



Patient Oriented Research in ethnocultural minority communities : challenges and opportunities

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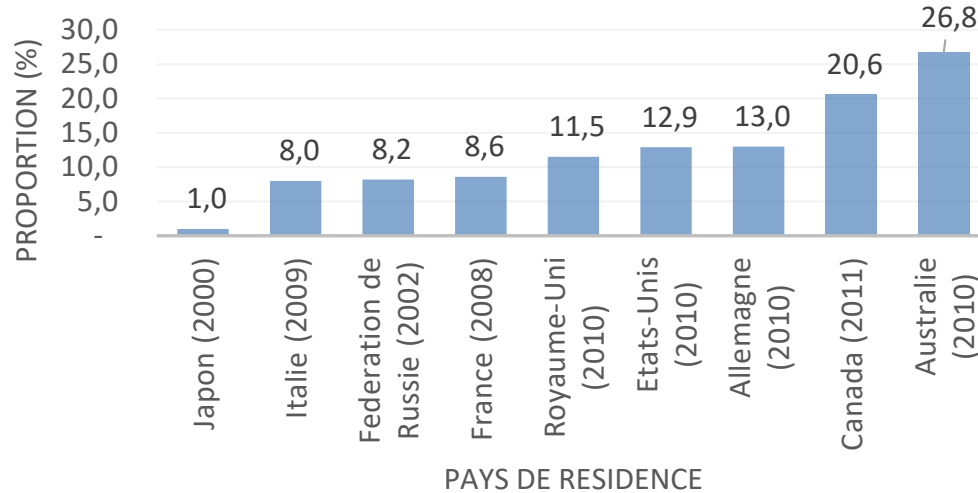
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THE RATIONALE

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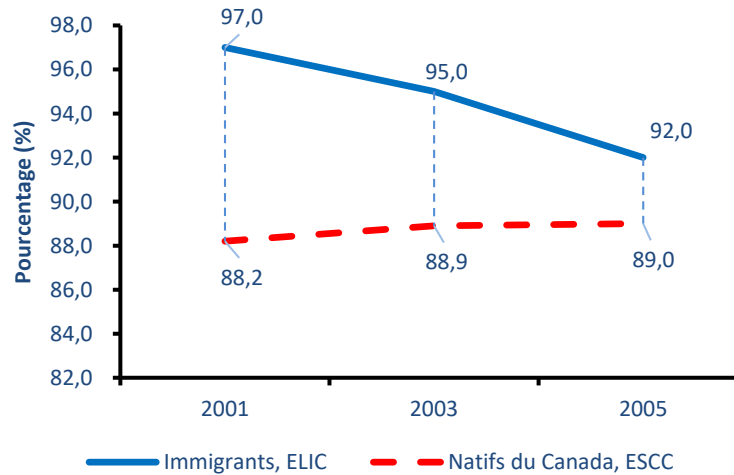
POPULATION NEE A L'ETRANGER EN PROPORTION
DE LA POPULATION TOTALE, PAYS DU G8 ET
AUSTRALIE



Source: Organisation de coopération et de développement économiques (OCDE). 2013. Perspectives des migrations internationales 2013. Paris, Éditions OCDE et et Statistique Canada: Enquête nationale

Immigration and Health

Figure : Part des immigrants et des personnes nées au Canada se déclarant en bonne santé

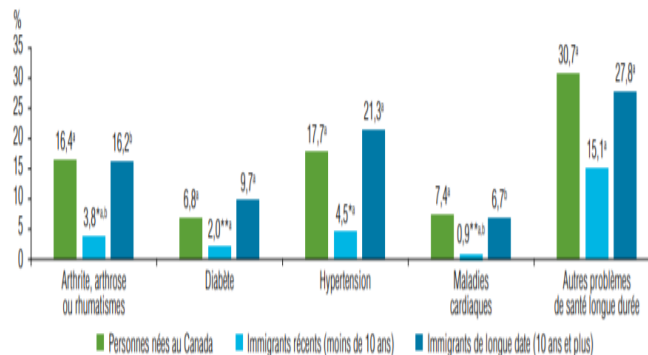


Source : ELIC (2005), ESCC (2000-2005)

Health iniquities

Figure 2

Problèmes de santé de longue durée selon le statut d'immigration, Québec, 2010-2011



^a Coefficient de variation entre 15% et 25%; interpréter avec prudence.

^{a,b} Coefficient de variation supérieur à 25%; estimation imprécise, fournie à titre indicatif seulement.

a, b Pour la variable statut d'immigration, les différences significatives au seuil de 5% entre deux catégories d'une variable sont indiquées par le même exposant.

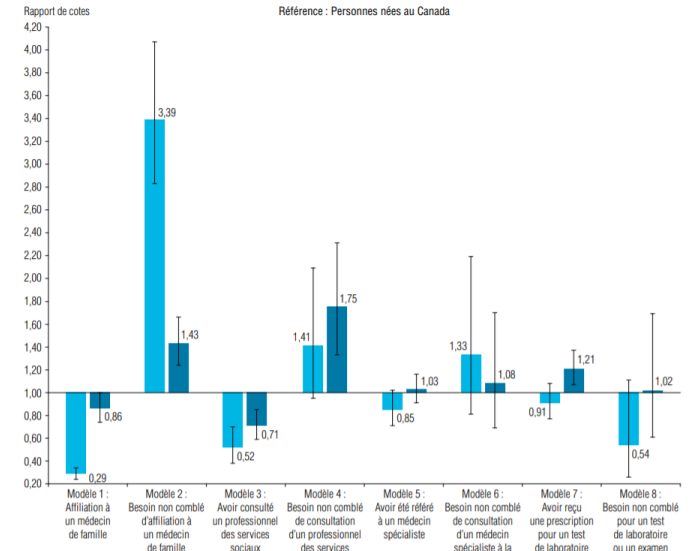
Source: Institut de la statistique du Québec, Enquête québécoise sur les limitations d'activités, les maladies chroniques et le vieillissement 2010-2011.

Health iniquities

- Immigrants are in general more affected by :
 - Cardiovascular diseases(South Asian)
 - Type 2 diabetes (Africans, Asians et Hispanics)
 - HIV/AIDS
 - Prostate Cancer (Africains)
 - Stress-related disorders (refugees)

<https://journals.sagepub.com/doi/10.1177/1757975913512159>

Figure 4
Utilisation des services de santé et besoins non comblés selon le statut d'immigration, synthèse des modèles de régression logistique, Québec, 2010-2011



Different
pattern of
using health
services
(unmet needs)

Lessons from 2 Case studies

- Case 1 : Diabetic retinopathy screening project
- Case 2 : Patiented Oriented Research Network, the case of Diabetes Action Canada

Understanding the barriers and enablers to attending diabetic retinopathy screening by people with diabetes from ethnocultural minority settings



Theme	Sub-Theme	Representative Quote
Perceived Physical Harm		"... Definitely, since pupil dilation is uncomfortable. Since the vision is blurred, I'm worried that the checkups may have an impact on my eyes, right?"
Practical Appointment Issues	It's hard to remember when my appointment is	"Well, he [the doctor] told me to go every year, but I always forget about it."
	It's hard to make an appointment	"It's hard to make an appointment with an ophthalmologist here. I've only done it once."
	Distance to Clinic	" It was faraway too! I had to go by bus and transfer three times since I don't drive."
	Cost of screening	"Economy is definitely one factor. I don't have work or income here. If the expense is high, then I won't be able to do it"
Social / Professional Influence	Influence of physicians and family were important determinants of attendance	"The doctor just told me to control the glucose level and exercise more. He hasn't mentioned anything about eyes"
	I need support from my family/friends to do it	"I will need my children to drive me there."
	I haven't spoken about it with anyone else with diabetes	"I don't have a lot of chances here (for the checkup)... since I don't know any fellow patients, or the kind of events I should go to"
Knowledge Gaps		"This is the first time I am learning about the retinopathy aspect of diabetes. It is the first time, since I did not previously have this knowledge. "
Language barrier		"In Canada, I can't really go to the screening due to the language barrier"
Preference for care outside Canada		"Actually, I only stay in Canada for half a year every year and spend the rest of the time in China. I mostly go to the doctors in China since it's convenient, considering that I can't speak the language here. Furthermore, I have access to health care in China too."
Priorities	Getting my eyes screened is more of a priority than other things in my life	"Since I take my health very seriously, I make the screening my first priority. I'll go to the screening even if that means cancelling everything else."



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CHALLENGES

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“ Political ” or “apolitical” space



The space of partnership is not neutral



It is both political and apolitical (Fortin, 2013)

apolitical : professional status ;
political constant negotiation of values,
norms which are contextual, cultural and
historical, in constance movement

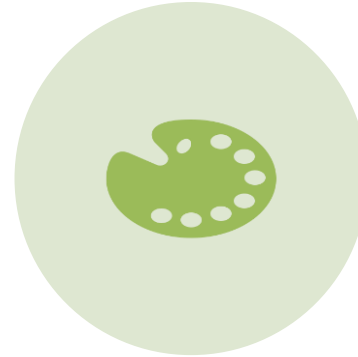


It is a social space : relations of power and inequities

“ Political ” or “apolitical” space



DEFINITION OF ROLES ARE
BEYOND INTENTIONS



HISTORY AND ITS
INTERPRETATION SHAPES THE
SOCIAL SPACE

2 Case studies

- Case 1 : Diabetic retinopathy screening project
- Case 2 : Patient Oriented Research Network, the case of Diabetes Action Canada



Diabetes Action Canada

Preventing complications. Transforming lives.

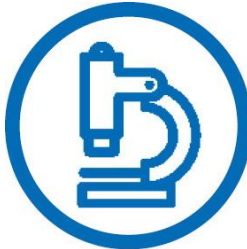
Gary Lewis, Jean-Pierre

Després

Cathy Whiteside



À PROPOS | VIVRE AVEC LE DIABÈTE | RECHERCHE | PARTENAIRES | NOUVELLES | EN | FR



70 Researchers



37 Partners



7 Provinces





Patient Engagement within DAC



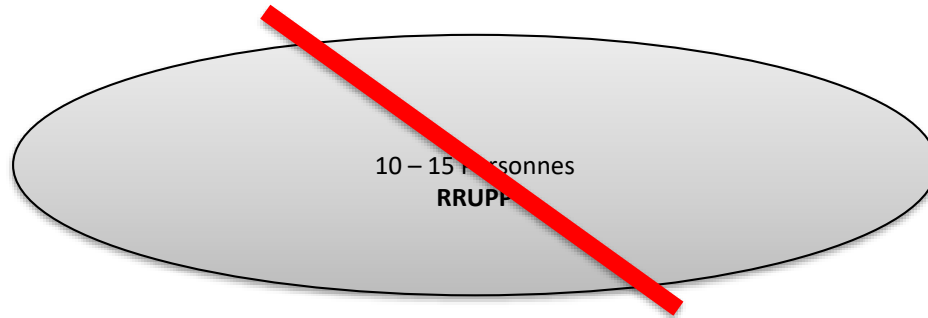
- Initially planned as a unique platform RRUPP (Research and Research Users' Partnership Platform)
- With
 - People living with diabetes
 - Indigenous
 - Immigrants
 - People from other categories
 - Researchers
 - Managers
 - Other partners

Initial Platform

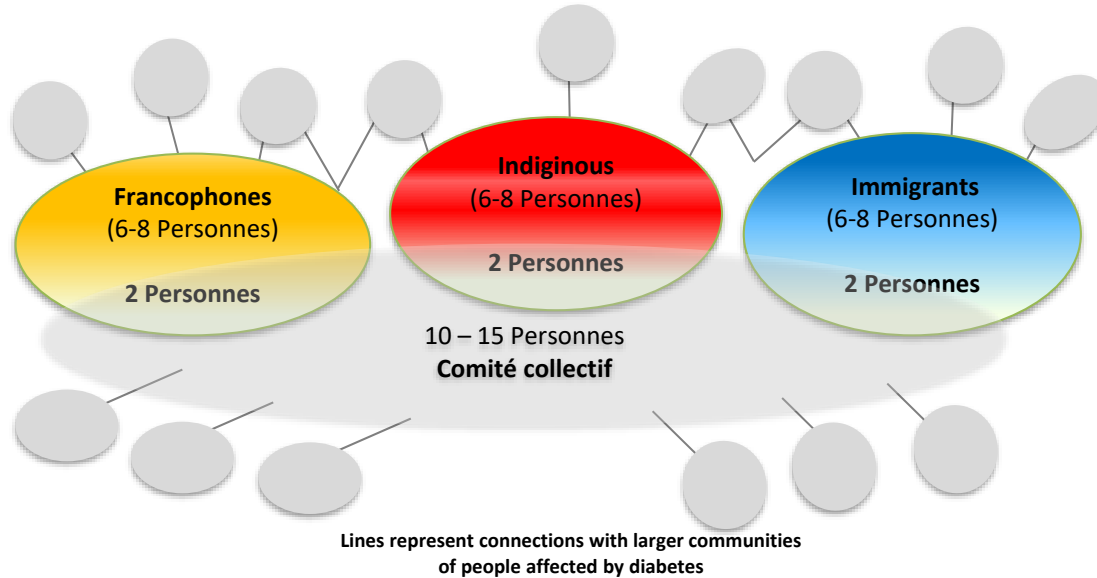
- Research and Research Users' Partnership Platform



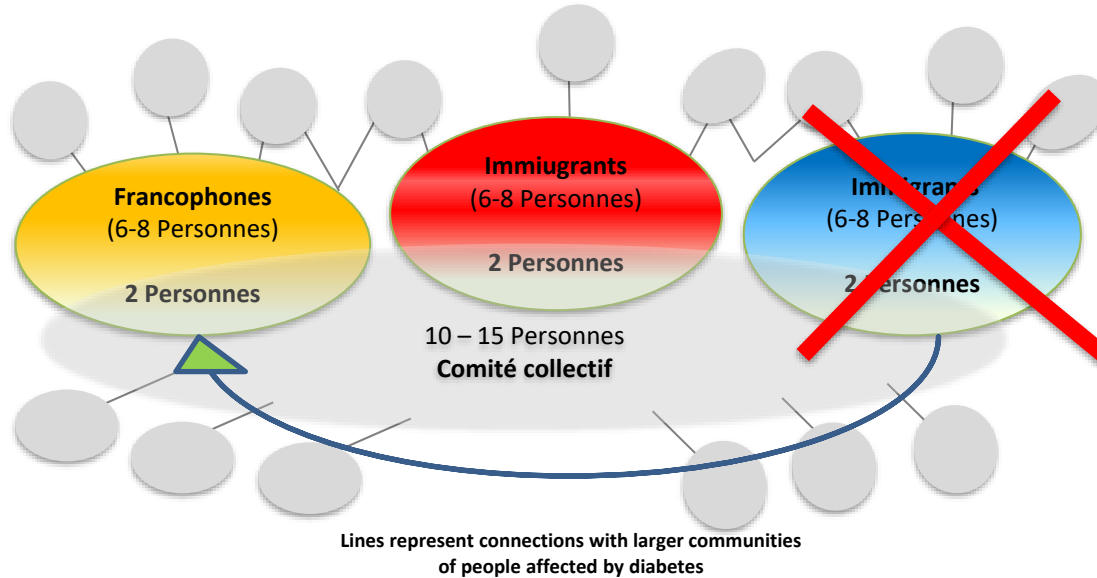
One size does not fit all



New “structure”



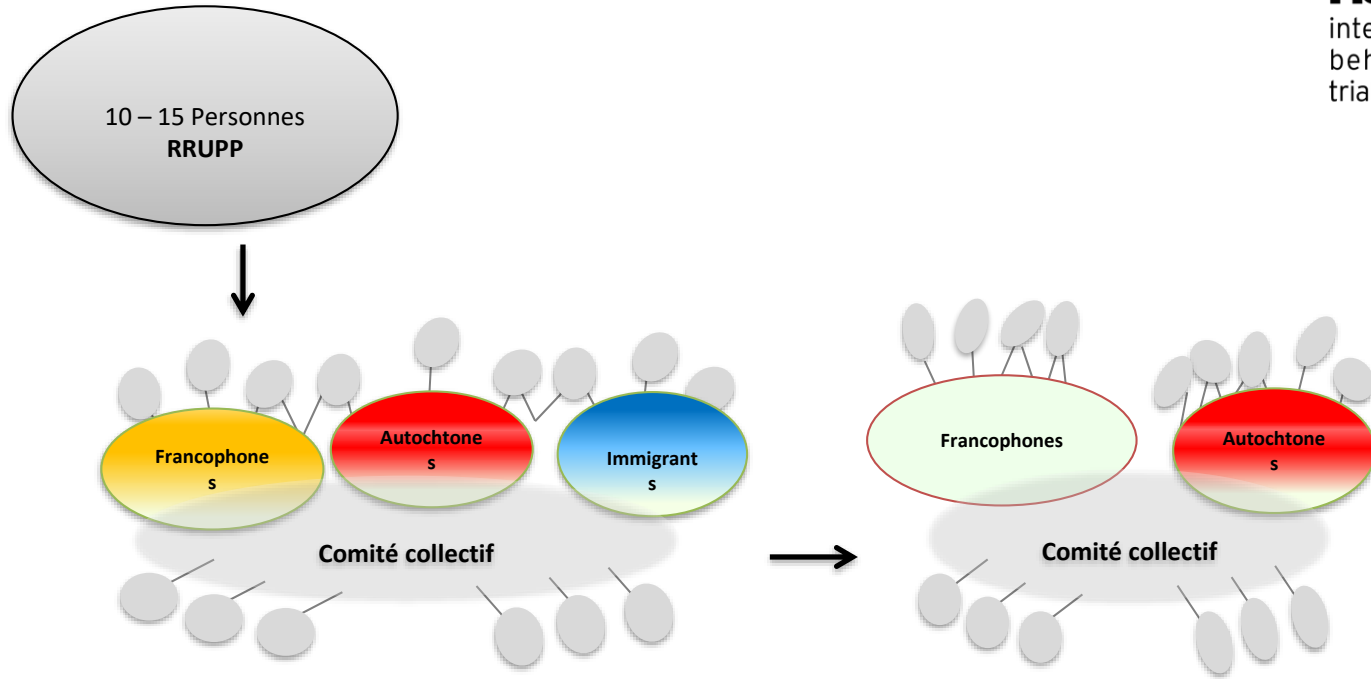
New “structure”



Arguments for merging

- Feeling of non belonging
- Administrative heaviness (anglais/français et nombre de cercles)
- Second generation immigrants

- Social discomfort ? Tension between the fear of losing one's identity while accomodating others ?
- What lesson for the researchers ?



Lessons learned and opportunities

- The magic recipe is yet to be discovered !
- Needs to be intentional !
- Acknowledge the interconnexions between our world and the world !
- Neutral ! Apolitical engagement ?
- Change withouth lobbying ?

Dos and don'ts

- Uniqueness of each group
- Co-designing a buzzword but also the secret
- Taking into account cultural aspects
- Community organisations can be helpful
- Always increase trust
- Time : the best ennemy



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THANK YOU

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