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International Alliance of
Patients' Organizations
A global voice for patients

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Using Report Cards as an advocacy tool — The Canadian Experience

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Session outline

The CSPA report card and the CAPP report card

The campaigns

How you can replicate this experience, and increase your credibility and impact



Who I am

Past CEO:

Canadian Skin Patient Alliance (CSPA)

Canadian Association of Psoriasis Patients (CAPP)

Founder and current CEO

International Alliance of Dermatology Patient Organizations
aka GLOBALSKIN

Board member

Cicatricial Alopecia Research Foundation (International)

Best Medicines Coalition - Canada (Past)

Canadian Skin Patient Alliance

The **Canadian Skin Patient Alliance** is a 'for patients, by patients' umbrella organization that has been:

- serving Canadians with skin disorders almost 9 years

- Advocating to government for research and access to appropriate care

The challenge: Skin is NOT "in"! No credibility, no sense that skin diseases matter

The Challenge: Healthcare in Canada

National Health Care Plan

No national

Pharmaceutical plan

Health Care is federally
funded, but provincially
regulated and administered

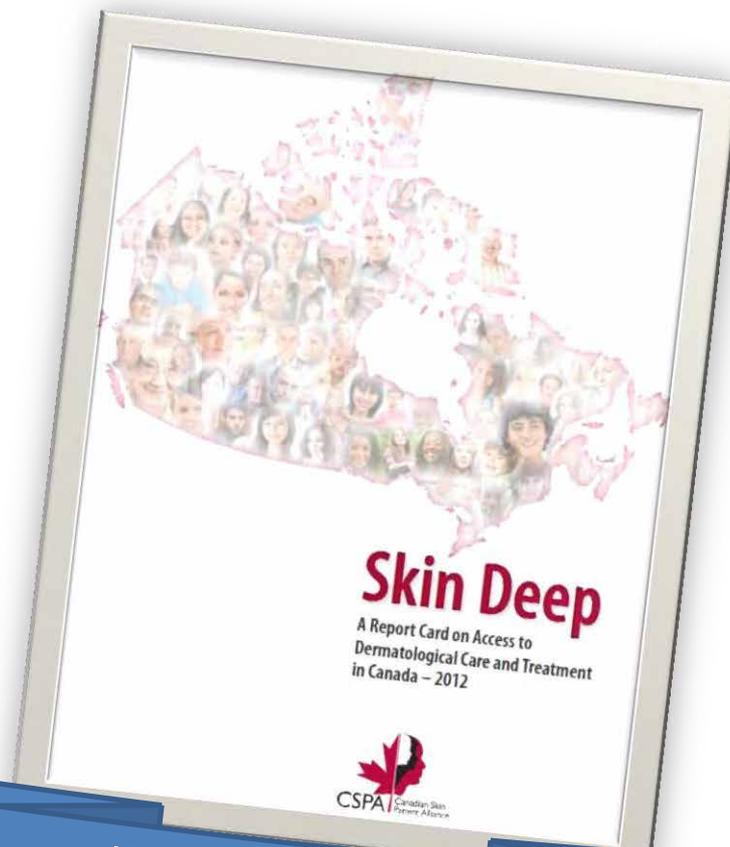
10 provinces and 3
territories

13 Health Ministers

12 Drug plans



***Skin Deep* –
Canada's first
Report Card on
Dermatology
access issues,
2012**



Winner – 2012 Public
Education Award

Skin Deep – Objectives

Raise CSPA's credibility/profile

With payers (government and insurance)

In advocacy circles

With sponsors/partners

Raise visibility on the dire access issues faced by dermatology patients - **Force change**

Create an advocacy tool to be used by all stakeholders

Provide patients with a tool to help them self-advocate

Compare,
compare,
compare.

***Skin Deep* – Methodology**

1. Defined core issues – access to care, to procedures and to medicines, and measurement standards
2. **Chose 7 representative skin diseases (from \approx 3000)**
3. Hired researcher who culled data from public domain and submitted draft
4. Medical advisory board validated facts per province
5. Board agreed on recommendations
6. Multiple edits, copy edit, layout and info-graphic design
7. Crafted release and advocacy strategy
8. Time from start to finish – 1 year+



Skin Deep — What we found

1. Dermatological diseases underrated
2. Long wait times
3. Shortage of dermatologists
4. Few dermatologists – especially in outlying areas
5. Problems with access to procedures
6. Complex barriers to access to medications





Skin Deep

Access to Dermatological Care
and Treatment in Canada

At any given moment, approximately half of Canada's population is grappling with a skin condition, disease or trauma. Some of these are life-threatening and others severely reduce the quality of life for patients and their families.

Canada is FAILING in 3 key areas

The basic needs of the millions of Canadians with skin diseases are not being met.

1 ACCESS TO
DERMATOLOGICAL CARE

2 ACCESS TO
MEDICAL PROCEDURES

3 ACCESS TO
MEDICATIONS

ACCESS TO MEDICAL PROCEDURES

Canada falls far short of the CSPA's benchmarks.

11/13 PROVINCES & TERRITORIES

FAIL

to provide adequate access to medical procedures.



● Represents location of phototherapy clinics *

Excel = >75%

Pass = 51-75%

Needs Improvement = 35-50%

Fail = <35%



Phototherapy is a widely used, effective and non-invasive treatment for several skin conditions, including **PSORIASIS, VITILIGO, ECZEMA, LICHEN PLANUS, ACNE, ITCHY SKIN, GRANULOMA ANNULARE** and the list goes on...

THE FOLLOWING PROVINCES DO NOT COVER...



MOHS MICROGRAPHIC SURGERY

complex skin cancers



PHOTOPHERESIS

cutaneous T-cell lymphoma



ACCESS TO MEDICATIONS

Canada falls far short of the CSPA's benchmarks.

11/13 PROVINCES & TERRITORIES
FAIL

to provide adequate access to dermatological medications.

Excel = >75%

Pass = 51-75%

Needs Improvement = 35-50%

Fail = <35%

OVERALL, COVERAGE IS **LOW**

Of the skin disease medications recently approved by Health Canada, **ONLY A SMALL % ARE FULLY COVERED**

100

60

20

Fully funded medications
BY DISEASE*

PSORIASIS

ECZEMA

VIRAL INFECTIONS

SKIN CANCERS

	BC	AB	SK	MB	ON	QC	NB	NS	PEI	NL	YK	NIHB**
PSORIASIS	4/11	5/11	4/11	1/11	3/11	4/11	2/11	1/11	1/11	1/11	4/11	3/11
ECZEMA	0/3	0/3	0/3	0/3	0/3	0/3	0/3	0/3	0/3	0/3	0/3	0/3
VIRAL INFECTIONS	5/7	3/7	4/7	5/7	1/7	4/7	4/7	4/7	4/7	4/7	4/7	5/7
SKIN CANCERS	1/3	0/3	0/3	1/3	1/3	1/3	1/3	0/3	1/3	0/3	0/3	1/3



While some medications are universally covered for these diseases, this chart addresses only the drugs that are covered by special access or not covered at all even though they are Health Canada approved.

** NIHB=

Non-Insured Health Benefits is a federal program which covers the costs of medications, medical supplies and medical travel, within certain restrictions, for registered First Nations and Inuit beneficiaries.

ACCESS TO DERMATOLOGICAL CARE

Canada falls far short of the CSPA's benchmarks.

11/13 PROVINCES & TERRITORIES

FAIL

to provide adequate access to dermatological care.



Excel = >75% Pass = 51-75% Needs Improvement = 35-50% Fail = <35%



* The concentration of dermatologists is largely in southern, urban areas. The shortage of dermatologists is startling in rural and remote areas of Canada.

Long wait times...

BENCHMARK = 5 weeks



38%

OF DERMATOLOGISTS ACROSS CANADA REPORTED THEIR ACCESSIBILITY AS POOR OR FAIR



WAIT TIMES ARE INCREASING



0 DERMATOLOGISTS. THEY RELY SOLELY ON OUTREACH SERVICES

Access to Care: Overall wait time ratings

Table 3: Median wait times in weeks for routine consultation

	Bench-Mark	CDN	BC	AB	SK	MB	ON	QC	NB	PE	NS	NL
Median wait time (weeks) for routine consultation	5	12	10	8	14*	14*	12	18	23*	n/a	23*	23*
Performance Grade	Pass	NI	NI	NI	Fail	Fail	NI	Fail	Fail		Fail	Fail

* Wait times data for Saskatchewan, Manitoba and the Atlantic provinces were combined due to the small number of responses in each individual province.

Some Facts

Accessibility fails in 7/10 provinces

Average age of specialists is 55

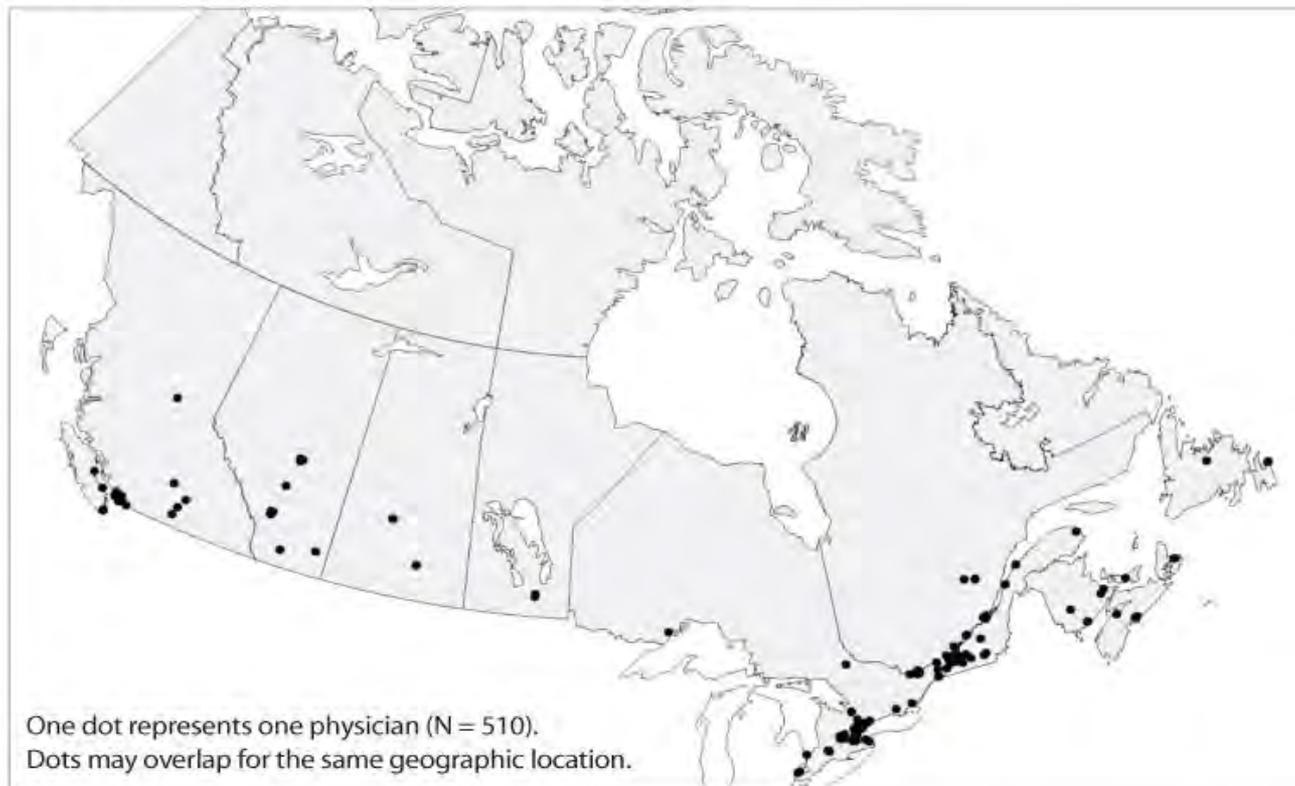
More than 20% over 65

FTE needs to increase by 6.2% annually

In 5 year period ending 2008/9 , increase in
of dermatologists was only .08%

Lack of access in rural and remote areas

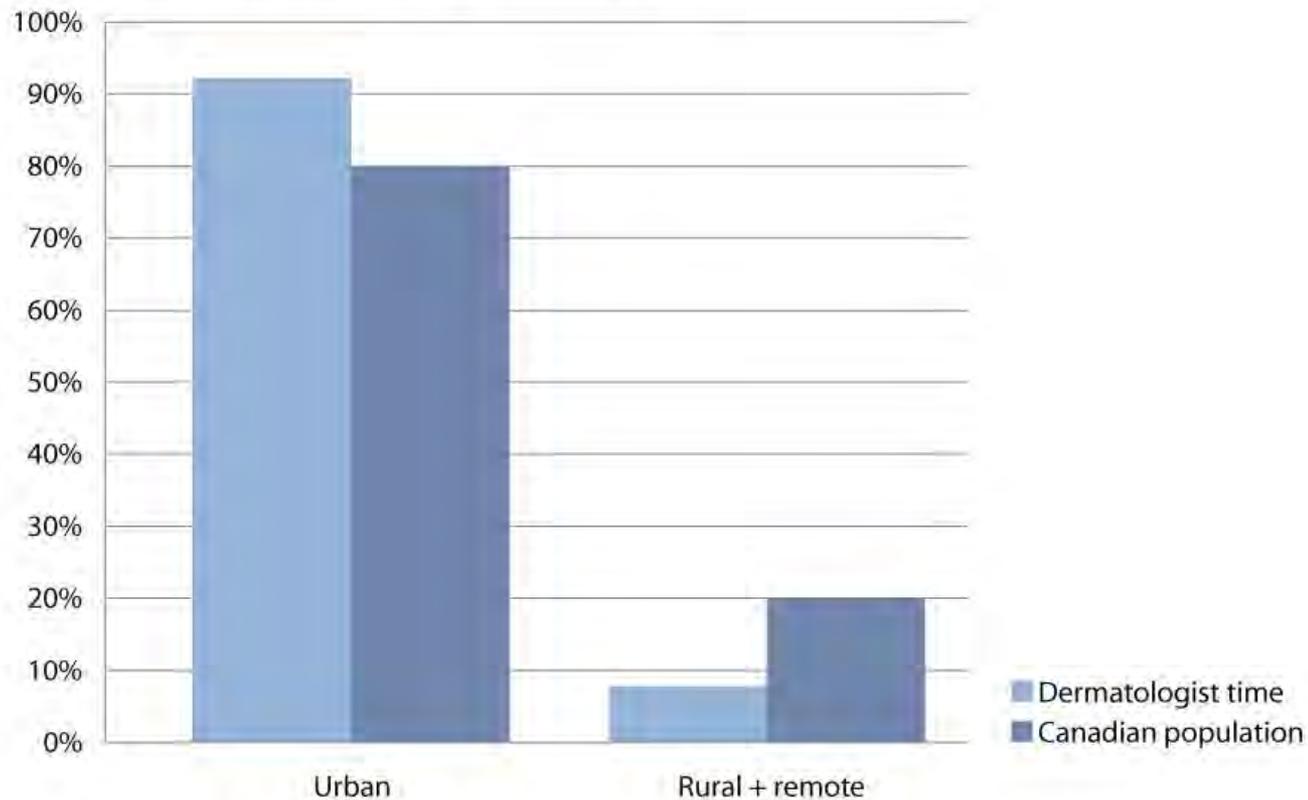
Figure 3: Distribution of Dermatologists in Canada



Source: Geographic Distribution of Physicians in Canada: Beyond How Many and Where. Canadian Institute for Health Information (CIHI) 2005.

Urban concentration of dermatology practices

Figure 4: Urban concentration of dermatology practice



Sources: CDA Workforce Survey 2006, Statistics Canada

Comparison of dermatologist fees per province and territory: 2011

Table 5: Comparison of dermatologist fees by province and territory

Appointment Type	Prov. Avg.	BC	AB	SK	MB	ON	QC
Fee per comprehensive consultation	\$78.99	\$59.66	\$69.03	\$78.20	\$64.45	\$70.25	\$62.20
Fee per repeat office visit	\$29.77	\$22.55	\$39.68	\$30.20	\$28.30	\$21.40	\$25.80

Appointment Type	Prov. Avg.	NB	PE	NS	NL	YT	NT
Fee per comprehensive consultation	\$78.99	\$102.95	\$85.00	\$119.60	\$78.51	\$108.30	\$116.70
Fee per repeat office visit	\$29.77	\$37.70	\$33.00	\$29.90	\$29.16	\$75.50	\$63.65

Legend:

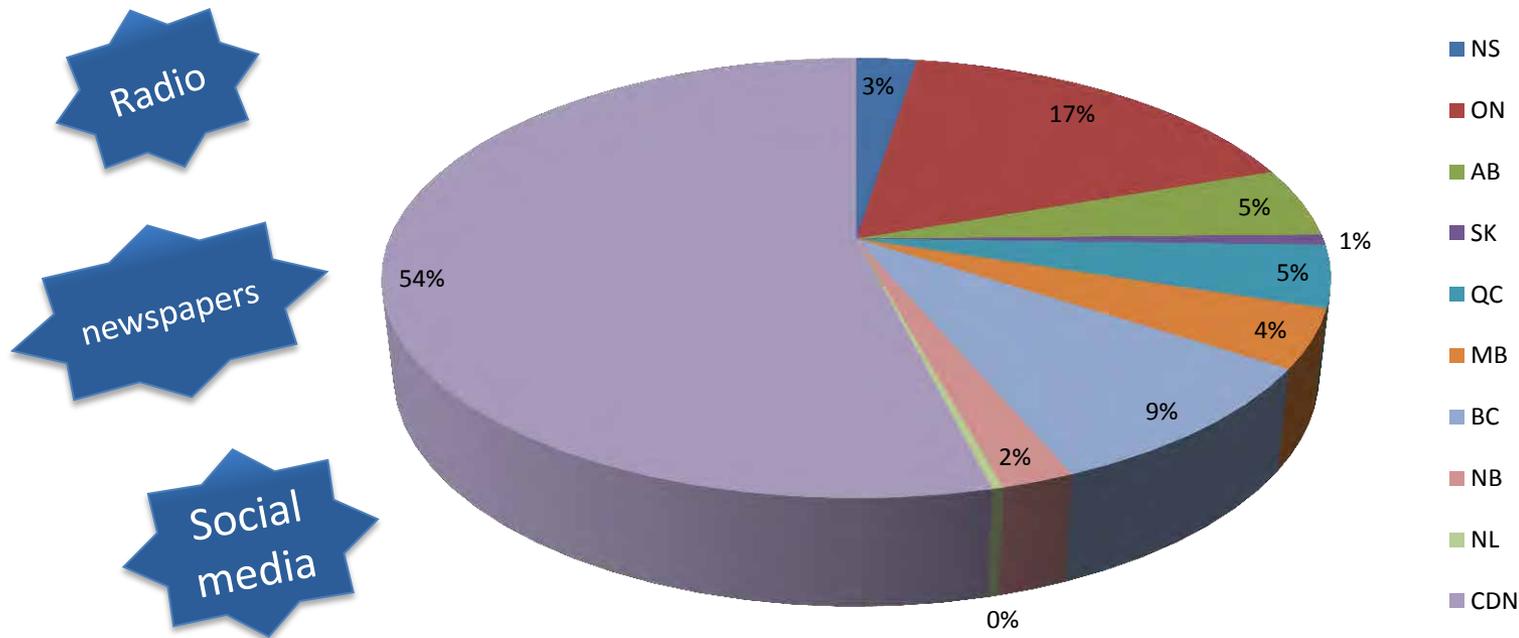
-  20% or more above provincial average
-  within +/- 20%
-  > 20% below

CDA Public Education Award for *Skin Deep*



Media Campaign for *Skin Deep*

Reach by Province



The total reach for the program was 16,965,935. Coverage from outlets with a nation-wide reach make up the majority (54 per cent) of the total reach

***Skin Deep* Report Card – Outcomes**

Easier access to all levels of decision-making

Increased visibility/*respect* for dermatological diseases

Government decision-makers book longer meetings
- *take our issues seriously*

New dermatology training spots created in several provinces.

Dermatologists and Pharma used the document heavily for their own advocacy

CSPA and CAPP

Since 2007 CSPA was primary psoriasis organization in Canada

In 2013, assisted in formation of CAPP

Separate Board, separate finances, shared staff

Same high standards as CSPA - unbiased

Goals — Education, advocacy and patient support

WHY do a Psoriasis Report?

Raise awareness of the seriousness of the disease with payers and decision-makers

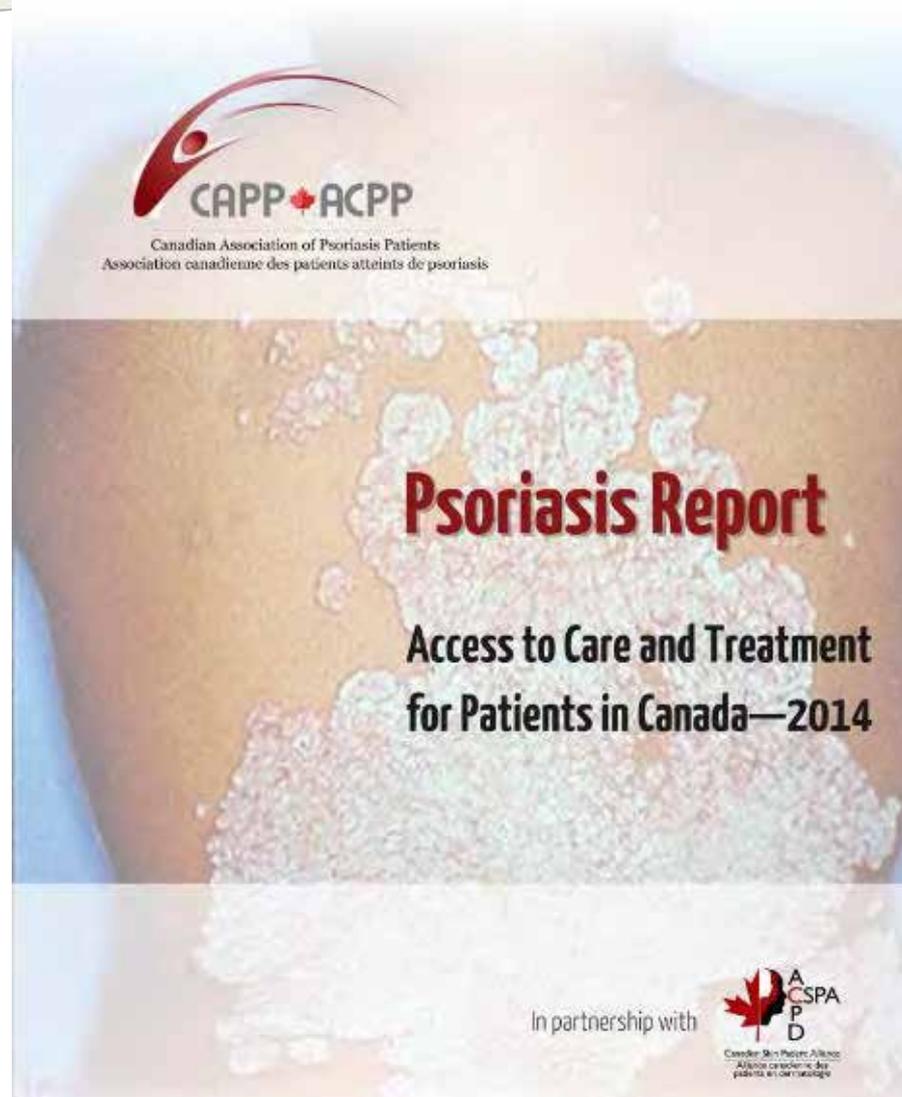
Improve access for Pso and PSA patients

Update dermatology stats

Provide an **new advocacy tool** for all stakeholders

Create a discussion point around psoriasis with key stats

CAPP - **Credibility** with multiple stakeholders as a go-to organization representing psoriasis/PSA patients



Methodology and Target audience

Methodology – Same as for *Skin Deep*

Launched on World Psoriasis Day, 2014 with a social media and press campaign

Target audiences – same as for *Skin Deep*

Planned follow-up advocacy tour in January.

Issues raised in the Pso REPORT

Access to dermatologists

(some won't see psoriasis patients!)

Access to phototherapy

Access to medications considered to be the standard of care

Tiered access via private insurance

Concerns with SEB's substitution and post market surveillance



2012 vs 2014

How is Canada performing?

	Access to Dermatological Care	Access to Medical Procedures	Access to Medications
Canada	Fail	Fail	Fail
British Columbia	Fail	Fail	Fail
Alberta	Fail	Fail	Fail
Saskatchewan	Fail	Fail	Fail
Manitoba	Needs improvement	Fail	Fail
Ontario	Fail	Needs improvement	Needs improvement
Quebec	Fail	Fail	Needs improvement
New Brunswick	Needs improvement	Fail	Fail
Prince Edward Island	Fail	Fail	Fail
Nova Scotia	Fail	Fail	Fail
Newfoundland & Labrador	Fail	Fail	Fail
Yukon	Fail	Fail	Fail
Northwest Territories	Fail	Fail	Fail
Nunavut	Fail	Fail	Fail
Non-Insured Health Benefits*	N/A	N/A	Fail

* Non-Ins

How is Canada Performing?

	Access to Dermatological Care	Access to Phototherapy	Access to Medications
Canada	Needs improvement	Fail	Fail
British Columbia	Fail	Fail	Fail
Alberta	Pass	Fail	Needs improvement
Saskatchewan	Fail	Fail	Needs improvement
Manitoba	Needs improvement	Fail	Needs improvement
Ontario	Needs improvement	Fail	Fail
Quebec	Pass	Fail	Needs improvement
New Brunswick	Fail	Needs improvement	Fail
Prince Edward Island	Fail	Fail	Fail
Nova Scotia	Needs improvement	Fail	Fail
Newfoundland & Labrador	Needs improvement	Fail	Fail
Yukon	Fail	Fail	Fail
Northwest Territories	Needs improvement	Needs improvement	Fail
Nunavut	Fail	Fail	Fail
Non-Insured Health Benefit (NIHB) program	Not applicable	Fail	Fail

Access to medications

Funding status by province of medications to treat psoriasis and psoriatic arthritis

Psoriasis drugs

Brand name (generic name)	BC	AB	SK	MB	ON	QC	NB	PE	NS	NL	YT	NIHB
Methotrexate	Full											
Dovonex (calcipotriol)	Full	Full	Full	SA	SA	Full	Full	Full	SA	Full	Full	Full
Dovobet (calcipotriol + betamethasone) ointment	Full	Full	Full	No	Full	SA	No	No	SA	No	Full	Full
Dovobet (calcipotriol + betamethasone) gel	Full	Full	Full	No	Full	SA	SA	SA	SA	SA	No	Full
Silkis (calcitriol cream)	No	No	No	No	SA	Full	No	No	No	No	No	No
Tazorac (tazarotene)	Full	Full	Full	SA	No	No	No	No	SA	SA	Full	Full
Neoral (cyclosporine)	SA	SA	SA	SA	SA	Full	SA	No	SA	SA	Full	No
Soriatane (acitretin)	Full	Full	SA	Full	Full	Full	Full	SA	Full	Full	SA	Full
Humira (adalimumab)	SA	No	SA	SA	SA	SA						
Enbrel (etanercept)	SA	No	SA	SA	SA	No						
Remicade (infliximab)	SA	SA	SA	SA	No	SA	SA	No	SA	SA	SA	No
Stelara (ustekinumab)	SA	No	SA	SA	No	SA						

Abbreviations: SA = Special Authorization (also called "limited use" and "exceptional drug status".)

NIHB = Non-Insured Health Benefits. Covers registered First Nations and Inuit. NIHB formulary is used by NT and NU.

Challenges

Launch on World Psoriasis Day –
lots of competition for media

Engaging patients

Sponsor follow-through

“Shock and awe”



Next Steps

Print and mail hard copies to KEY officials

Secondary media campaign during a low news cycle

Advocacy tour



Key Learnings

Funding from “core”
funds only

Media campaign can be
sponsored

Officials may ‘say’ they
don’t care about
rankings—but they do

Use media to support
advocacy

Use facts

Use pictures

Bring patients with
personal stories to the
meetings and to the media



Key Elements

1. *Compare jurisdictions to each other*
2. *Give them a grade*
3. *Provide LOTS of information that most people never see*
4. *Provide recommendations on how they can improve*
5. *Let them know you'll do a follow up*
6. *Be reasonable*



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Thank you!

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