Who is a family caregiver?

- **Family caregivers:** Refers to the people—family members. friends, neighbours—who provide critical and often ongoing personal, social, psychological and physical support, assistance and care, without pay, for loved ones in need of support due to frailty, illness, degenerative disease, physical/ cognitive/mental disability, or end of life circumstances. (The Change Foundation, 2016)

- **Informal care:** Care provided by family caregivers

Background

- In Canada:
  - 8.1 million caregivers (Sinha, 2012)
  - Provide more than 80% of care needed by individuals with long-term conditions (Fast et al., 2011)
  - Their contribution was equivalent to about $25 billion in paid work (Hollander et al., 2009)

Background

- Caregiving comes at a price:
  - Adverse health effects (Hillis et al., 2016; Pinquart et al., 2007; Schulz et al., 2004; Schulz et al., 1995)
  - Economic consequences (Koopmanschap et al., 2008; Lacey et al., 2016;)

Background

- In Ontario: (3.3 million caregivers)
  - 75% of ON caregivers balance between caregiving and work (The Change Foundation, 2016)
  - Distress doubled among ON caregivers of long-stay home care patients in the 5 years leading to 2016 (HQO, 2016)
  - Almost half of all caregivers (47% or 1.6 million individuals) report having some level of stress (The Change Foundation, 2016)

Rationale


The economic value of family caregiving is as big
as the world's largest company,
bigger than
Medicaid and out-of-pocket (O
health care.
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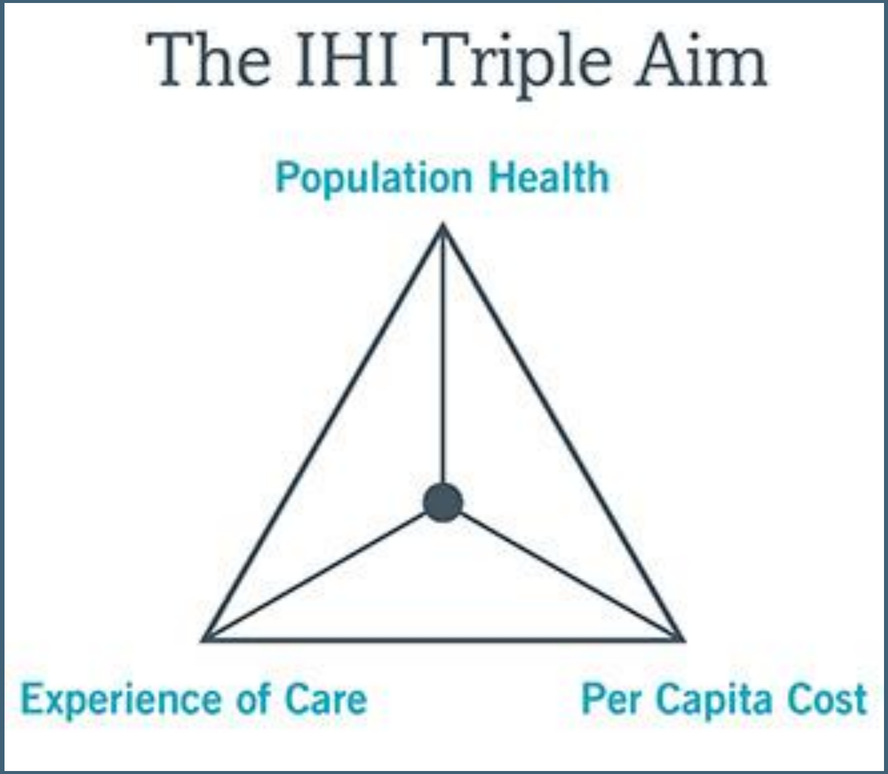
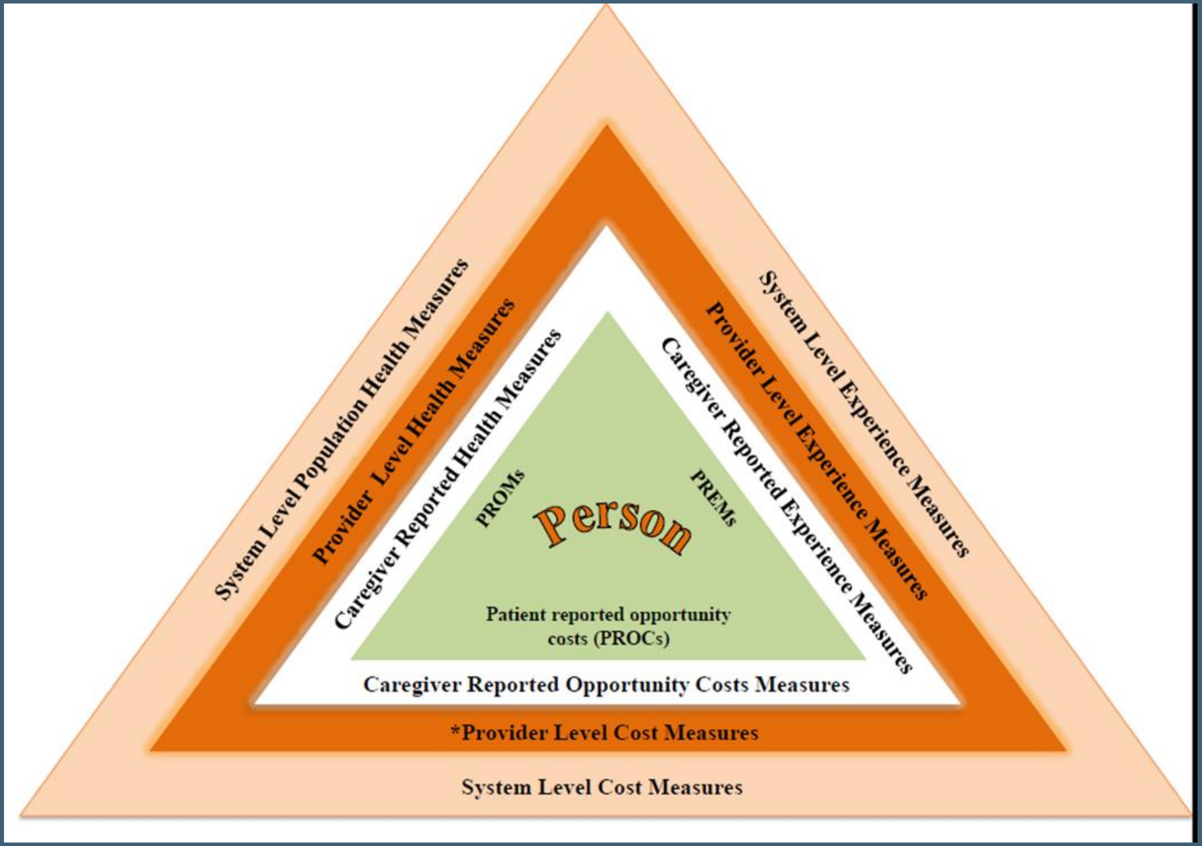
Conceptual Framework

- Triple Aim:



Conceptual Framework

- Triple Aim: Developed by Better Access and Care for Complex Needs (BeACCoN, 2016)



Objective

- Objective:

  Phase 1: Identifying caregiving measures

  – To identify measures of informal caregivers' experiences ,costs, & health outcomes

  Phase 2: Measuring caregiving

  – Develop a tool to measure caregiving

  Phase 3: Including informal care in healthcare decision making

  – Using the results to include informal care in current evaluation of a healthcare intervention (Integrated Funding Model)

Phase-1

- Research Question:
  - What methods/tools/instruments have commonly been used to measure caregivers costs, health outcomes, and experiences?

Methods- Phase 1

- Three approaches were used to identify common caregiver measures:
  - Grey literature review
  - Scoping Review
  - Consultation with experts (caregivers, patients, researchers, & policy makers)

Methods – Phase 1

- Inclusion criteria:
  - Grey literature review
    - Reports published in English by government and non-for-profit agencies on caregiving since 2000.
    - Quantitative in nature
  - Scoping review
    - Economic evaluations of Alzheimer/Dementia interventions
    - Three databases (Ovid MEDLINE, EMBASE, and Scopus) for the period of 2011 to 2016 and published in English
    - Quantitative in nature

Results- Characteristics

- Grey Literature Review
  - 97 reports were closely assessed against the inclusion criteria
  - 27 reports were included
- Scoping Review
  - The initial search resulted in 1179 articles
  - 14 articles met the inclusion criteria

Results - Reviews

Domains of the survey based on the Triple Aim	Measures	Data Source
Health	Health Related Quality of Life, overall physical and mental health, anxiety, depression, distress, burden, and coping	Self-reported
Experience of care	Satisfaction Involvement in decision making	Self-reported
Cots	Out-of-pocket cost	Self-reported
	Opportunity Cost	Self-reported
	Healthcare Utilization Cost	Admin + Self-reported

Results - Reviews

Domains	Tools	Data Source
Health	Generic: EQ-5D, SF-36, SF-12, General Health Questionnaire-28, Hospital Anxiety and depression Scale, COPE Index, Relative Stress Scale, WHO5 Wellbeing Index	Self-reported
	Specific: Carer Quality of Life, Zarit Burden Index, Carer Strain Index, Subjective Burden Scale, Burden Scale for Family Caregivers, Caregiver Quality of Life	

Results - Reviews

Domains of the survey based on the Triple Aim	Measures	Data Source
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	Healthcare Utilization Cost	Admin + Self-reported

Results (Triple Aim)- Experience

	Canada	US	Others
Experience	N=2	N=1	N=7
Components	Clear, consistent, reliable communication and exchange of information with providers; coordinated and connected care; comprehensive care; engaged in patient care; respectful, empathetic and considerate care; timely and convenient care	Ease of care, coordination, training, inclusion in care, clear discharge structure, caregivers asked about her/his needs	Lack of respect for caregivers, unwillingness of clinicians to listen to caregivers and their knowledge of the individuals they care for, insufficient integrated recovery-based care, more and better trained staff, who to get info on how to care, included in planning, Quality of services received by both patient and caregiver, satisfaction

- 2006 onward, self reported, & mainly in mental health setting)
- Mental Health Survey of 2011
- Satisfaction, quality of services received, involvement in decision making

Results - Reviews

Domains of the survey based on the Triple Aim	Measures	Data Source
Health	Health Related Quality of Life, overall physical and mental health, anxiety, depression, distress, burden, and coping	Self-reported
Experience of care	Satisfaction Involvement in decision making	Self-reported
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	Healthcare Utilization Cost	Admin + Self-reported

Results - Consultation

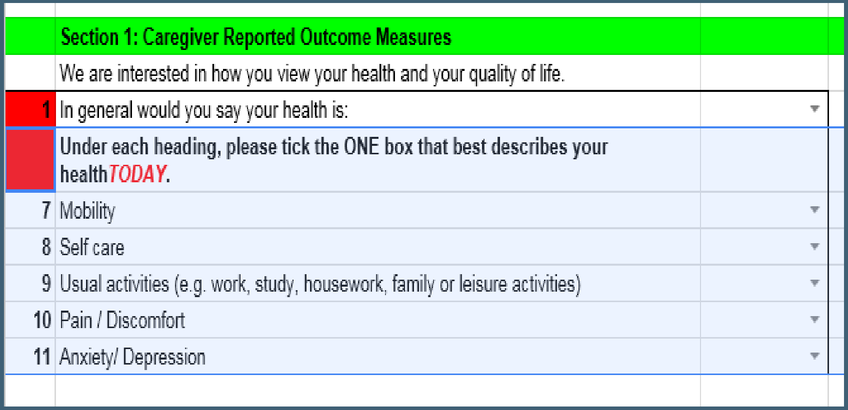
Domains	Recommendations
Health	Dyadic patter of care/ Positive outcome
	Simple and brief measures
Experience of care	Caregiver recognition
Cots	Caregiving task (Care coordination, emotional support, navigation of care system, medical care)

Phase-2

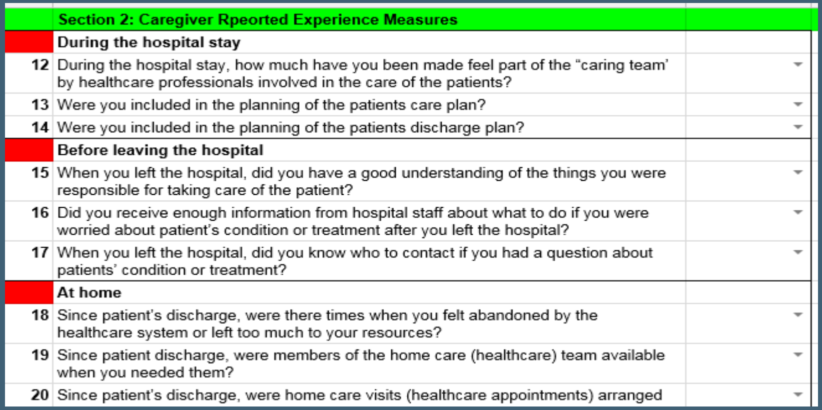
Measuring Caregiving

The Caregiving Survey

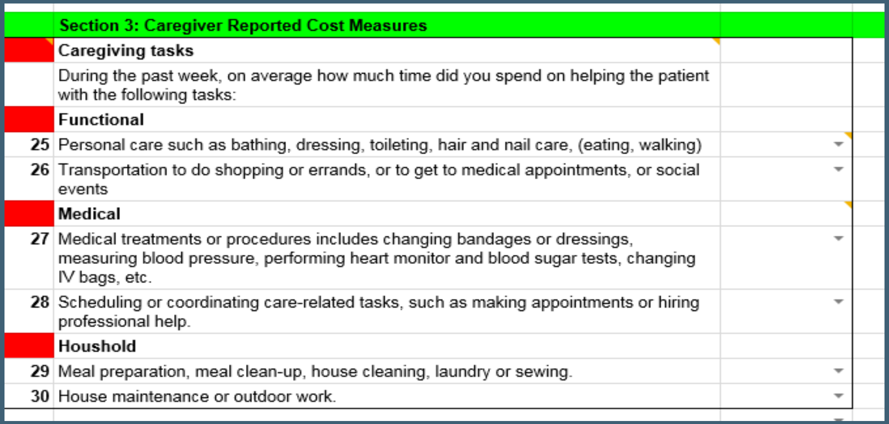
- A survey with three dimensions is being developed



	Section 1: Caregiver Reported Outcome Measures
	We are interested in how you view your health and your quality of life.
1	In general would you say your health is:
	Under each heading, please tick the ONE box that best describes your health *TODAY*.
7	Mobility
8	Self care
9	Usual activities (e.g. work, study, housework, family or leisure activities)
10	Pain / Discomfort
11	Anxiety/ Depression



	Section 2: Caregiver Rpeorted Experience Measures
	During the hospital stay
12	During the hospital stay, how much have you been made feel part of the "caring team' by healthcare professionals involved in the care of the patients?
13	Were you included in the planning of the patients care plan?
14	Were you included in the planning of the patients discharge plan?
	Before leaving the hospital
15	When you left the hospital, did you have a good understanding of the things you were responsible for taking care of the patient?
16	Did you receive enough information from hospital staff about what to do if you were worried about patient's condition or treatment after you left the hospital?
17	When you left the hospital, did you know who to contact if you had a question about patients' condition or treatment?
	At home
18	Since patient's discharge, were there times when you felt abandoned by the healthcare system or left too much to your resources?
19	Since patient discharge, were members of the home care (healthcare) team available when you needed them?
20	Since patient's discharge, were home care visits (healthcare appointments) arranged



	Section 3: Caregiver Reported Cost Measures
	Caregiving tasks
	During the past week, on average how much time did you spend on helping the patient with the following tasks:
	Functional
25	Personal care such as bathing, dressing, toileting, hair and nail care, (eating, walking)
26	Transportation to do shopping or errands, or to get to medical appointments, or social events
	Medical
27	Medical treatments or procedures includes changing bandages or dressings, measuring blood pressure, performing heart monitor and blood sugar tests, changing IV bags, etc.
28	Scheduling or coordinating care-related tasks, such as making appointments or hiring professional help.
	Houshold
29	Meal preparation, meal clean-up, house cleaning, laundry or sewing.
30	House maintenance or outdoor work.

Phase-3

Including informal care in healthcare decision making

Next Steps

- Complete the Survey
- Cognitive Testing
- Use the Survey
- Validate the Survey
- Use the results in evaluation and economic evaluation of Integrated Funding Model

Limitations

- Limitation:
  - Did not use a team approach to design the study selection
  - Reviews were limited to electronic databases
  - Economic databases were excluded from this study
  - Scoping review was limited to Alzheimer/Dementia
  - Long survey
  - Identifying caregivers
  - Recruitment
- Strengths:
  - Consultation with stakeholders

Conclusion

- It identifies three main areas that require further investigation, including
  - caregiver’s experience with the healthcare system
  - caregiver’s healthcare utilization cost
  - the dyadic pattern of care

Thank you