FACILITATING TRUSTING RELATIONSHIPS TO HELP IMMIGRANT OLDER ADULTS ACCESS DEMENTIA CARE

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BACKGROUND

- Nearly one third of BC's seniors are served by the Fraser Health Authority
- Increasing number of immigrant older adults, esp. South Asians
- **Kathleen Friesen**, Director, Clinical Programs and Population Health, Fraser Health Authority:

  "How can the health authority improve dementia care services for minority older adults, particularly South Asians?"

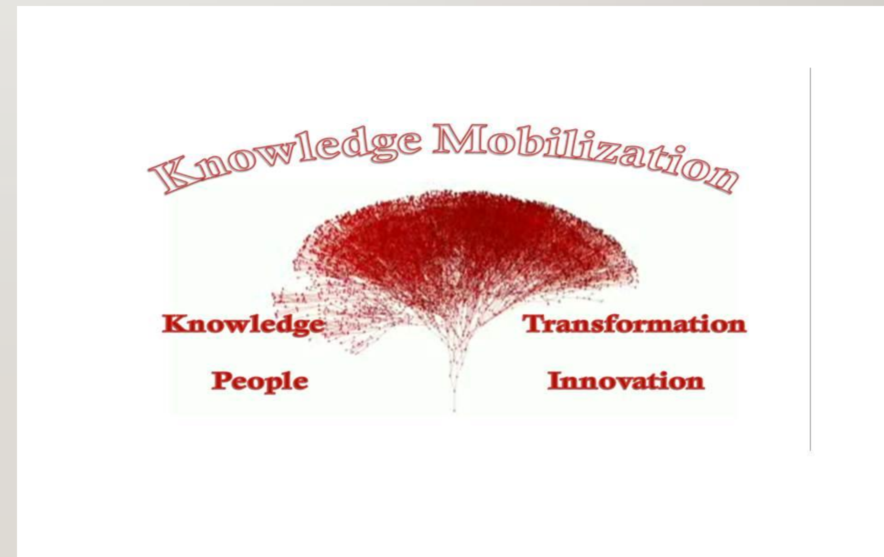
BUILDING TRUST TO FACILITATE ACCESS TO DEMENTIA CARE FOR IMMIGRANT OLDER ADULTS: THE ROLE OF THE MULTICULTURAL SERVICES SECTOR

- Partners
  - Fraser Health
  - Alzheimer Society of BC (ASBC)
  - MOSAIC
  - PICS
- Co-investigators
  - Dr Neil Drummond (U Alberta)
  - Dr Fabio Feldman (FH & SFU)
- Funding:
  - Alzheimer's Society Research Program, Canada [Grant # 17-26], awarded to Dr Sharon Koehn (skoehn@sfu.ca)
- We are indebted to numerous staff, community partners, and most especially participants who have contributed to this study

TWO-PHASE PROJECT …

PHASE I: DATA COLLECTION AND ANALYSIS (2016-2017)

PHASE 2: KNOWLEDGE MOBILIZATION (2018-19)



… WITH TWO COMMUNITIES IN THE FH REGION

- Punjabi
  - B.C.'s largest South Asian community lives in FH region
  - South Asians = 15% of FH population
  - Most immigrant older adults to FH are South Asian
  - Punjabi is the second most commonly spoken home language by seniors within FHA (8%)
- Korean
  - Among top 3 minority language groups in some communities within the Fraser Health region (Coquitlam, Port Moody, Maple Ridge)
  - Very little in Canadian literature on this group

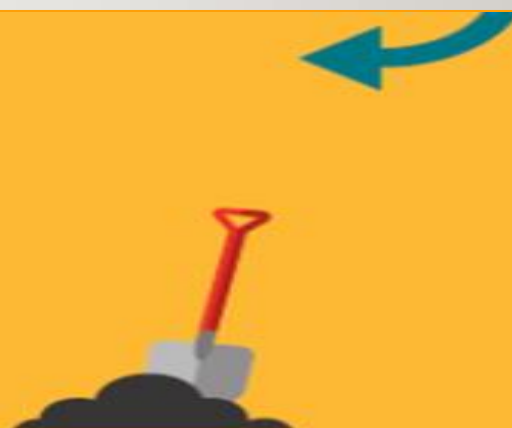
DATA COLLECTION & ANALYSIS

PHASE I

METHODOLOGY

QUALITATIVE DATA COLLECTION, CANDIDACY APPROACH

INTERVIEWS AND FOCUS GROUPS TO DIG DEEPER



15 DYADS

10 PUNJABI DYADS
5 KOREAN DYADS

PERSONS WITH DEMENTIA

FAMILY CAREGIVERS

6 FOCUS GROUPS

PUNJABI-SPEAKING

10 OLDER WOMEN
10 OLDER MEN
9 WORKING AGE MEN & WOMEN

KOREAN-SPEAKING

9 OLDER WOMEN
8 OLDER MEN
8 WORKING AGE MEN & WOMEN

20 STAFF

11 FROM DEMENTIA SERVING AGENCIES

PHYSICIANS NURSES
MANAGERS COORDINATORS
FRONT LINE STAFF

9 FROM IMMIGRANT SERVING AGENCIES

MANAGERS
FRONT LINE STAFF

THE CANDIDACY FRAMEWORK

"…Accomplishing access to healthcare requires considerable work on the part of users, and the amount, difficulty, and complexity of that work may operate as barriers to receipt of care. The social patterning of perceptions of health and health services, and a lack of alignment between the priorities and competencies of disadvantaged people and the organization of health services, conspire to create vulnerabilities"

(Dixon-Woods *et al.* 2006: 11)

SEVEN DIMENSIONS OF CANDIDACY

SELF-/FAMILY **IDENTIFICATION** OF NEED

NAVIGATION: IDENTIFYING SERVICES AND GETTING THERE

PATIENT'S **PRESENTATION** OF THEIR CLAIM FOR CARE

PROVIDER'S **ASSESSMENT** OF THAT CLAIM (REFERRAL, TREATMENT?)

PATIENT'S **ACCEPTANCE /REJECTION** OF TREATMENT OFFER

EASE OF ACCESS TO SERVICES (FLEXIBIITY, LOCATION, TIME…)

LOCAL CONDITIONS AFFECTING ACCESS (POLICIES, REPUTATION…)

WE DID THIS TO HELP

UNDERSTAND THE PROCESS OF GAINING ACCESS TO DEMENTIA-RELATED INFO, DIAGNOSIS, AND SERVICES

EXPLORE THE COMMUNITY'S UNDERSTANDING OF DEMENTIA AND AVAILABLE SERVICES

UNDERSTAND WHAT RESOURCES ARE AVAILABLE, THE CONTEXT OF POTENTIAL INTERVENTIONS, & WHAT GAPS CAN BE FILLED

THROUGHOUT THE INTERVIEWS, WE IDENTIFIED DIFFERENT DIMENSIONS OF ACCESS AS UNDERSTOOD THROUGH THE LENS OF THE

CANDIDACY FRAMEWORK

FINDINGS

FOCUS GROUPS AND DYADS

SELF-/FAMILY **IDENTIFICATION** OF NEED

- Barriers
  - Lack of understanding of disease/normalization, ascription to ‘old age’
  - Protection of self
  - Assumptions about cultural roles
  - Stigma

ID BARRIER - NORMALIZATION

- “Oh, they just start saying that he is just getting old. That’s why he is doing all those things and he doesn’t understand. They think that some people just need rest and they tell you to let him rest and that will be enough, but they don’t ask the doctor for proper treatment and what they need to know.” (FCP-P)
- “My friend will say things like: ‘What are you forgetting?’ ‘It’s okay, we forget things easily too’, ‘Sometimes I forget what I went to the store for.’ Even…my neighbors, they will tell me not to worry because they forget things too. They say this to me often.” (PWD-P)
- [In the past] “We thought dementia was the same thing as stroke (brain stroke/palsy) and is a normal aging process.” (FCP-K)

ID BARRIER – PROTECTION OF SELF

- “So, I thought, ‘I do not think she is okay.’ She goes to a hospital and such but she never admits it. When we say, ‘I lost something because so and so,’ she says, ‘Oh, yeah? You, too.’ It seems she gets consoled by it. She claims she doesn’t have it and says ‘you also forget things’. Even though her condition is severe she doesn’t acknowledge it. She doesn’t acknowledge that she has dementia.” (FG-KW)
- “If the elderly person is having symptoms, but they don’t want to admit it and their family members want to talk to them about it…that can create a disconnect in their relationship just like that. Because the elderly person might be upset like “How dare you say it?”…you know, become very defensive about the talk.” (FG-PW)

ID BARRIER – CULTURAL ROLE ASSUMPTIONS

- "I didn't think this was related to dementia, but things that made me think 'Why is she like this? She has a strange personality' (laughs) …when she would suddenly tell me something completely different when I was doing everything correctly. So I kind of like felt like I was being stabbed in the back. There were a few times like that, but I didn't think it was dementia. I just thought it was stereotypical of mothers-in-law." (FCG-K)
- "…they will go to the person they trust in the family. If suppose, for example, if they are living with son and daughter-in-law and they don't get along with the daughter-in-law…they will try to find somebody outside of the house" (FG-PW)

ID - STIGMA OR SHAME

- If a family member has dementia, it becomes an absolute secret. That's the problem with Korean people. Here in Canada these days, …there is a lot of Parkinson's disease patients that are Korean. And Alzheimer's, it's all kept a secret." (FG-KW)
- "Korean people tend to pretend. They like to show off. We don't know what's going on inside…someone's mind, because people put on a face. And first off, if there's someone in that household who is ill, we as neighbours need to provide support, and pray for them, but rather people talk behind their back." (FG-KW)
- "We need information or education for dementia for Korean people. Koreans still view dementia as something to hide and to be ashamed of having." (PWD-K)

ID-STIGMA OR SHAME

- "Sometimes people think that person's life is over. For example, we used to go to the seniors centre and he had friends there. They would always come and talk to him. Now there is only two or three that come and shake his hand. Otherwise, they just stay away. ... Those people think it is a contagious thing. That is not the case." (FCP-P)
- "For us people, who come from India, we get ashamed when our children don't take care of us. We worry too much about what other people will think. They could say things like, 'Oh, they raised their children and now when it was time for the children to take care of their parents, they didn't. They dumped them at the care home instead.' We don't understand that there is better care available at the care homes." (FCP-P)

NAVIGATION: IDENTIFYING SERVICES AND GETTING THERE

- Barriers/Facilitators
  - Finding information - internet
  - Family assistance
  - Lack of or limited family support

NAVIGATION – FINDING INFORMATION

- “When I’m at home I watch those health related shows on the internet …According to information I gathered from internet I know that not being active enough isn’t good but…” (PWD-K).
- “If you go on the Internet, there’s a lot of information there as well.” (FG-KM)
- “Depends on level of education at home…what kind of thinking you have, right? Not everybody does research on internet.” (FG-PWAA)

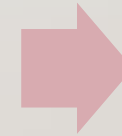
NAVIGATION – FAMILY ASSISTANCE

- "…it is easier to isolate and not share with community and other family members if one of the family have dementia because there are multi-generational family members living in the home. So there might be grandparent and sometimes even great grandparents living in the same home, so they have the support" (FG-PW)
- "I can't walk. I can't leave the house. My family takes me." (PWD-P)
- "My daughter came for me (with a proud smile) to live with me for a couple of years. Because I was sick, she came all the way and lived with me from Toronto. She came by herself to care for me leaving her family behind." (PWD-K)
- "My son speaks to doctors in both English and Korean. He always accompanies us." (PWD-K)

NAVIGATION – NO/LTD FAMILY SUPPORT

"No, they receive no help. Even the family members don't let them out or take them to appointments or the hospital to get them treated. They don't get them treated." (FG-PM)

"I say to my children, "Please help me." If they have time, then they help me, but if they are busy, then I just have to manage on my own. They are so busy. They get off work at 6:00 or 7:00pm. Then they have to go home and do chores. …it is very seldom that they can come and help" (FCP-P)



PWD-K: "My husband is not helpful at all, so sometimes my daughter-in-law comes with me. [RA: *Oh… so is your daughter-in-law more fluent in English?*] PWD-K: Well, she's okay. My son was educated here, so he's better, but he's busy and needs to rest. I usually go on my own."

PATIENT'S **PRESENTATION** OF THEIR CLAIM FOR CARE / PROVIDER'S **ASSESSMENT** OF THAT CLAIM

- Barriers
    - Language incongruency
    - Time and respect
    - Cultural differences
    - Intersections of identity

PRESENTATION/ASSESSMENT - LANGUAGE

“When the patients don’t understand English, some of their daughters or sons leave notes for the workers such as, ‘Please clean something, do laundry for my mom.’ When they post them on refrigerator the workers see them and follow instructions.“ (FG-KWAA)

"For people like us the elderly, we don’t know English. Any doctor you go to, he speaks English. This is also a very big hurdle for us that we cannot explain ourselves very well. Secondly, English is our second language. We cannot express our feelings and troubles the same way in English than we can in Punjabi. It is very important for services to be in Punjabi.“ (FG-PW)

PRESENTATION/ASSESSMENT - LANGUAGE

"I had to take a detailed examination for something and I don't understand the language. Those medical terms are difficult. So an interpreter was sent but the wait time is so long. … I heard this person charges a certain amount per hour… I knew I didn't need to pay for that but I just didn't feel comfortable." (FG-KW)

RA: "Does your family doctor call an interpreter?"
P: "No, I have to do it myself. I have to call on my own and pay for cab fee, too." (FG-KW)

PRESENTATION/ASSESSMENT – CULTURE

"P: Koreans are usually appreciative and apologetic. We're not stiff-necked, and we dress clean and show up for appointments, so doctors usually treat Koreans kindly. We don't dress too casually like wearing slippers or jeans." (FG-KW)

"P1: In the Korean culture, we might perceive it as something serious or not, but here, the same illness might be perceived in a different way. When this happens, there could be a conflict in opinions with regards to how to approach an illness. … P2: I think that in Korean culture, people have different perspectives on medication." (FG-KWAA)

PRESENTATION/ASSESSMENT – CULTURE

- "Person that has moved from India, Indian people tell a detailed story to doctor and doctor diagnose him or herself. But over here the doctor asks, 'Are you feeling comfortable?', 'Do you feel like this?', 'How do you feel?' Then 'do you want to do this?' or 'You don't want to do this?'. Even about medicine. Then sometimes they feel confused." (FG-PWAA)

PRESENTATION/ASSESSMENT – TIME, RESPECT

RA: "…your family doctor? You said he speaks Punjabi?" PWD-P: "No, no, if I have a disease, he will tell me about that disease, but he doesn't explain it any further. He never tells me anything further."

"He doesn't even touch me. Not even a stethoscope on me. He just does paperwork and tells me (to wait). He is useless. At first, I didn't want to see him, but I have no other choice now." (FCP-K)

"I was told it's up to me to come back to see the doctor or not. … They don't provide detailed explanations." (PWD-K)

PRESENTATION/ASSESSMENT – TIME, RESPECT

- P1: “their attitudes... the attitudes are…” P2: “They’re too insincere, too insincere.” P3: “They try to wrap things up quickly and send you off.” (FG-KW)
- “Unlike some family doctors, specialists tend to come off a bit cold or they often go through patients quickly. Because their time is valuable and there’s a lot of patients waiting.” (FG-KWAA)

PRESENTATION/ASSESSMENT – INTERSECTIONS

- P1: So if you speak the language it's better to see Canadian doctors but because we can't communicate (in English) we see Korean doctors. When my husband sees a (Korean) doctor and says, 'I have pain here,' then the doctor says, 'oh, that's common for your age,' then you have nothing more to say. You can't say anymore so you just let it be… P2: Yes, we're not satisfied but we can't talk. RA: *So you're saying you have some complaints about Korean medical professionals here…* P3: There're many. P1: …That's why people here go to Korea (FG-KW)

KEY FINDINGS

FAMILY INVOLVEMENT – BARRIERS AND OPPORTUNITIES

CULTURALLY DISTINCT VIEWS OF AGING AND ILLNESS – STIGMA

LIMITED UNDERSTANDING OF DEMENTIA - STIGMA

LOW EDUCATION AND LITERACY, LOW ACCESS TO COMPUTERS (*P)

YOUNG-OLD KOREANS MORE COMPUTER SAVVY AND LITERATE

MORE RESOURCES IN PUNJABI THAN KOREAN IN BC – NAVIGATION DIFFICULTIES (*K)

LANGUAGE AND CULTURAL INCONGRUENCE IMPEDES ASSESSMENT

ATTITUDE OF FAMILY PHYSICIAN, SPECIALIST IS KEY

FINDINGS

STAFF – DEMENTIA SERVICE (DS) &
IMMIGRANT SERVING (IS) AGENCIES

SEMI-STRUCTURED INTERVIEWS WITH 20 STAFF

11 from dementia serving agencies

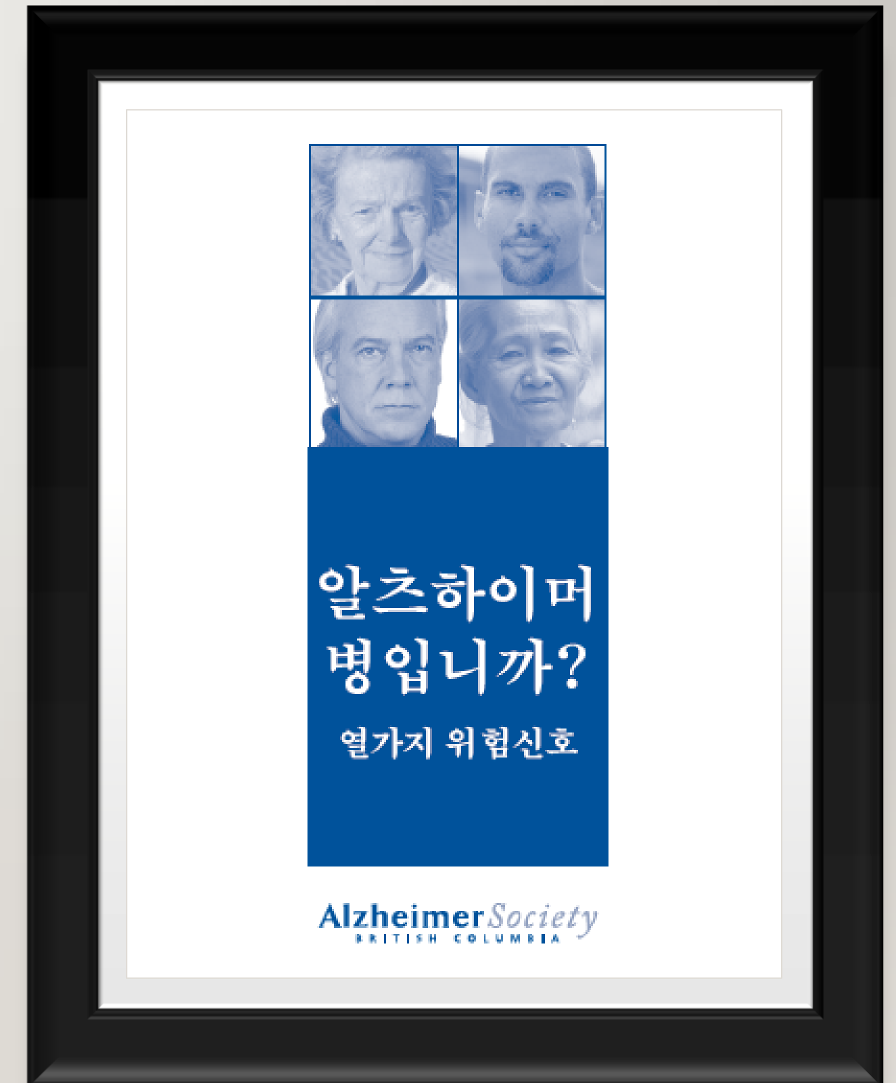
- Health Authority and Alzheimer's Society of BC (ASBC) chapter
- physicians, nurses, managers, coordinators and frontline staff

9 from immigrant-serving agencies

- Serve Punjabi and Korean-speaking older adults
- frontline and managers

DEMENTIA SERVICE AGENCIES

- Have valuable resources on dementia and other health and social supports
- Familiar with each other but know little about the services offered by IS agencies
- Have limited multilingual/cultural capacity
- Focus primarily on language as a barrier



IMMIGRANT SERVING AGENCIES

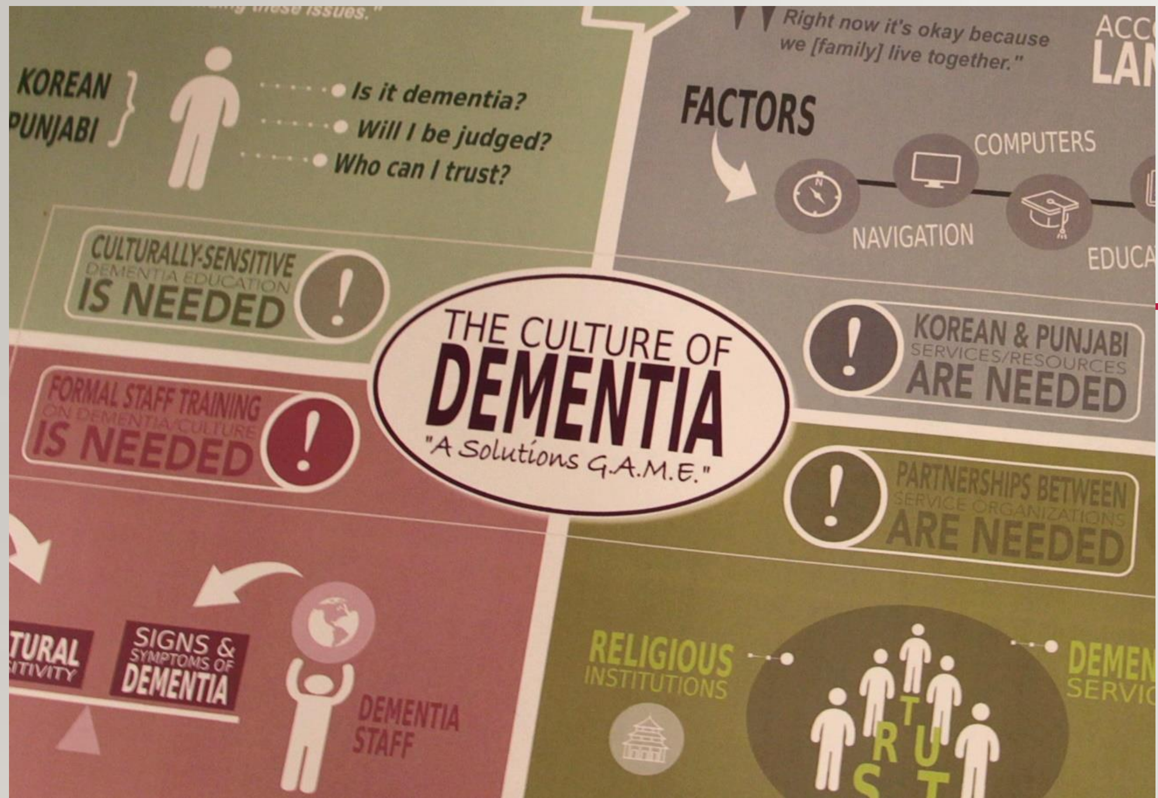
- Are consulted by and have the trust of immigrant older adults and their families on many health-related issues, including dementia
- Know little about the characteristics of dementia and dementia service resources (e.g. First Link®) and referral procedures
- Identified other barriers to access for immigrant older adults (besides language)
  - perceptions that services in the home country were more advanced and/or accessible
  - stigmatized nature of dementia (culture-specific expressions)
  - a lack of social support needed to bridge knowledge and cultural gaps

BUILDING TRUST

Fostering knowledge exchange and building trust between dementia service and immigrant service agencies holds great potential for increasing access to information and supports for immigrant older adults.

KNOWLEDGE MOBILIZATION

PHASE II



STAKEHOLDER FORUM

PUNJABI-LANGUAGE LIAISON WORKER

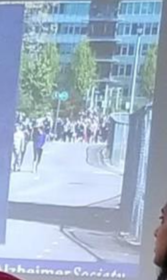
INCONSISTENT STAFFING CHALLENGES

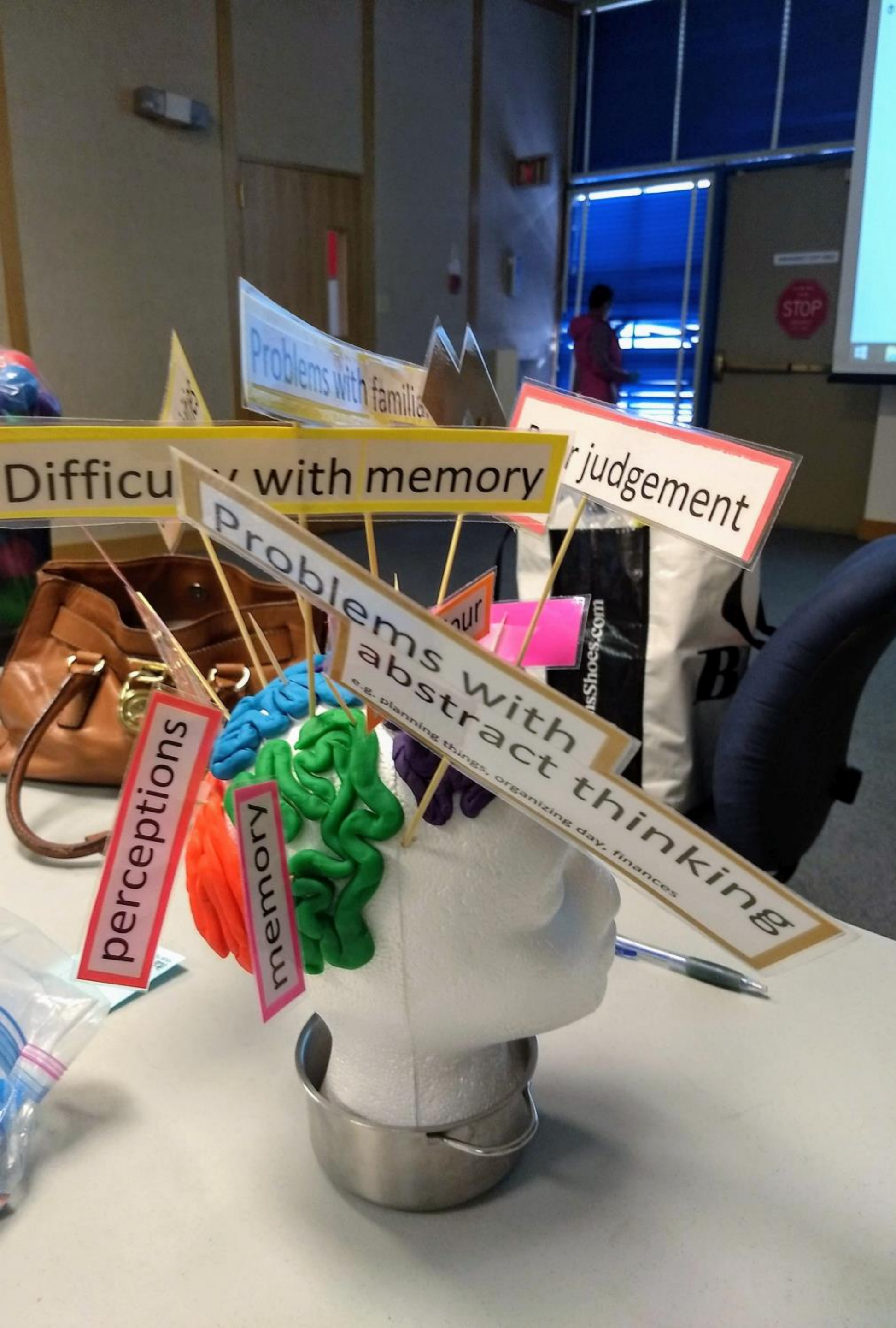
- Staff turnover and parental leaves within all partner groups
- Adds time and diminishes understanding and possibly trust
- Research team turnover - different skills and time commitments
- PI the consistent thread

DEMOCRATIC MISSION & PRINCIPLES

PRODUCTS OF COLLABORATION

PUNJABI-ADAPTED DEMENTIA FRIENDS PRESENTATIONS





DEMENTIA-IN-THE-WORKPLACE ENGLISH LANGUAGE CLASS FOR NEWCOMERS

SYSTEM NAVIGATION VIDEO IN KOREAN

EVALUATION

- For each intervention we have collected
  - Demographic questions (who is our audience?)
  - Pre- and post dementia knowledge questions, for example …

How much do you know about Alzheimer's Disease and other types of dementia?	A lot	Quite a bit	A little	Nothing	
Can you name any signs of dementia?	Yes, more than 5	3-5	1 or 2	None	

DEMENTIA FRIENDS 1 – DEMOGRAPHICS (N = 38. BUT 34 COMPLETED EVALUATIONS)

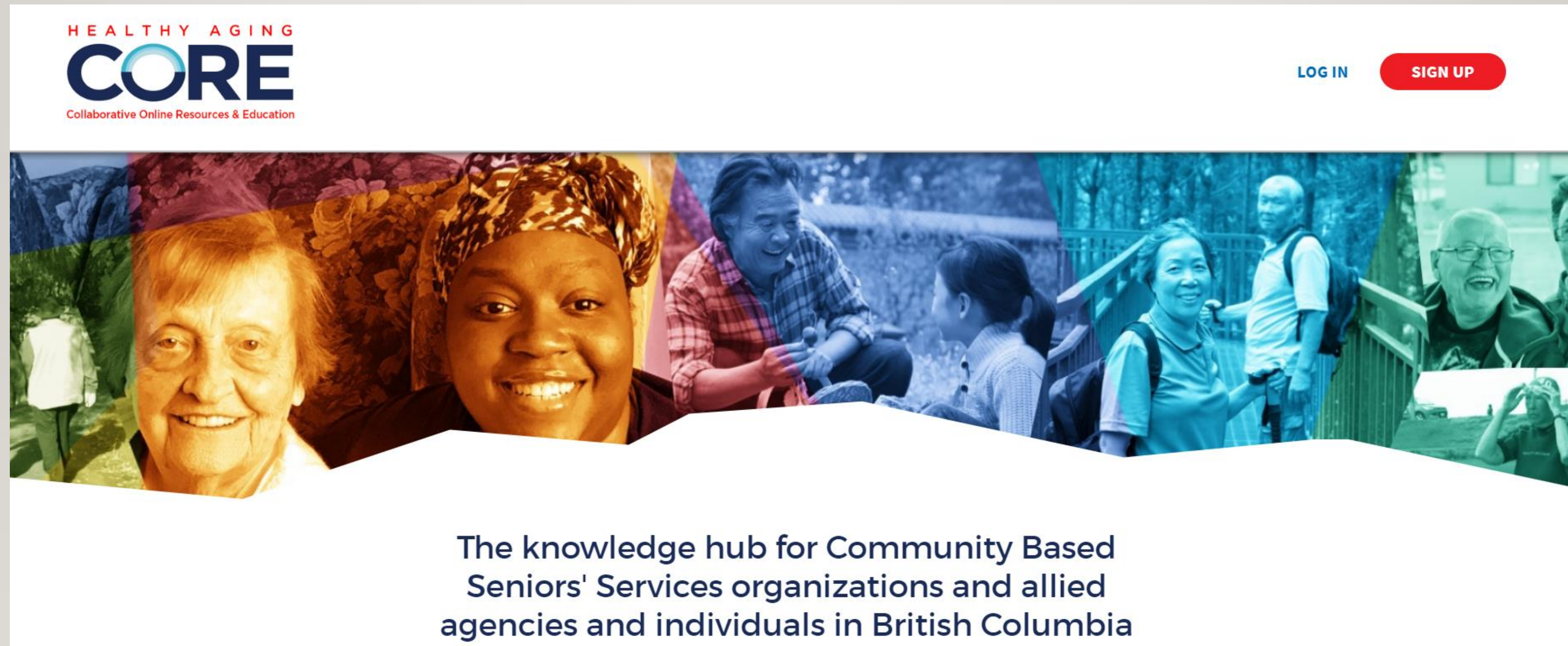
- Gender: No response (NR): 4, Male:16, Female:14
- The majority (19) were aged between 61 and 70
- Most (17) had a high school education (but some less and some more)
- 75% were from India and mainly Punjabi speakers
- <25% spoke English
- Majority (14) had been in Canada 5-9 years
- Most (23) were Family Class (sponsored) immigrants
- >50% knew somebody with dementia but, typically, people not close to them

DEMENTIA FRIENDS 1 – PRE-POST

- Sample responses

	PRE	POST
How much do you know about dementia?	18 knew nothing/not much; none knew a lot	Majority (28) knew quite a bit or a lot
Can people lead meaningful lives with dementia?	Most (17) said they did not know	29 said that 'maybe' or 'definitely' they could (only 4 said they did not know)

MATERIALS TO BE UPLOADED TO PAGES ON UNITED WAY OF THE LOWER MAINLAND WEBSITE



CONCLUSIONS

- Ongoing partnerships and reciprocal training between IS and DS agencies could go a long way toward enhancing identification, referrals, and the cultural responsiveness and hence acceptance of dementia services by older immigrants.
- Relationship development and trust building between these agencies takes time and patience.
- Such intersectoral partnerships entail relational commitment and accountability, sharing of knowledge and resources, and most importantly, a shared goal towards increasing cultural capacity and alignment within mainstream services.

THANK YOU

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