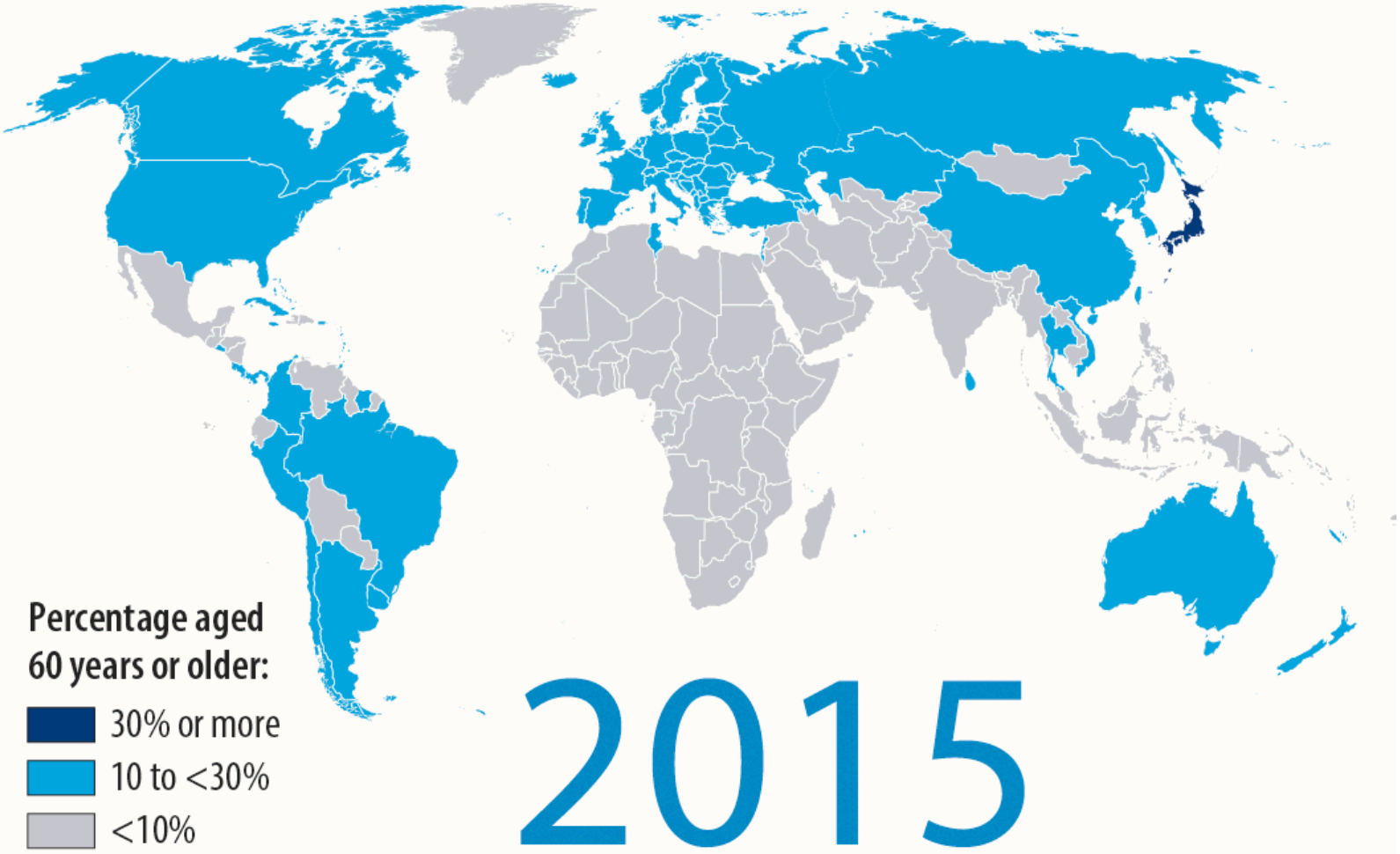
Multiple Moves Through the Health System:

Using data and lived experience to understand and change

Dr. Saskia Sivananthan

Populations are getting older



Source: WHO World Report on Ageing and Health, 2015

World Health Organization

What are the symptoms?

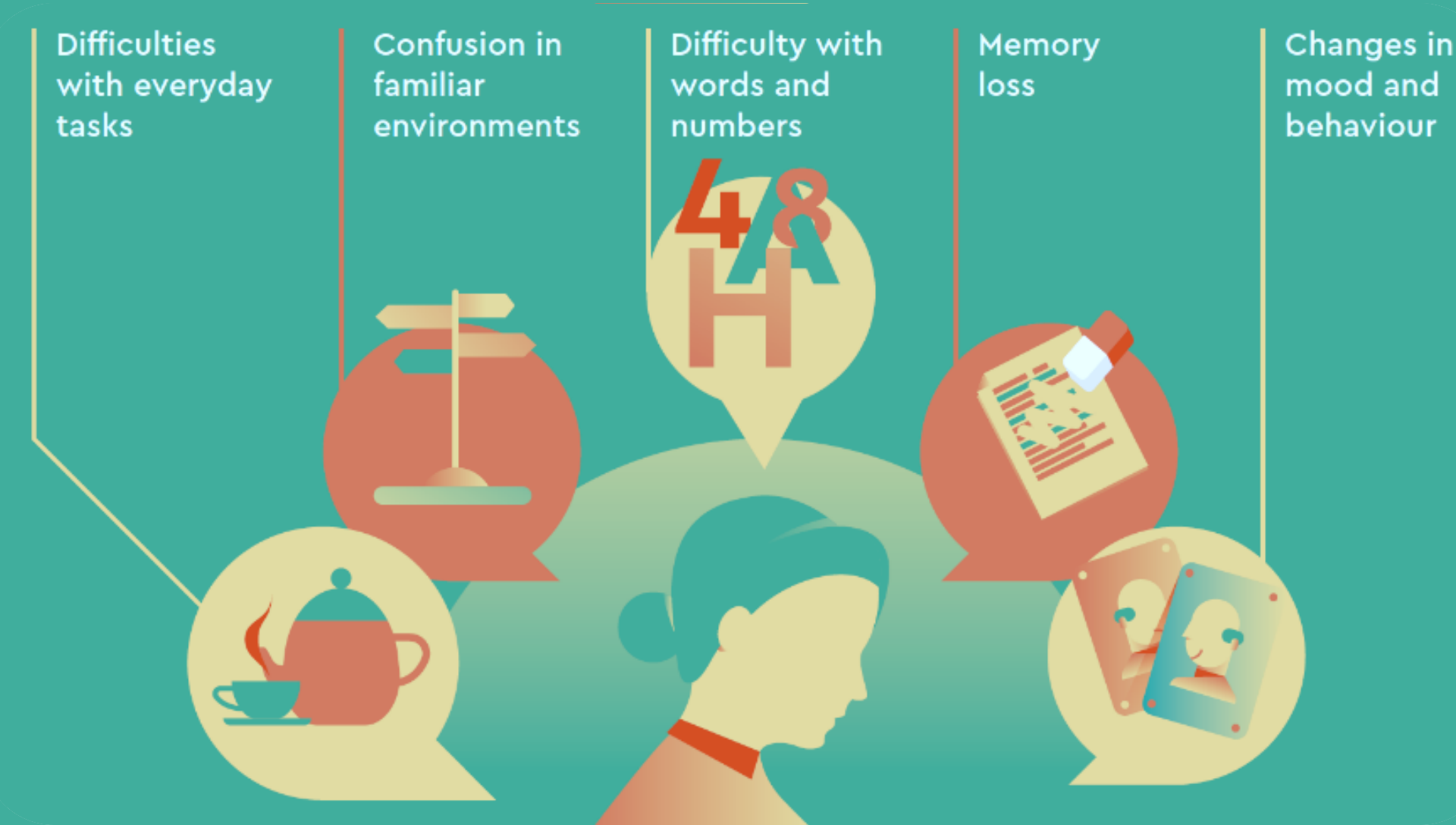
Difficulties with everyday tasks

Confusion in familiar environments

Difficulty with words and numbers

Memory loss

Changes in mood and behaviour



LIVED EXPERIENCE

as a resident at two nursing homes

Definitions

Autonomy

"Respect for the right to autonomy is meant to protect the ability to act out of genuine preference or character or conviction or a sense of self"

Dworkin R, 1986

"Liberty, self-governance, self-determination; immunity from the arbitrary exercise of authority; choices; and freedom"

Fox N et al., 2005

Definitions

Risk

“ The amount of harm and the probability of that harm occurring. Risk is therefore a matter of degree, and risks range from those where harm is serious, permanent, and likely, down through various lesser degrees of seriousness, duration, and likelihood, to those where harm is not serious, permanent, or likely ”

Fraser Health, 2012

Opinion / Editorials

Help dementia residents thrive with gentler nursing approach: Editorial

Policy-makers should listen as the Alzheimer Society of Canada launches a campaign for "person-centred" care in nursing homes.

TORONTO STAR

INSIGHT

thestar.com

News / Insight

Long-term health care: A look inside the often-baffling system

Howard Cohen was told he had five days to find a long-term care home and move his mother out of hospital. Is this any way to run a health-care system?

A kinder, gentler approach to Alzheimer's sufferers, as recommended by the Alzheimer Society of Canada, makes plenty of sense.

THE GLOBE AND MAIL

SASKIA SIVANANTHAN

Old like me. Why elderly care needs more risk

Saskia Sivananthan
Contributed to The Globe and Mail
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MEASURING MOVES

When are they highest and what factors contribute to it

Why transitions?

ER visit

2nd ER visit

Acute hospitalization

Acute hospitalization

Move to AL

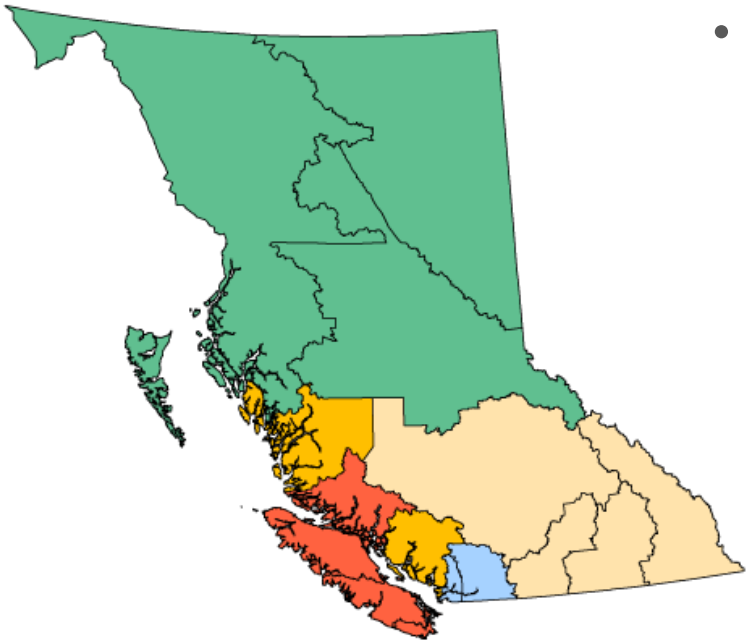
Move to LTC

2001 **2002** **2003** **2008** **2010**

Transitions

> *"A physical relocation from one place to another that involves at least one night's stay"*

What is “big data” or administrative data?



- **Health service lens** – to provide scientific evidence to influence health services policy at all levels so as to improve the health of the public

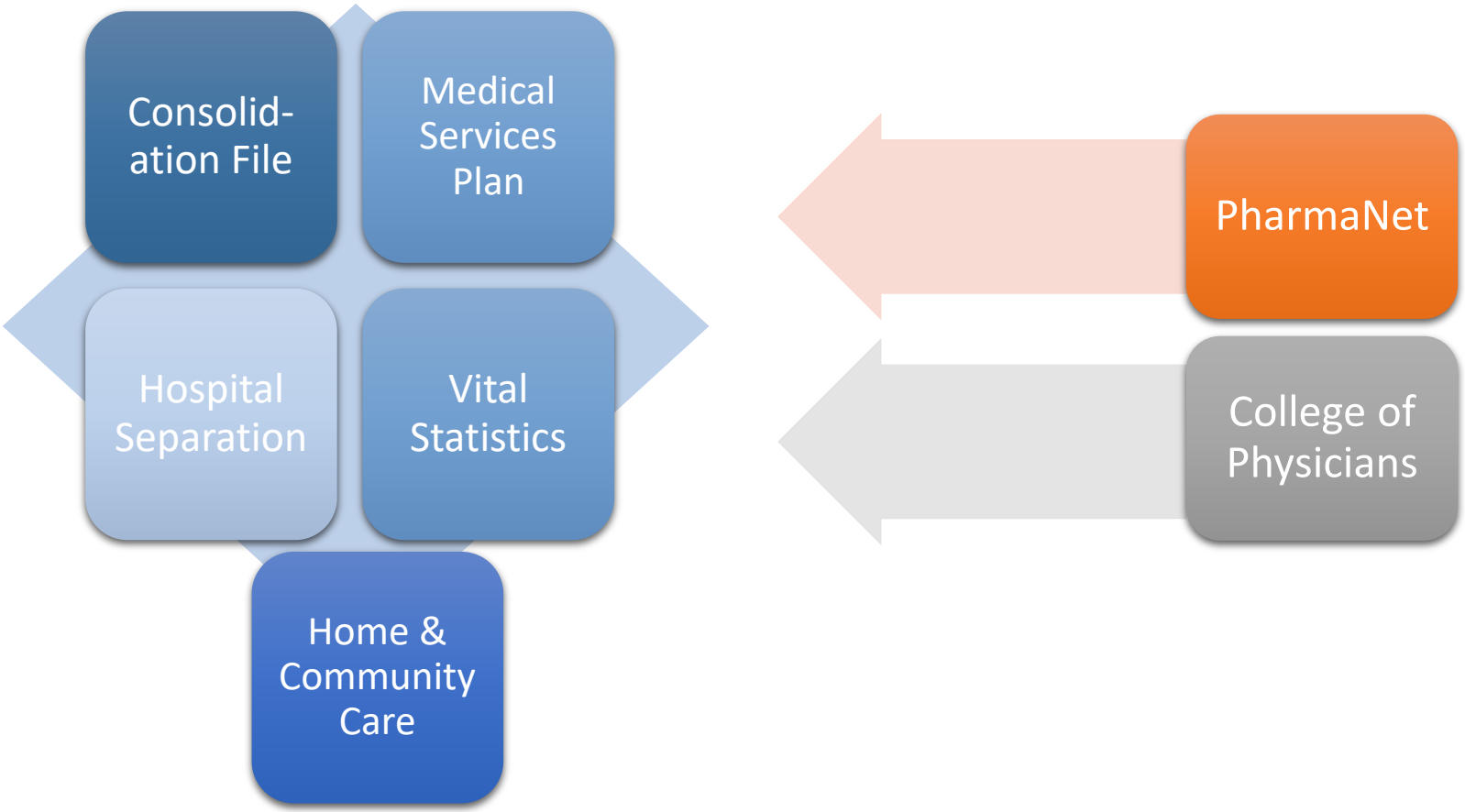
Attempts to answer universal questions that support healthcare decision making processes

- **Administrative data** - pre-existing data that have been collected for different administrative or operational purposes (not research) eg. registration, enrollment, payment (physician, pharma) or clinical care

- Key advantage, availability of data for an entire population, low cost, limited issues with sampling size or bias

Administrative data utilized

BC Administrative data: Individual patient-level analysis



Identifying Multiple Moves through the Health System

QUESTION 1: What is the rate of transitions experienced over the study period (10-years)?

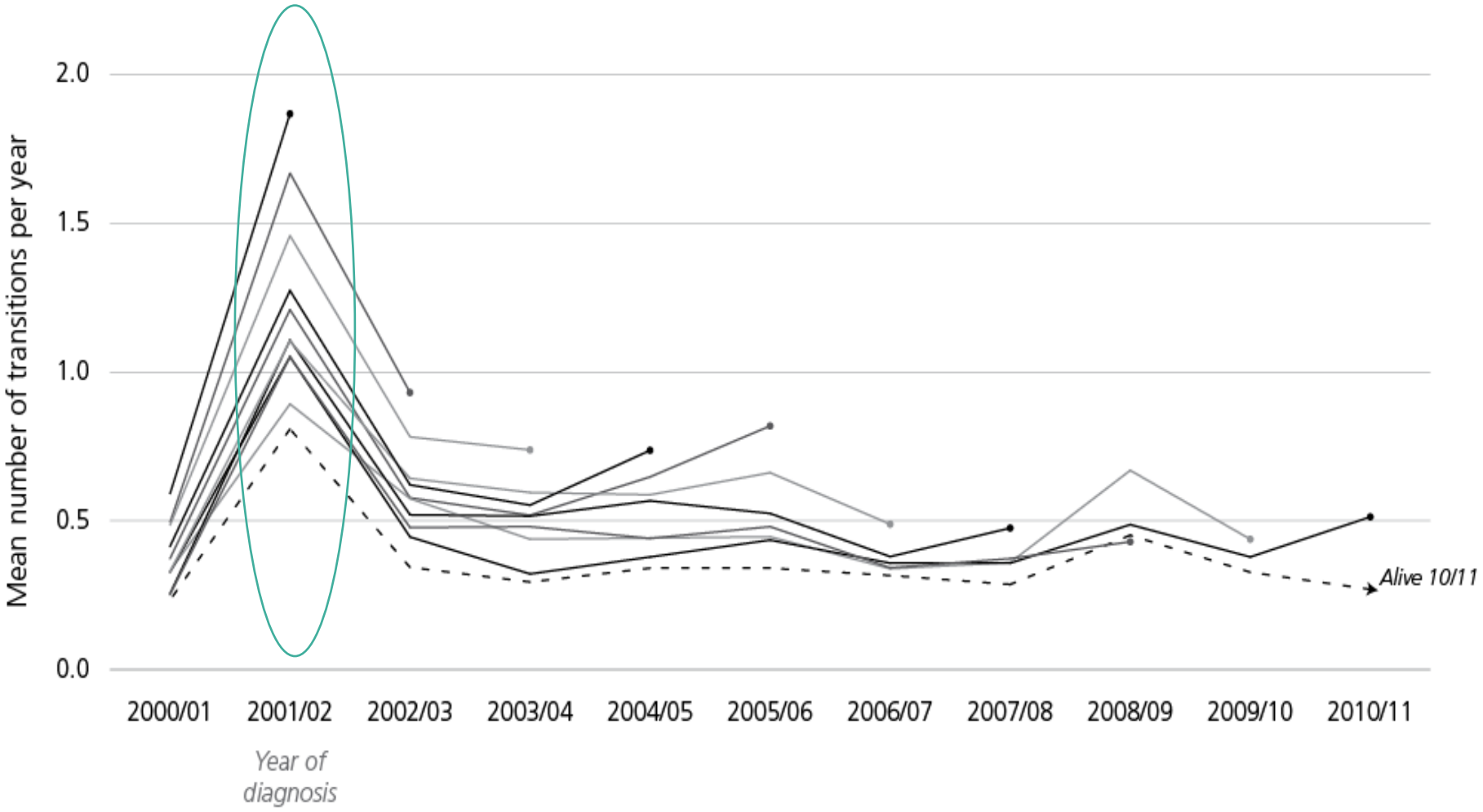
QUESTION 2: Are there points where transitions are high?

QUESTION 3: What are the types of transitions experienced?

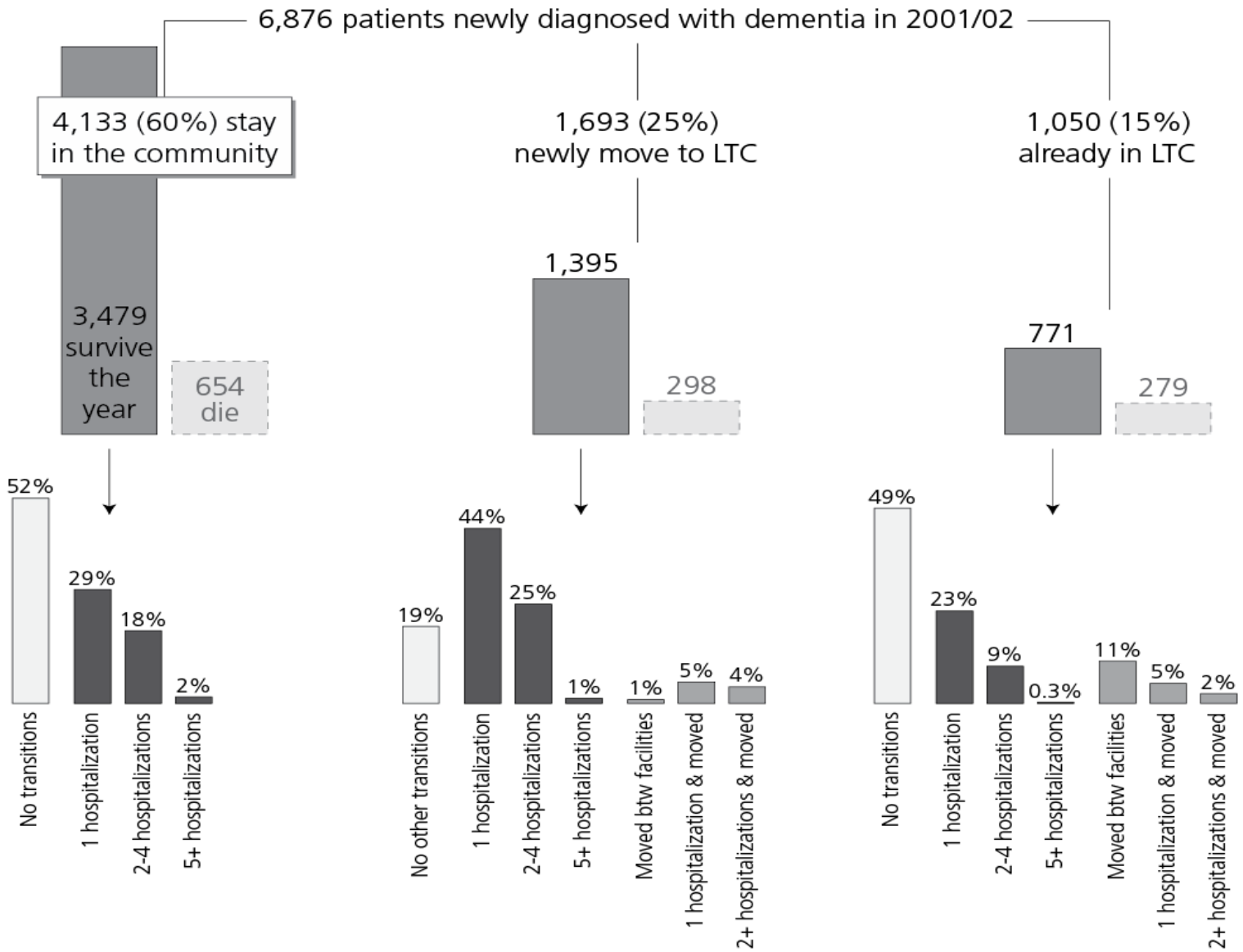
Aggregate Healthcare Use

	Entire Study Period (n=6,876)
Total transitions (mean ± SD)	3.7 ± 2.9
Transitions per year alive (mean ± SD)	0.9 ± 0.8
Total years alive (median)	4.6
Patients with any hospital stay, %	87.5%
Total hospital days accrued (median)	32.3
Patients with LTC use, %	57.6%

Rate of Transitions over time by Year of Death



Type of Transitions Experienced in Year of Diagnosis



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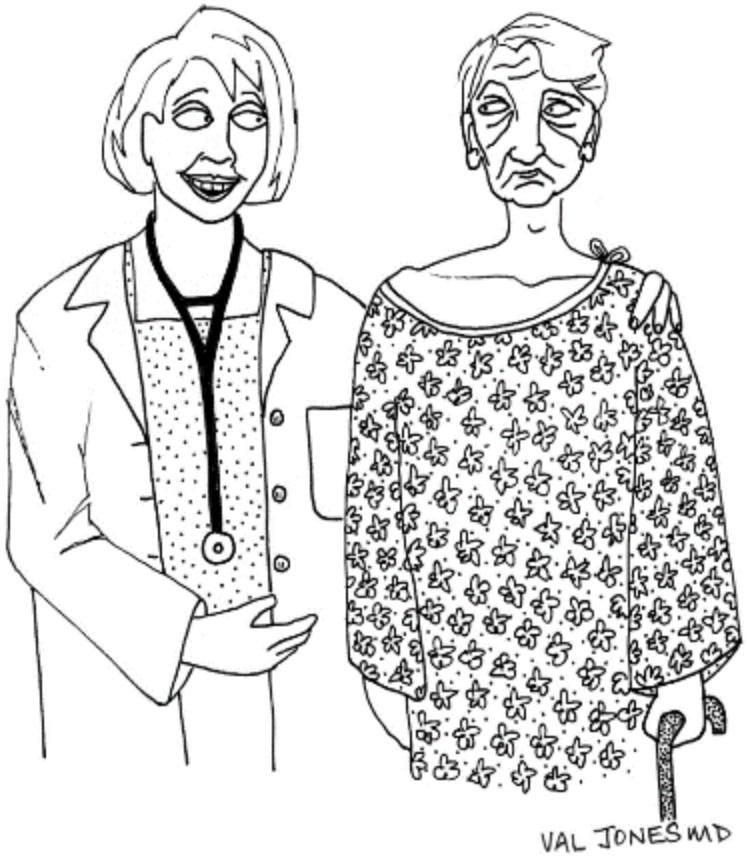
MEASURING MOVES

What can be done in the health system

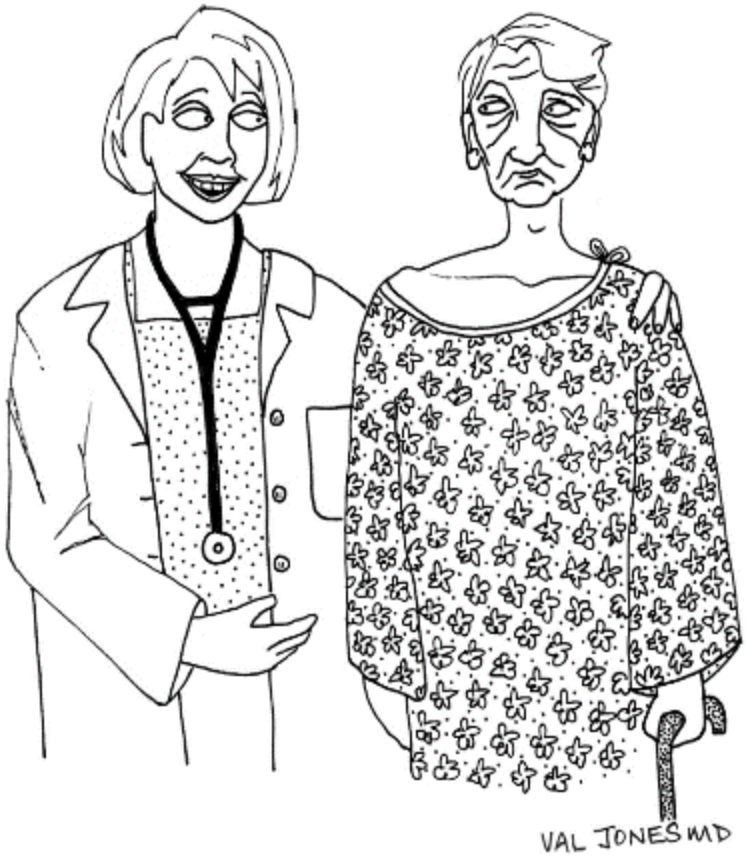
Primary care's role in dementia

- Primary care physicians are the first point of contact
- (often) provide a diagnosis, set in motion decisions about clinical care and long-term management
- People with dementia want to remain in the community, primary care provides ongoing support
- High quality primary care contributes to better outcomes for patients



Primary care's role in dementia: challenges

- Dementia in primary care is complex
- People with dementia often have co-morbidities:
  - requires higher level of care
  - impacts management of both conditions
- Despite evidence, poor detection and management persists
- Chronic nature of dementia require long-term planning



The Influence of Guideline Dementia Care and Primary Care on Moves

QUESTION 1: Does receiving good dementia care influence the number of transitions the patient experiences?

QUESTION 2: Does receiving high quality primary care influence the number of transitions the patient experiences?

HIGH QUALITY PRIMARY CARE DIMENSIONS

Access	first point of access for each new need, care in alternate settings or outside regular office hours
Continuity	longitudinal person-focused (not disease-focused) care across the spectrum of patient needs
Coordination	coordination of care provided in other settings or by other practitioners including specialists and laboratory testing
Comprehensiveness	comprehensive care that addresses most health needs

Barbara Starfield's definitions

GUIDELINE CONSISTENT DEMENTIA CARE DIMENSIONS

Laboratory Testing	Laboratory tests for complete blood count, TSH, serum calcium, electrolytes, fasting glucose and Vit B_{12}
Imaging	Head CT at any point during year of dx
Prescriptions	Prescriptions for AChI, antipsychotics, benzodiazepine and trazadone
Physical Examination	Physical exam to identify neurological abnormality or other conditions
Counselling	Billing of MSP Counselling fee codes for prolonged counselling visits of minimum 20 mins
Specialist Referrals	Referral to neurologist, geriatrician, psychiatrist

NOTE: Unable to measure memory testing, MRIs and referral to community services.

Relationship between Dementia Care, Primary Care and Transitions

Care Processes	Dementia Care
Laboratory tests	0.9 (0.8-1.0)†
CT scan	1.1(1.0-1.1)*
AChI	0.7 (0.6-0.7)‡
Antipsychotics	1.2 (1.1-1.3)‡
Benzodiazepines	1.2 (1.1-1.3)‡
Trazodone	1.1 (1.0-1.2)
Antidepressants	1.1 (1.0-1.1)*
Counselling	0.8 (0.7-0.9)‡
Physical examination	0.7 (0.6-0.9)‡
Referrals for dementia	0.9 (0.8-1.0)†
HCC assessment	2.2 (2.0-2.4)‡

‡ - P value <0.001, † - P value <0.01, - P value <0.05*

Adjusted for age, sex, health status, geography ,income, behvaioural symptoms, location of diagnosis and physician practice patterns

Relationship between Dementia Care, Primary Care and Transitions

Care Processes	Dementia Care	Primary Care
Continuity of Care		0.4 (0.4-0.5) ‡
Coordination of specialist referrals		0.9(0.8-0.9) ‡
Coordination of lab referrals		1.0 (0.9-1.1)

‡ - P value <0.001, † - P value <0.01, - P value <0.05*

Adjusted for age, sex, health status, geography ,income, behvaioural symptoms, location of diagnosis and physician practice patterns

Relationship between Dementia Care, Primary Care and Transitions

Care Processes	Dementia Care	Primary Care	Dementia & Primary Care
Continuity of Care		0.4 (0.4-0.5) ‡	0.5 (0.4-0.6) ‡
Coordination of specialist referrals		0.9(0.8-0.9) ‡	-
Coordination of lab referrals		1.0 (0.9-1.1)	-
Laboratory tests	0.9 (0.8-1.0)†		0.9 (0.8-1.0)†
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Brain Pause

How could these results be translated into information that would be of value to policy-makers?

THE HEALTH SYSTEM MATRIX 6.1:

Understanding the Health Care Needs of the British Columbia Population through Population Segmentation

February 2015
Health Sector Planning and Innovation Division,
British Columbia Ministry of Health

Big Data: Privacy, Governance and Data Linkage in Health Information

How BC's Health System Matrix Project Met the Challenges of Health Data

Health System Planning and Innovation Division
Ministry of Health, British Columbia, Canada

BRITISH COLUMBIA

Recommendations

1. Reframing primary care physicians' education to emphasize dementia as a chronic, complex condition which can benefit from timely diagnosis and management *addressing patients' need prior to a crisis that triggers an acute hospitalization*

2. Guidelines would be more effective if they provided more detail around long-term management and treating dementia *in the context of the patient's other conditions*

3. Recognizing that physicians alone cannot provide adequate dementia care and that more resources are needed to support them: case management programs, interdisciplinary teams, increased role of other skilled staff

4. Explore interventions that are effective at reducing transitions: advanced care planning, patient navigators, case coordinators

Alberta Dementia STRATEGY AND ACTION PLAN

Reduce the number of health care transitions experienced by Albertans with dementia and ensure transitions are only undertaken when in the best interests of the individual.

Individuals living with dementia frequently experience **transitions** between their home, hospitals and continuing care facilities. These transitions are disruptive and sometimes cause irreversible decline in condition. We need to explore innovative models of care to integrate services, reduce and improve transitions, and avoid unnecessary hospitalizations.

> ***"Not only do I want to live well with dementia, I want to live with purpose…and with help I can."***

Health care transitions often have significant negative impacts on the experience of individuals living with dementia and their caregivers, especially those transitions that involve changing care providers and locations. Transitions adversely affect health status and increase stress and worry for the individual and their caregivers.

All efforts should be made to minimize the number of transitions and make them as smooth as possible. Reducing the number of required transitions can be achieved by:

- supporting individuals to receive the care they need in their home rather than in an emergency department;
- developing continuing care residences that enable individuals to age in place rather than having to move to receive more care; and
- ensuring that all care providers understand the needs of individuals living with dementia and adapt accordingly.

Enhancing timely access to restorative and rehabilitative care can also reduce transitions by providing more time and support to assess needs, develop individualized care and service plans and improve individual function.

Ensure everyone with a diagnosis of dementia receives assistance to navigate the health and social systems and coordinate services.

Albertans living with dementia and their caregivers have told us that they need one person to help them access and organize the services and supports they require over time. This coordinator could be any care provider involved in the care of an individual, from a primary care physician to a community organization representative or case manager. The care and services coordinator's role would be to support the individual and their caregiver, ensure early planning to reduce negative impacts of dementia, and take a leading role in the planning, coordination and provision of care and supports.

Build capacity, and spread evidence-informed best practices in recognizing, diagnosing and clinically managing dementia among primary health care teams.

As the foundation of dementia care, primary health care providers must be supported to increase their ability to recognize, diagnose, and clinically manage dementia. Models for dementia service delivery should be developed or adapted, shared and integrated across primary health care.

GLOBAL ACTION PLAN

on the Public Health Response to Dementia

Vision

A world in which dementia can be prevented and people with dementia and their carers can live well and receive the care and supports they need to fulfil their potential with dignity, respect, autonomy and equality

Goal

To improve the lives of people with dementia, their carers and families, while decreasing the negative impact of dementia on them as well as on communities and countries

Cross Cutting Principles

1. Human rights of people with dementia
2. Empowerment and engagement of people with dementia and their carers
3. Evidence-based practice
4. Multisectoral collaboration
5. Universal health and social coverage
6. Equity
7. Appropriate attention to dementia prevention, cure and care

Seven action areas & global targets by 2025

Dementia as public health priority	75% of countries have dementia policy
Dementia awareness & friendliness	100% of countries have awareness raising campaign; 50% have dementia-friendly initiatives
Dementia risk reduction	NCD global targets are met
Dementia diagnosis, treatment and care	At least 50% of countries have diagnostic rate of 50% or more
Support for dementia carers	75% of countries offer carer training and support
Health information systems for dementia	50% of countries routinely collect data for dementia core indicators
Dementia research and innovation	Doubling of research output

Global Action Plan on the Public Health Response to Dementia 2017-2025

[a Nursing Home should be place where]…old people can drink, laugh and love themselves into death.

Thyra Frank
Danish Dementia Leader

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Patient Factors Associated with Transitions