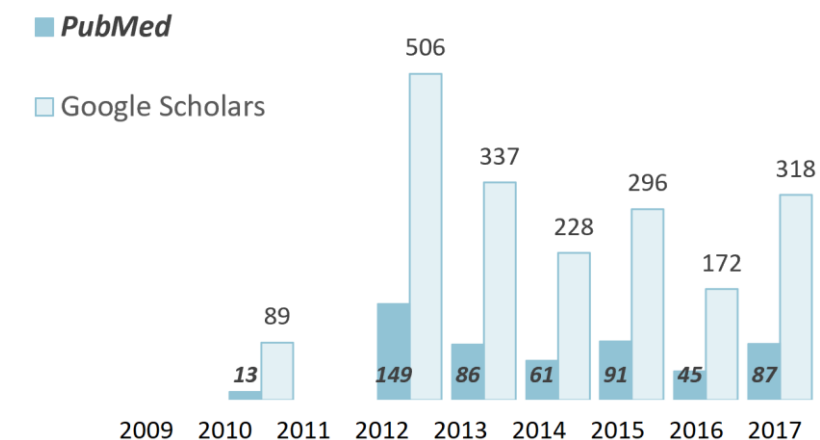


35 Canadian & International projects using the GRP (April 2019)

68% Canadian projects | **32%** International projects

RHSCIR has contributed to at least 120 publications (cited more than 2,100 times)

Papers published in 2012 and 2015 cited the most to date.



	2009	2010	2011	2012	2013	2014	2015	2016	2017
# papers (n=93)	-	5	-	9	15	11	7	8	38
Avg Citations in PubMed	-	3	-	17	6	6	13	6	2

Most KT topics related to the validation of standards/instruments, the development of models/data relationships & of SCI registry

	Total (n=698)	KT Activites (n=578)	Papers (n=120)
Math. model & algorithm dev. / data relationships, validation & linkages	16%	15%	20%
Validation / evaluation of standards & methods / best practices	15%	15%	19%
Registry development / KT / planning / outreach	14%	15%	10%
Interventions (acute)	13%	13%	12%
Access to care & timing / care pathway / length of stay	10%	8%	17%
Patient outcomes / quality of life / socio-economic impacts	9%	9%	12%
Interventions (rehabilitation) / secondary complications management	6%	7%	3%
Prevalence / incidence	6%	5%	8%
Other / Unknown or n/a	11%	14%	

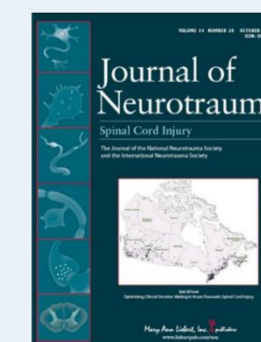
RHSCIR contributions to SCI research also include...

- With 7,500+ participants enrolled, there are more data available for research and the etiology of tSCI is better understood as a result of analysing them.
- The larger dataset allows researchers to move away from small cohort groups to larger, more representative cohorts – from 10s of participants to 100s of participants.
- More targeted research can be undertaken on more specific SCI patient outcomes topics.
- The RHSCIR protocol / GRP provides researchers with:
 - A common lexicon and standardized measures with which they can compare and contrast their work
 - A common tool that is compliant with research and ethics boards across its user groups and with international standards on data management and standards (CRF21.11)
- The 2012 change in data strategy led to significant increases in research and knowledge translation
- The development of international groups / datasets is an unintended impact of RHSCIR
- RHSCIR can now be linked to other data sources, e.g., imaging, biomarker data, provincial health, and local administrative data

...and the ACT Focus Issue (13 articles) published in 2017 in the *Journal of Neurotrauma*

38 citations in **PubMED**

73 citations in **Google Scholar**



Goal Helping facilitate the translation of **research into clinical practice** and to promote evidence-based practices

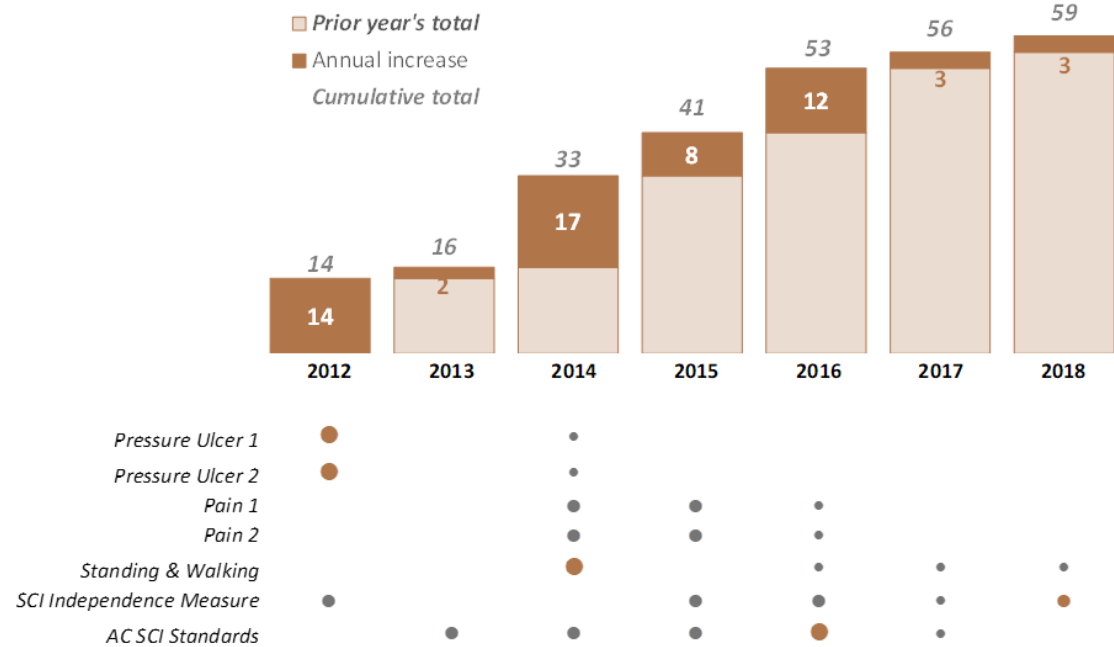
18 facilities in 13 cities report implementing best practices / standards

Peaks in reporting such implementation observed in 2012, 2014, 2016.

Annual reports of best practice and standards implementation

18 facilities in 13 cities have reported implementing best practices / standards

Peaks in reporting such implementation observed in 2012, 2014, 2016



RHSCIR has supported development, revision or implementation of 9 other best practice tools and standards in 5 areas

This includes through the use of RHSCIR’s dataset/algorithm, network and content or through RHSCIR’s implementation of the guidelines e.g., through its best practice implementation.

Environmental Scan of care practices

- Rehabilitation Environmental Scan Atlas: capturing Capacity in Canadian SCI Rehabilitation (e-Scan)

Data

- International SCI Data Sets
- NINDS Common Data Elements (CDE)
- Neurology
- ISNCSCI Algorithm

Evidence reviews and toolkit

- SCI Research Evidence (SCIRE)

Pressure ulcer guidelines

- Canadian Best Practice Guidelines (BPG) for the Prevention and Management of Pressure Ulcers in People with SCI: A Resource Handbook for Clinicians

Standards

- Accreditation Canada SCI Acute & Rehab Services
- SCI Rehabilitation Care High Performance Indicators (SCI-HIGH)

Research has informed other clinical improvement activities

	Participating RHSCIR sites
Prior to 2009	
Staff overtime costs	1
2013	
Delirium screening	2
New measures to screen for depression	2
2014	
Pressure injuries	2
2015	
Timing of surgery	14
Use of steroids	8
2016	
Implication of moving patients (increased complications)	2
2017	
Access to rehab and outcomes	9
Urban/rural health in BC	3
Catheters for the management of UTI in acute care	2
2018	
New measures of spasticity	1
Respiratory management e.g., tracheostomies	1

The ISNCSCI Algorithm developed for RHSCIR is used by others in Canada and around the world.

39 peer-reviewed articles on (or informed by) the Algorithm were published (2015 to 2018)

126 citations in PubMed

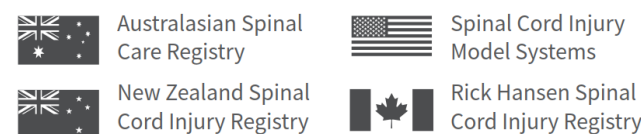
529 citations in Google Scholar

Worldwide reach via the website (2012 to 2018)

51,690 users in 161 countries

989 downloads of source code Used internationally

4 SCI registries use the Algorithm



5+ countries have integrated the Algorithm into electronic medical records

User uptake and benefits (user survey 2016-17)

74% increased use of ISNCSCI assessment

78% increased understanding of classification rules

84% increased confidence in classifying assessments

Demonstrated applications and uses

- For accurate and efficient clinical documentation
- To improve the ISNCSCI classification rules
- To support learning of a clinically important assessment
- To improve accuracy of key research data

Conclusions

Since the establishment of the Rick Hansen Spinal Cord Injury Registry, the field of SCI research and clinical practice has grown to the point that it is difficult to easily compare life today to what it was like before RHSCIR.

In the last 10 years, the RHSCIR protocol has been updated substantially and the last facilities and sites were established. As of 2019, there were **30** facilities in **18** sites. **7,586** people were enrolled, the **Global Research Platform** launched, and **35** clients now use it. **Four international collaborations** were established, and **71 clinical activities, best practices and standards** were informed or implemented.

Thirteen multi-site research studies were supported with participation from 16 RHSCIR sites and at least 28 international ones. Results of research and other knowledge translation activities were held **578** times, 75% of which were conferences. This is in addition to the **120 publications**, which had more than **2,100** citations. Since 2009, RHSCIR has provided at least **\$14 million** in research funding to sites.

RHSCIR has answered its initial *a priori* research questions set by RHI and grown to be used by researchers across Canada and internationally to answer a breadth of questions.

It is achieving its initial three goals of:

- **Linking clinicians, researchers, and health care administrators** with the goal of improving both research and clinical practice for individuals with SCI
- **Accelerating the discovery, validation and translation** of relevant treatments and practices with the goal of improving outcomes and quality of life for people living with SCI
- Helping facilitate the translation of **research into clinical practice** and to promote evidence-based practices

Significant changes and their benefits to people with SCI

- ❖ tSCI patient journeys, which include patient voices, are used as the basis for research data rather than discrete phases of care
- ❖ Multi-site research studies provide patients with access to innovative research and treatments
- ❖ Best practices such as accreditation and the ISNSCI algorithm improve the accuracy of SCI diagnoses and contribute to better care

Methods

The Retrospective Review was based on a review of documents and files shared by the Rick Hansen Institute with the review team as of August 2019. Additional information was gathered online and through interviews with internal RHI key stakeholders through September 2019. No external consultations or surveys were conducted as part of the review.

About RHSCIR

The Rick Hansen Spinal Cord Injury Registry (RHSCIR, Registry) is a pan-Canadian prospective observational registry of individuals who sustained traumatic spinal cord injuries (SCI) and who received treatment at participating facilities in Canada. There are collaborations in place in China, Israel, and New Zealand.

Acronyms

ACT	Access to Care & Timing Project	HHS	Hamilton Health Sciences	PG	Practice guidelines
ASIA	American Spinal Injury Association	ICES	Institute for Clinical Evaluative Sciences	PI	Primary Investigator
BPG	Best practice guidelines	ISNSCI	International Standards for Neurological Classification of Spinal Cord Injury	Rehab E-Scan	Rehabilitation Environmental Scan Atlas
CAMPER	The Canadian Multicentre CSF Pressure Monitoring and Biomarker study	KMN	Knowledge Mobilization Network	SCI	Spinal Cord Injury
CASPER	Canadian-American Spinal Cord Perfusion Pressure and Biomarker Study	MASC	Minocycline in Acute Spinal Cord Injury	SCI-IEQC	Spinal Cord Implementation, Evaluation and Quality Consortium
GRP	Global Research Platform	NINDS	National Institute of Neurological Disorders and Stroke	SCI-HIGH	SCI Rehabilitation Care High Performance Indicators
		NP	Neuropathic Pain	tSCI	Traumatic Spinal Cord Injury
				UTI	Urinary tract infection