

A close-up of a human eye, with the pupil acting as a window to a landscape. The landscape features rolling hills under a clear blue sky, with a path leading through the foreground. The overall color palette is warm, dominated by yellows and oranges, suggesting a sunrise or sunset. The text is overlaid on the image in a dark, sans-serif font.

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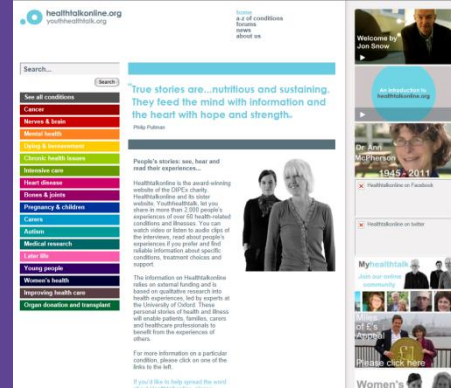
See, hear and read peoples' experiences
with health and illness

Today's presentation

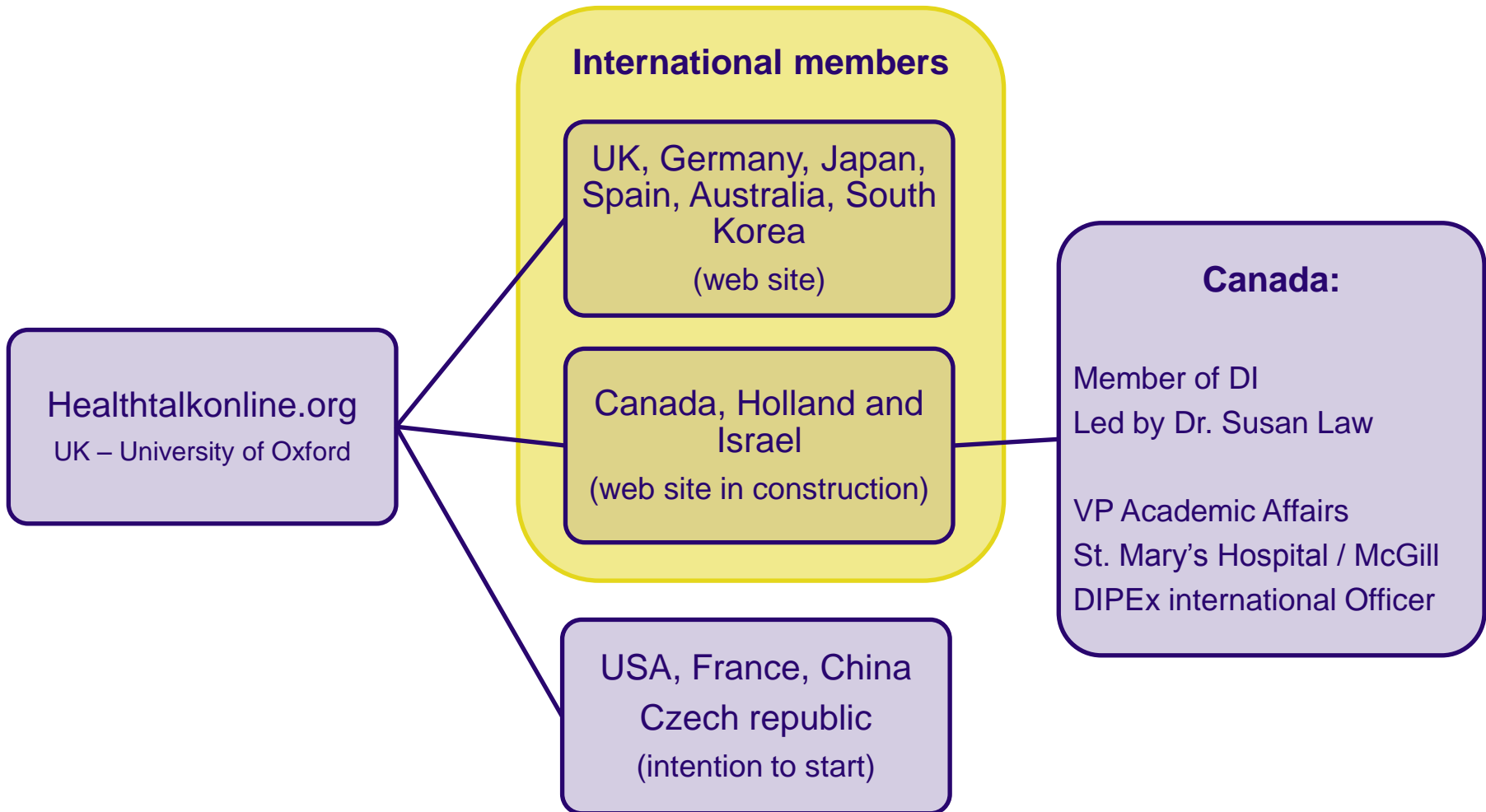


- 1. General overview – DIPEX International and Canada's participation**
2. Caregiving module
3. Results to date

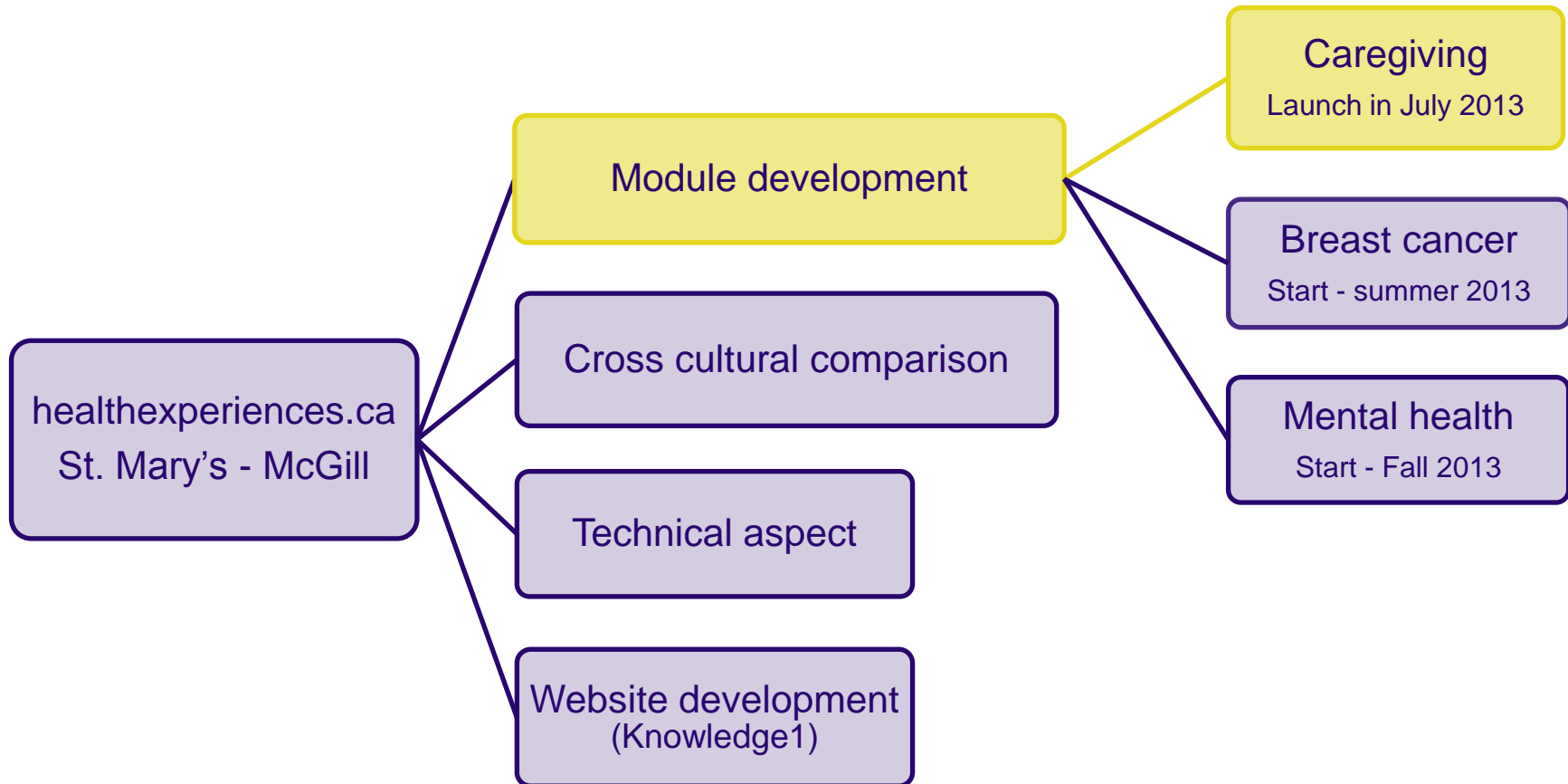
DIPEX International



International members



Health experiences in Canada



Today's presentation



1. General overview – DIPEX International and Canada's participation
2. **Caregiving module**
3. Results

A module



Research team

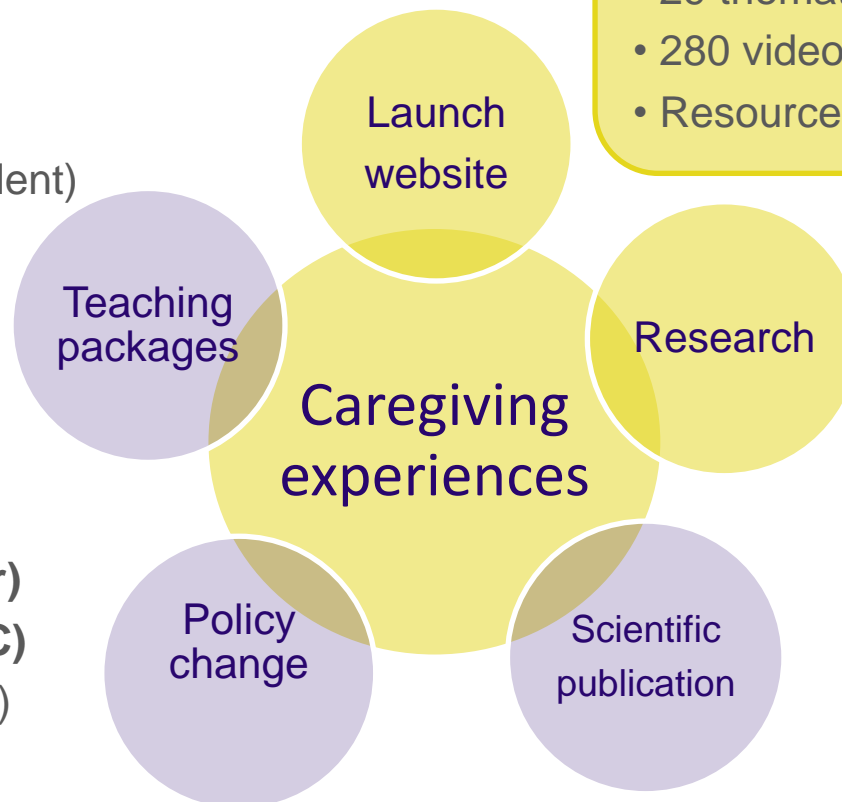
- Susan Law (PI)
- Ilja Ormel (Researcher)
- Brent Hopkins (RA)
- Tabitha Tonsaker (MSc Student)

Advisory panel

- Mark Yaffe (MD)
- Debbie Josephson (MD)
- Marc St. Cyr (Caregiver)
- Ann Macaulay (MD, PRAM)
- **Kerry Kuluski (Researcher)**
- **Renee Lyons (Chair in LTC)**
- Richard Hovey (Researcher)

Results:

- 37 autobiographies
- 29 thematic pages
- 280 video and audio clips
- Resources section



The research



Recruitment

- 40 interviews across Canada
- Max. variation sample

Methodology

- Qualitative research
- Thematic analysis with constant comparison
- Video/Audio recorded interviews
- In-depth semi-structured interviews at participants homes

Analysis

- Nvivo10

Participants

- 37 transcripts for analysis
- Current age: 23-88 yrs
- Start age: 14-88 yrs
- Caregiving time: 1-56 yrs
- Male caregivers: 28%
- Residence with CG: 67%

Today's presentation



1. General overview – DIPEX International and Canada's participation
2. Caregiving module
3. **Results**

The topic pages



Making the Diagnosis

When there are symptoms suggesting the onset of dementia the establishment of an accurate diagnosis is necessary from a carers point of view so that they can understand what is going on and make appropriate arrangements for future care. However many of the carers interviewed felt that the diagnosis had never been formally made. Where adequate care was available, gradually progressive dementia may have been accepted as part of normal ageing, and only when the carer no longer felt able to carry on without some additional support was a professional diagnosis looked for.



Describes how he at least was not aware that his father had ever actually been diagnosed with Alzheimer's disease.

But in other cases, and especially when the person showing signs of dementia is young, accurate diagnosis is critical. Many carers, especially those looking after people with one of the fronto-temporal dementias suffered agonies of uncertainty before a diagnosis allowed them to understand what they had been experiencing. Sometimes symptoms had been attributed to depression and again learning the true diagnosis offered an explanation for changes in behaviour which had up till then been causing annoyance and irritation.

Major categories

1. Being a caregiver
2. Resources and professional services
3. Personal challenges in caregiving
4. Impact on the caregiver
5. Advice



“I can’t see putting her in there (a facility) when we can still stay in our home as long as I’m able to cope with it and I guess that’s one of the keys; as long as I’m able to cope with it.” *(Donovan, xx yrs, cares for wife with MS)*

Caring for yourself



Reflection on the conference theme

Caregiving and link to system issues

The burden of caregiving and the enormous contribution of informal caregiving to our healthcare system is an important topic in the overall quality, cost and effectiveness of healthcare delivery

Organizing resources within the health and social care systems to support the caregiver is important to help them to continue care at home.

At the core: individual caregivers’ experiences, e.g.

Donovan: health (depression, suicidal thoughts), isolation, financial impact, caring for himself

“My best friend was telling me you’re not yourself anymore and I was just too tired and scared of my thoughts and not having a future of my own.... I thought I’m just leaving ”.

Trying to keep the balance



Challenges – Losing the balance

- A continuous balancing act (health, resources, support, medical care, socialization, caring for self)
- The caregiver is like a wheel and needs all supports in place to continue caring at home
- Christine was admitted to an emergency clinic for suicidal thoughts. Not having the right balance (health impact , resources, finances) eventually led to her stopping to care for her mother.

We're (caregivers) invisible. The toughest thing I think is we are invisible. *(Shoshena, xx yrs, cares for husband with MS)*

Caregivers and society



Reasons for limited support

- Lack of recognition for caregivers in society (employers, resources, population, health care professionals)
- Family and friends inability to understand and support the caregiver
- Focus is on the care recipient even though the caregiver is also impacted by the care

“They (caregivers) get to a point where they’ve just had it and the professionals should talk to people about that kind of stuff. To make sure that they take breaks every once in a while and also maybe look at the family a bit closer to see that the kids don’t suffer because of what they’re going through too. “

“Nobody’s going to be able to look after my mother better than I am so, so don’t even try to offer but if someone can offer to help support me in ways that allow me to continue to do that I would be a fool not to accept that.” (Drew, xx yrs, cares for mother)

Support from family and friends



Caregivers who continue to care for their care recipient at home

- Need support in their role (HC professionals, financially, resources, family and friends, employers)
- Information (timely, better access, centralized)
- Social recognition of the caregivers role and its importance

Anticipated conclusion

Caregivers will be able to find support through hearing and watching shared experiences of the participants, find resources and reliable information about caregiving experiences throughout Canada organized around specific themes.

Thank you



Any questions?

For more information:

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