

End of Life Care Surveillance and Research Capacity Development to Identify and Address the Needs of Vulnerable Populations

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and

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Capital Health



NELS | Network for End of Life Studies
ICE | Interdisciplinary Capacity Enhancement

Acknowledgement



Funding for this NELS ICE research team capacity development was received from the **Canadian Institutes of Health Research (CIHR)** strategic grant: **“Reducing Health Disparities and Promoting Equity for Vulnerable Populations”**

Lead CIHR Institutes for this ICE initiative are:

“Institute of Gender and Health” and
“Institute of Population and Public Health”

Outline

NELS ICE

Vulnerable Populations

Surveillance Reporting

Research Capacity Development

Knowledge Exchange

Questions

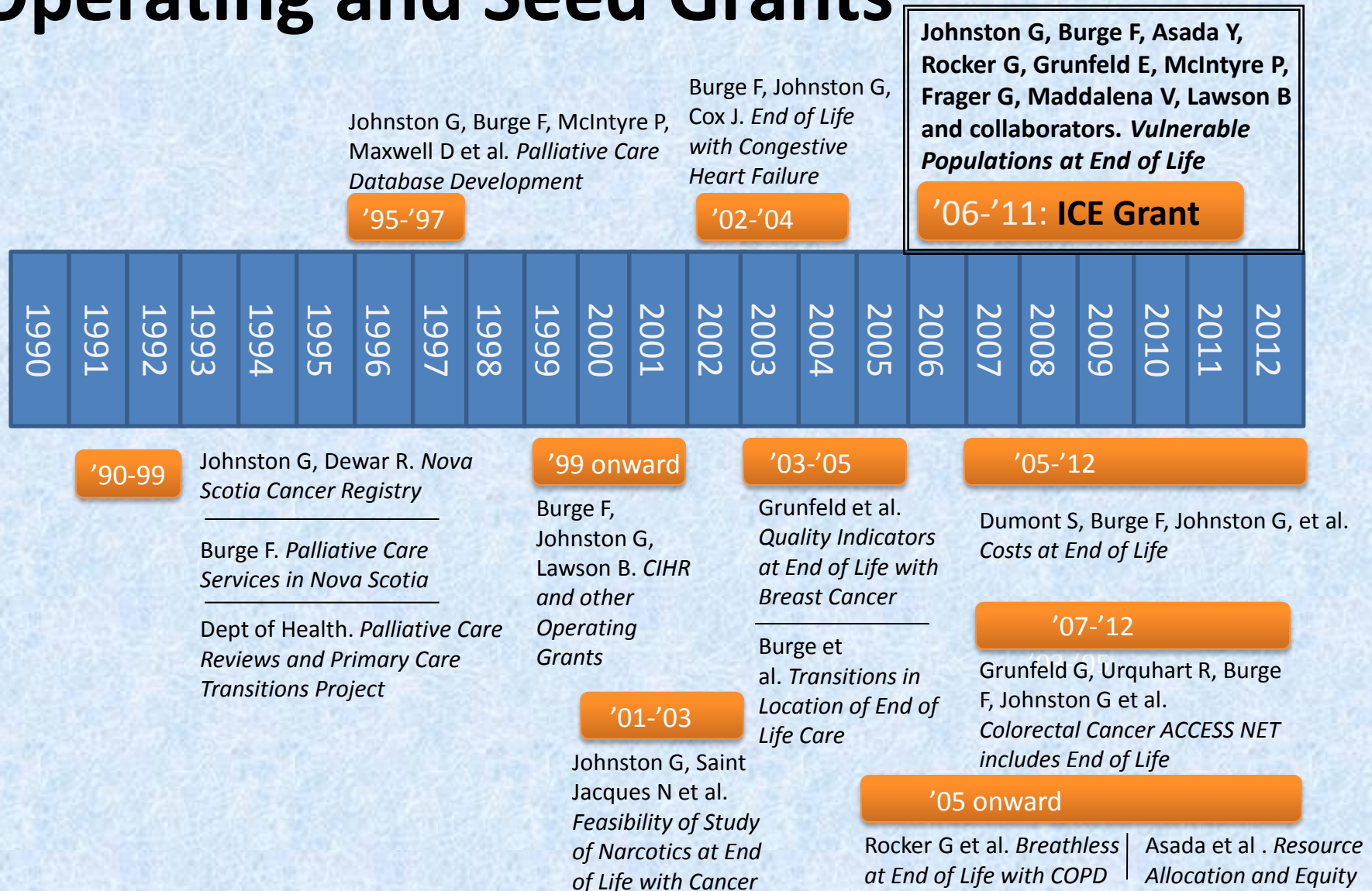
NELS ICE

Network for End of Life Studies (NELS):

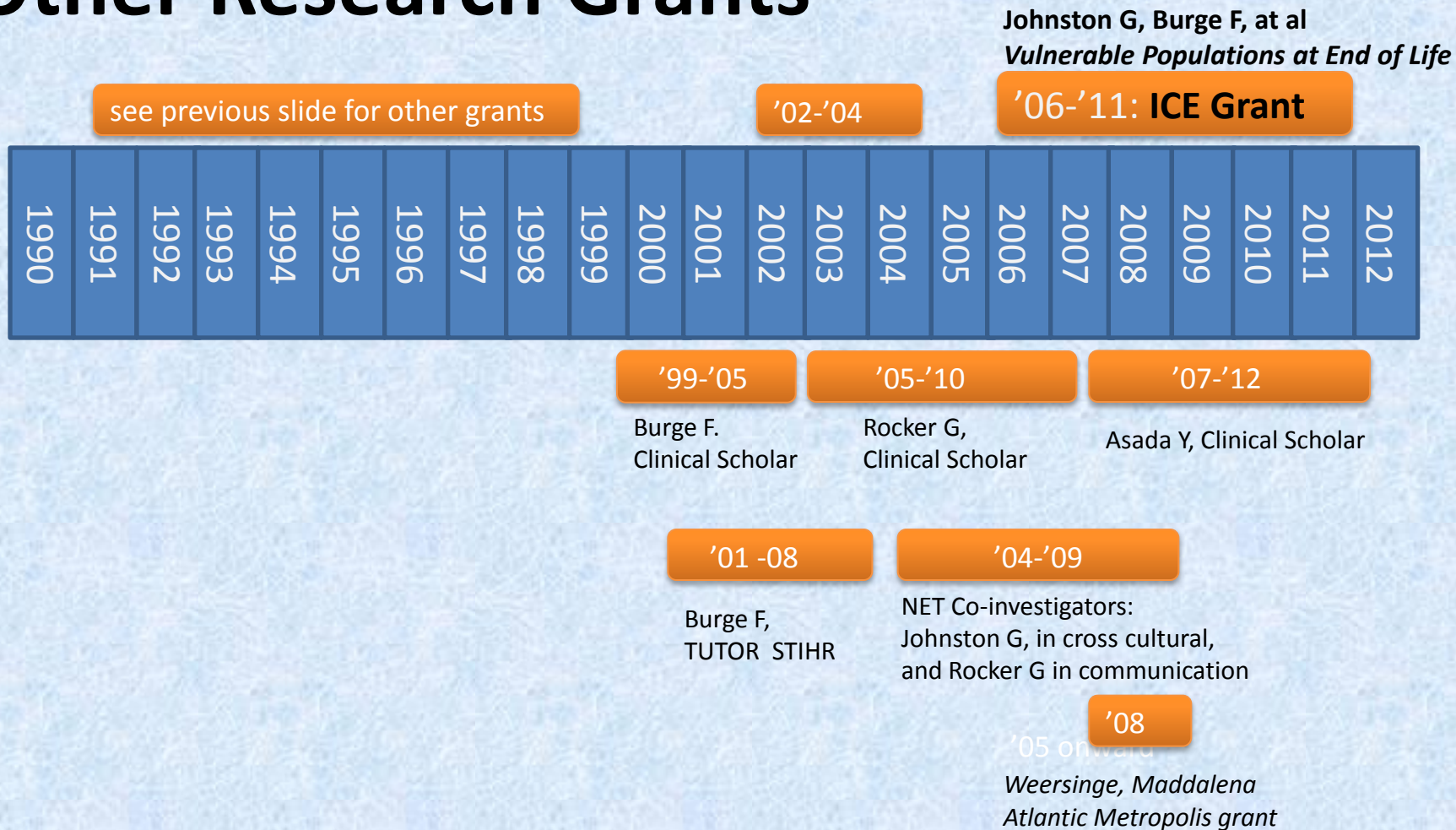
Projects over more than 10 years by Halifax based researchers to investigate end of life care

NELS was successful in obtaining an **Interdisciplinary Capacity Enhancement (ICE)** grant from CIHR. ICE grants are similar but differ from New Emerging Team (NET) grants, which funded the development of 10 palliative and end of life research teams across Canada starting two years prior to this NELS ICE grant.

NELS Development through ICE, Research Operating and Seed Grants



NELS Development in relation to ICE, Clinical Scholar, NET and STIHR, and Other Research Grants



Goals of NELS ICE

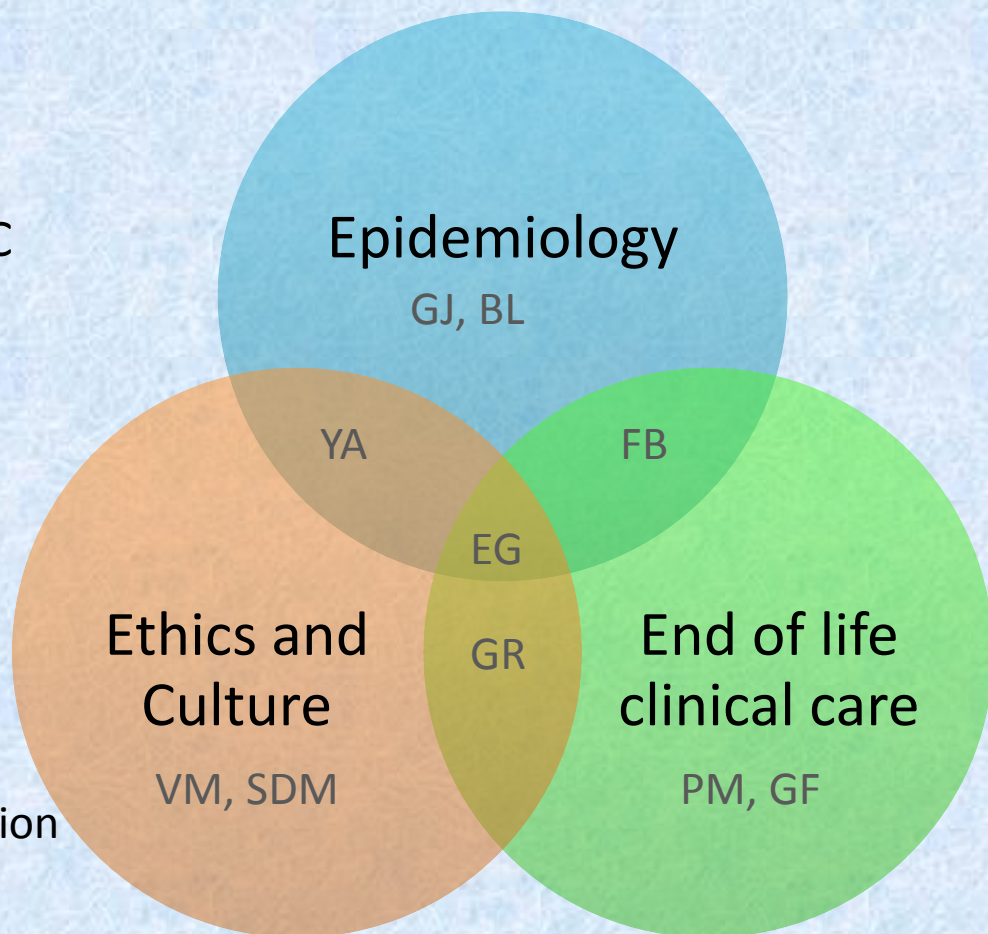
- 1) Create an **interdisciplinary team** of researchers, trainees, health professionals, and community partners
- 2) Develop **surveillance system** and reports to identify **vulnerable populations** at end of life
- 3) Design and conduct pilot studies for full **research** proposals to examine and address vulnerability and inequity in provision of quality end of life care
- 4) Engage in **knowledge translation**

NELS ICE Interdisciplinary Team

PI: Grace Johnston, MHSA PhD
Co-PI: Frederick Burge, MD FCFP MSc
Yukiko Asada, MSc PhD
Eva Grunfeld, MD DPhil CCFP FCFP
Graeme Rucker, MHSc DM FRCP FRCPC
Beverley Lawson, MSc
Paul McIntyre, MD FCFP
Victor Maddalena, BN MHSA PhD
Gerri Frager, MD FRCPC

PLUS
Trainees,
Staff, and
Collaborators

Julie Lachance, Health Canada
Gael Page / Ann McKim, Nova Scotia (NS)
Canadian Hospice Palliative Care Association
Sharon Davis Murdoch, NS Dept of Health
and others



22 NELS ICE Trainees as of Sept 2008

Victor Maddalena	Post Doctoral Fellow '06-'07, in '08 tenure track Assistant Professor at MUN
Judith Fisher	Post Doctoral Fellow, '09-'10, in '08 PhD student in Pharmacy at U of Toronto
Jessica Dooley	Community Health and Epidemiology (CHE) MSc candidate in '07 ICE Project 3
Ruth Lavergne	CHE MSc candidate, '07 ICE Project 2; '08-09 develop Surveillance measures
Jennifer Barnes	MN candidate, '08-'09 ICE Project 3 on end of life care in pediatric ICU
Farhana Kanth	MHSA candidate '07-'08 ICE Project 4 Immigrants; now Policy Analyst, NS DOH
Suha El Masalmeh	MHSA candidate '08 ICE Project 8 Review of Family Caregiver Policy
Shauna McVorrán	MHSA new graduate '07, develop Surveillance report and Knowledge Exchange
Patricia Murray	MHSA candidate '08 ICE Project 3 Documentation of End of Life Pediatric care
Junaid Kapra	MHI (Health Informatics) new graduate '07, palliative program data review
Alison Zwaagstra	MHI new graduate '07, develop Vulnerable Population Surveillance system

22 NELS ICE Trainees (continued)

Yukiko Asada	New Investigator, '05-'08 learn research team development/management
Yoko Yoshida	PhD candidate and new graduate, '08-'10, develop equity measurement
Dorianne Rheaume	Radiation Oncologist, '08 sabbatical, improve equity in palliative radiotherapy
Christine Beck	Family Medicine Resident, '08-'09 ICE Project 6 qualitative, nursing home
Elsie Rolls	CHSRF EXTRA Fellow, '08-'10 ICE Project 6 nursing home intervention
Joanne Young	Respiratory Therapist, '07-'10 ICE develop/manage ICE Project 7 home COPD
Jun Gao	Statistical Analyst, '06-'11, develop NELS ICE surveillance, reporting, measures
Monique Lanoix	PhD graduate, '08 develop ICE literature data base; now tenure track Asst Prof
Dorothy Barnard	PhD candidate, '06-'07 knowledge translation literature review for ICE
Robin Urquhart	NET Coordinator, PhD candidate, '07-'09 ICE knowledge exchange (KE) project
Nicole McQuinn	ICE Research Coordinator, BA graduate, '09-'11 management/KE trainee

Researchers and Collaborators are Learners too

NELS ICE Staff

Alison Zwaagstra:

Health Information Analyst



azwaagst@dal.ca

Room 568, Bethune Building

Nicole McQuinn:

Research Coordinator

nels@dal.ca

School of Health Administration

Fenwick Place

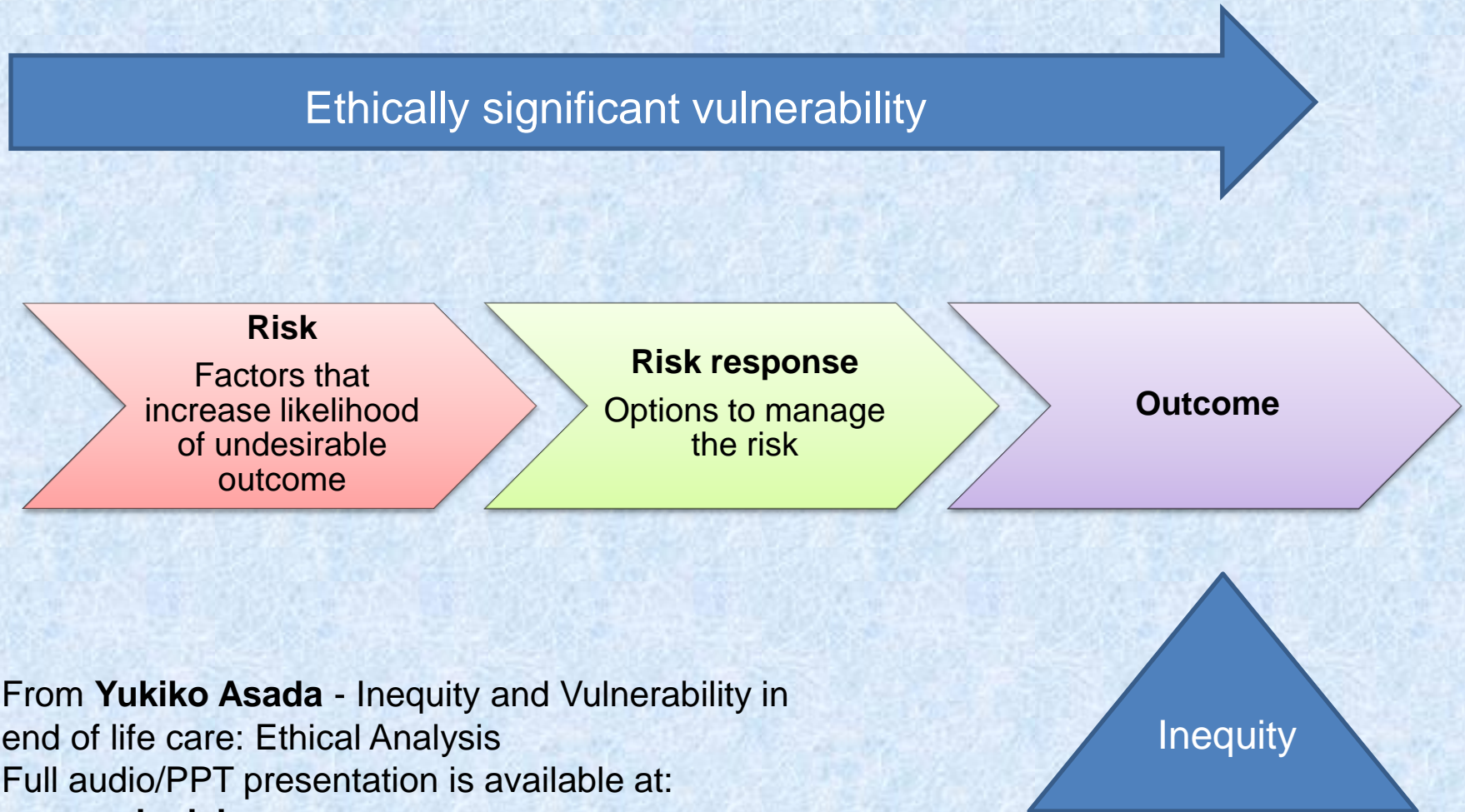
Inequity Analysis

to identify vulnerabilities and thereby vulnerable populations

End of life care is inequitable, when
access, utilization, or quality of end of life care is
inadequate as a result of lack of resources to
persons, given societal and clinical norms.

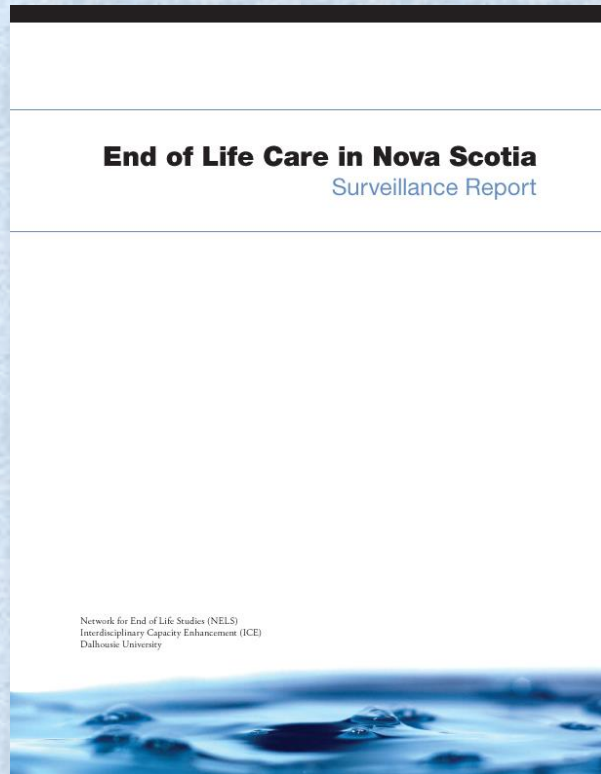
Combines epidemiology (measures of disparity,
difference) with ethical analysis of what is just
(fair) in the context of needs for end of life and
palliative care.

Identifying Vulnerable Populations

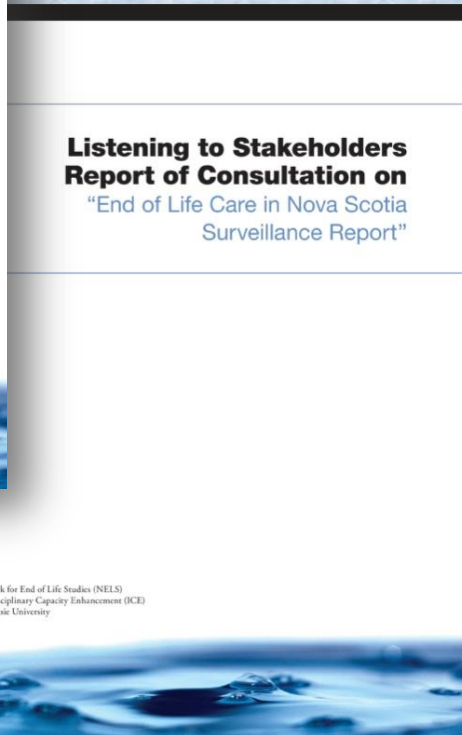


From **Yukiko Asada** - Inequity and Vulnerability in end of life care: Ethical Analysis
Full audio/PPT presentation is available at:
www.nels.dal.ca

Population-Based Surveillance Reporting



www.nels.dal.ca



In planning:

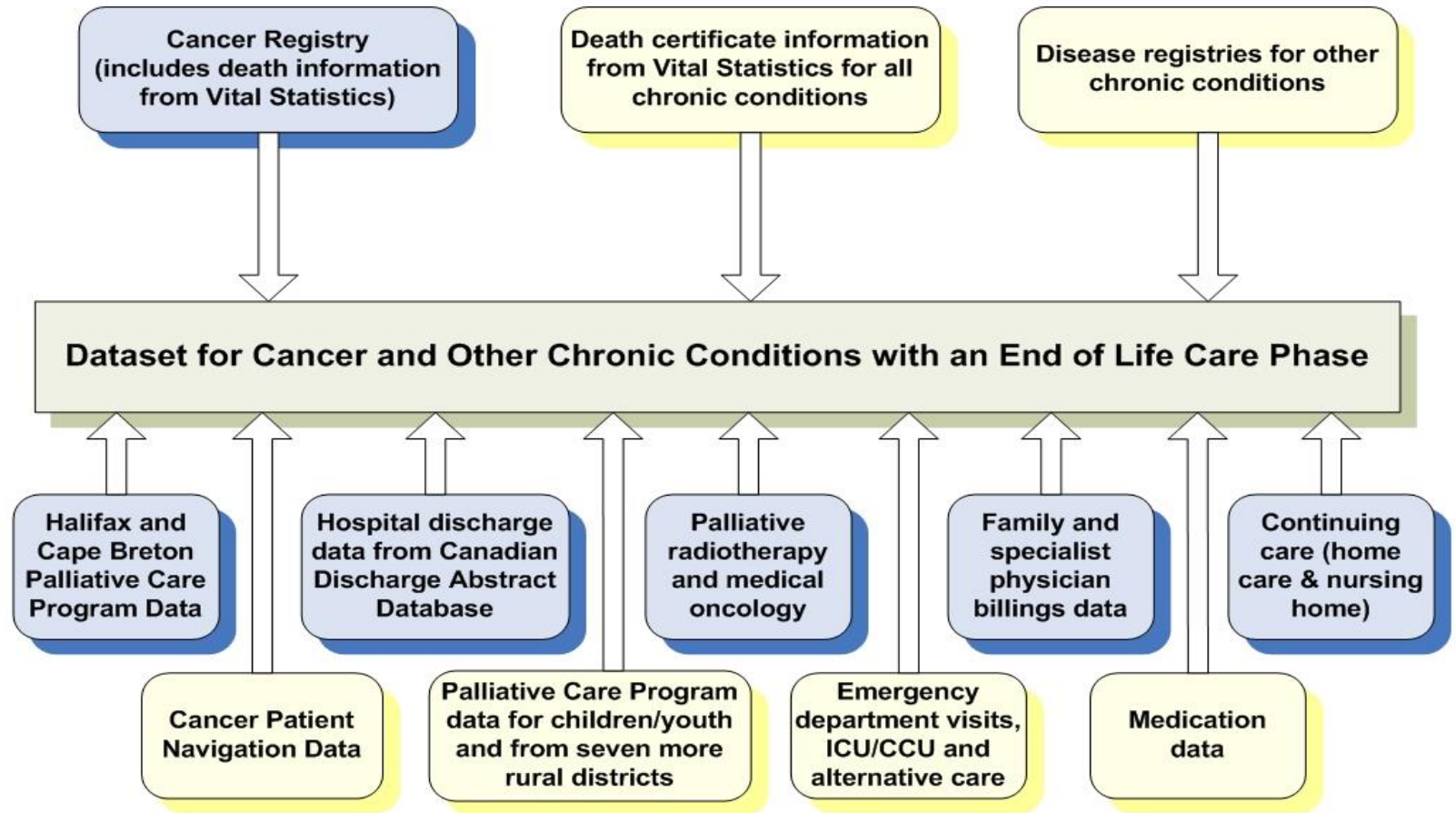
NELS Equity Report



*Cancer Care Nova
Scotia District
Reports*

*Canadian Cancer
Statistics 2010*

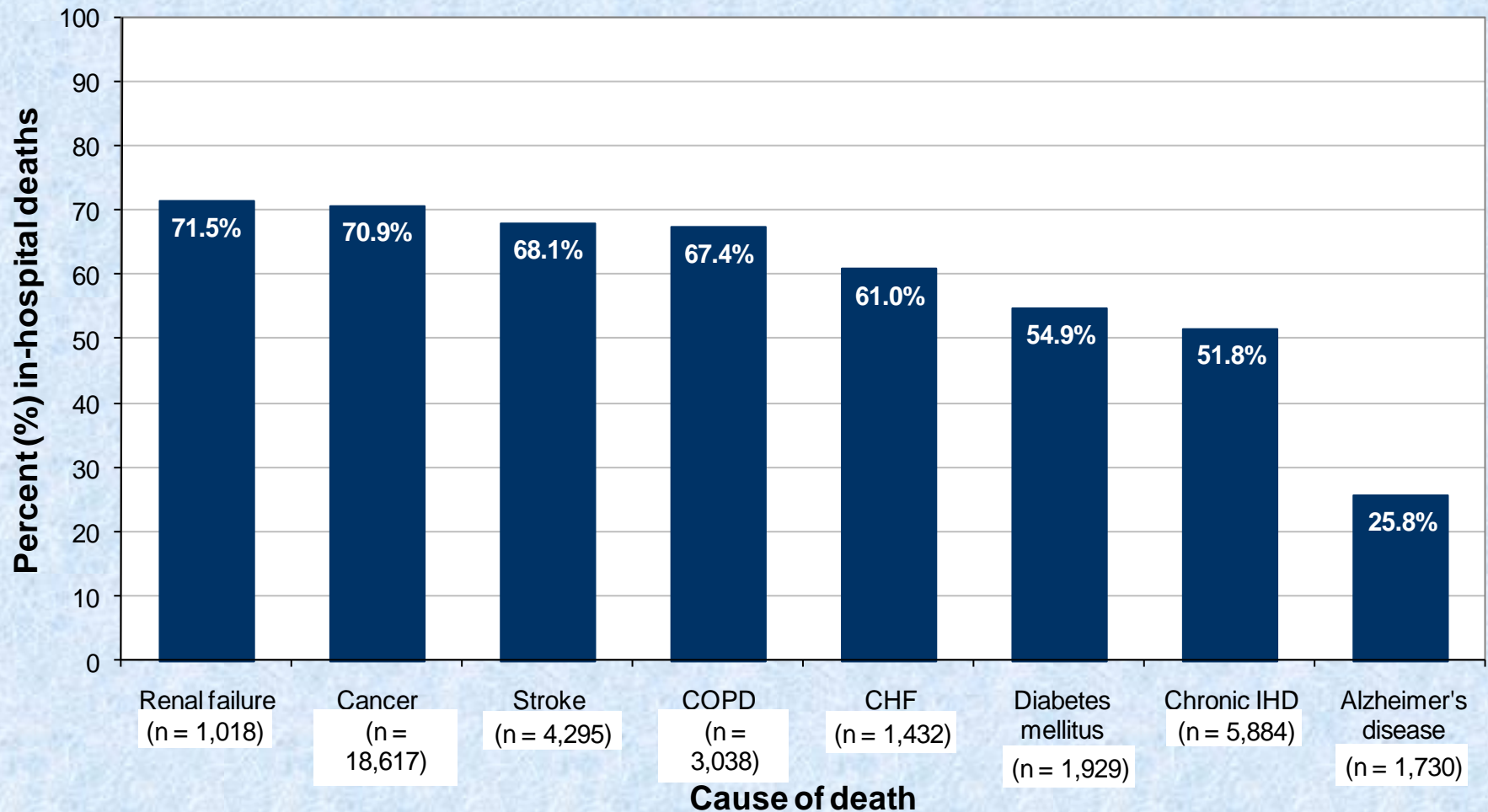
Population Surveillance Dataset

DECEASED
DATASET
SERVICES



-  Currently included in cancer data set
-  Proposed for chronic disease data set

In-hospital deaths by major underlying chronic disease causes of death, Nova Scotia, 1998-2005



Nursing Home Residents versus Others ≥65 years Dying of Cancer, 2000-2003

Quality Indicators	Nursing Home		Non Nursing Home	
	n	Statistic	n	Statistic
HOSPITAL DAYS IN LAST MONTH OF LIFE				
> 1 admission, # (%)	893	46 (5%)	6237	898 (14%)
> 14 days, # (%)	893	118 (3%)	6237	2220 (36%)
Mean days	893	5	6237	12
≥ 1 ICU admission	893	25 (3%)	6237	318 (5%)
Died in hospital # (%)	893	177 (20%)	6237	3697 (59%)
PALLIATIVE CARE PROGRAM				
Enrolled in CH/CB, # (%)	354	131 (37%)	2965	2040 (69%)

Nursing Home Residents versus Others ≥65 years Dying of Cancer, 2000-2003

Quality Indicators	Nursing Home		Non Nursing Home	
	n	Statistic	n	Statistic
CHEMOTHERAPY				
In last 6 months, # (%)	893	7 (0.8%)	6237	350 (6%)
Mean days from last chemo to death	7	112	350	74
EMERGENCY ROOM VISITS				
> 1 visit in last month, # (%)	893	25 (3%)	6237	399 (6%)
Mean visits in last month	893	0.2 visits	6237	0.4 visits
FAMILY PHYSICIAN VISITS				
Mean visits (for those with > 2 visits)	293	6.2	4867	8.0
Home/office visits in last two weeks, # (%)	870	139(16%)	6015	487(8%)

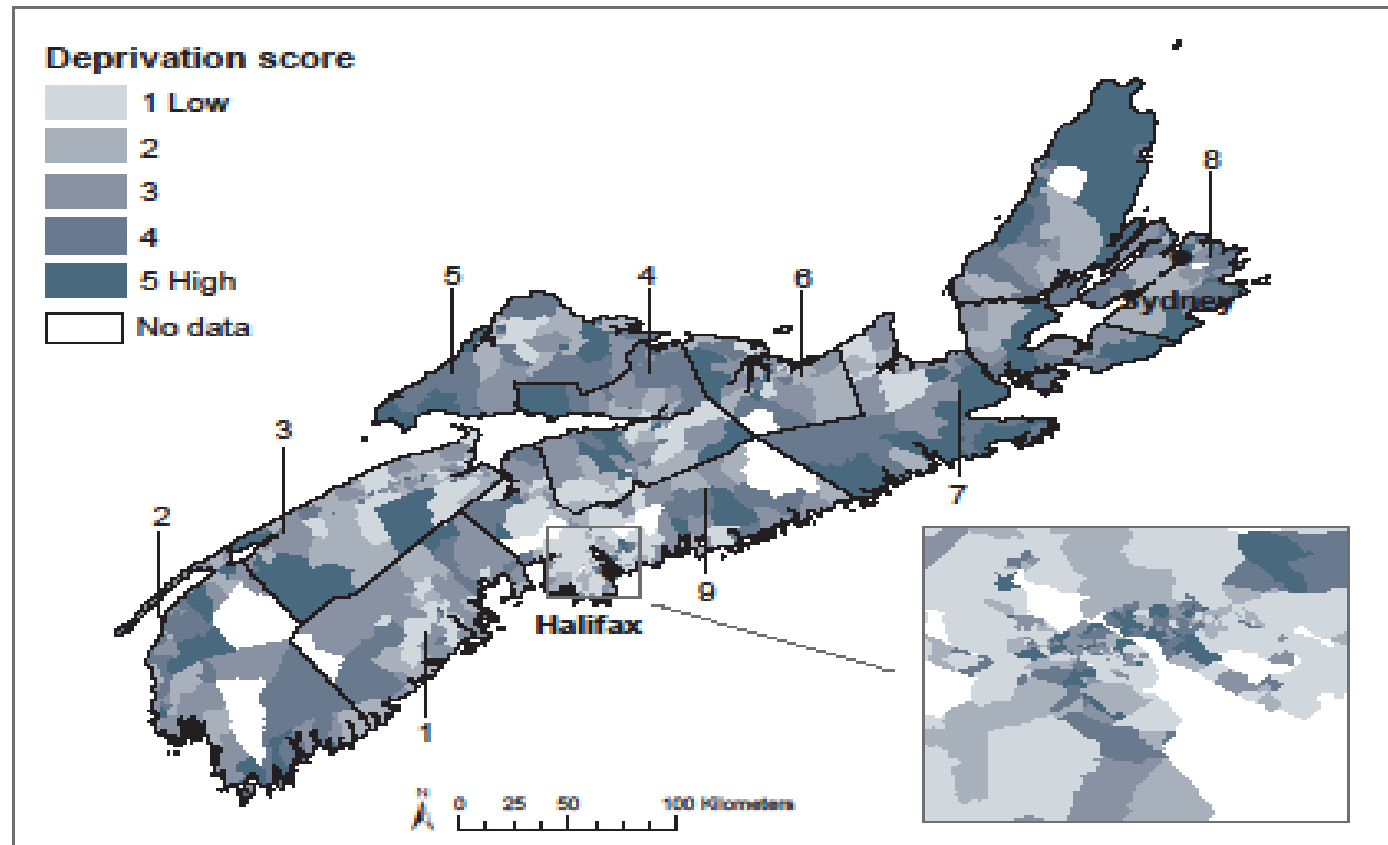
Gender and Sex Studies at End of Life

Sex: Biological basis of being male, female, or less commonly, hermaphrodite or neuter. Population census and administrative health services data include sex but not gender. Sex is correlated with nursing home residency, age, and disease for example breast versus prostate cancer.

Gender: Social role or personal identity distinct from biological sex; used in social and cultural contexts e.g., qualitative research on family caregiver policies.

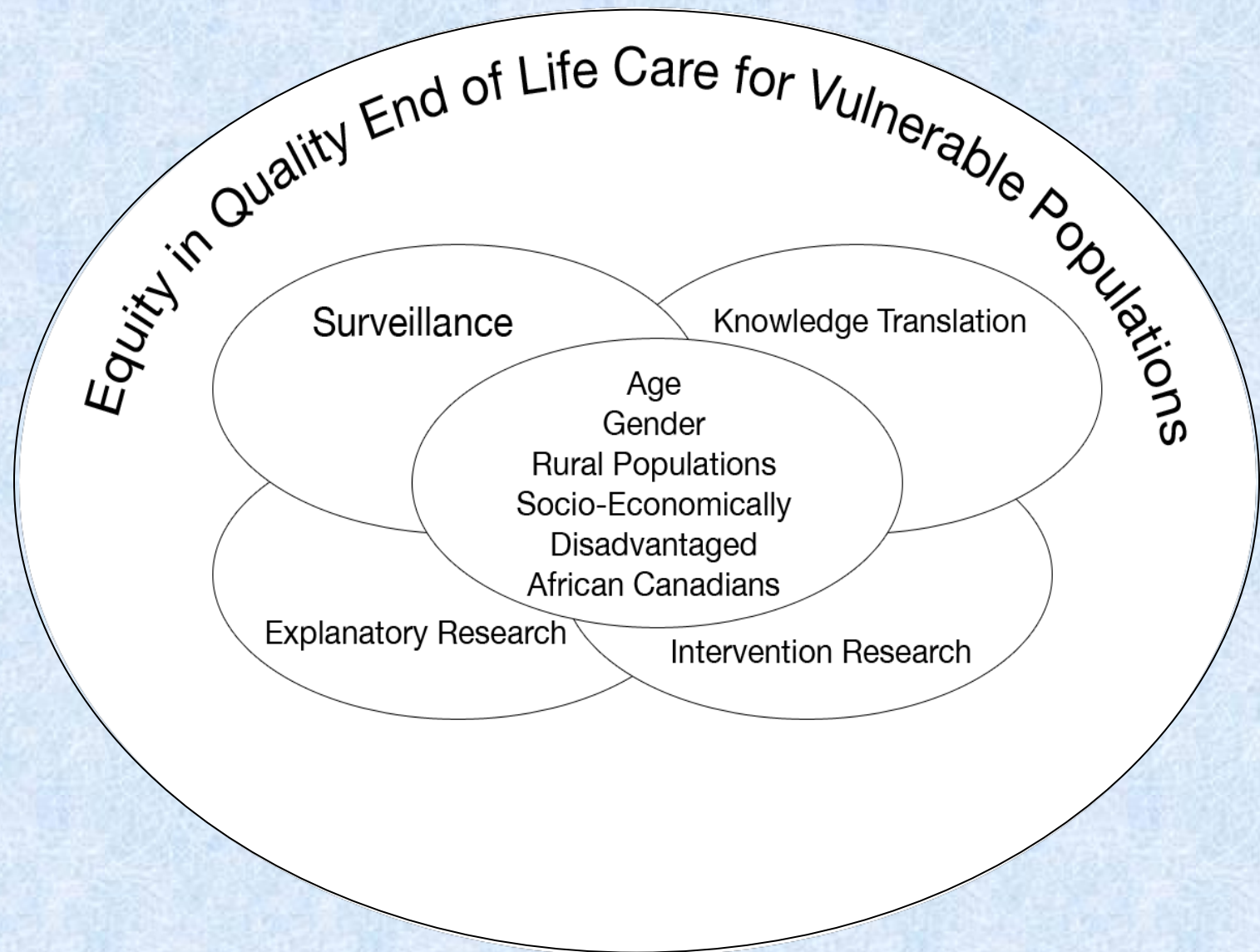
Both sex and gender are associated with vulnerability and influence access to end-of-life care

Census-based Deprivation Scores



NELS ICE Project Streams

1. Surveillance of Inequity in Quality End of Life Care
2. Vulnerable Populations at End of Life: An Ethical Analysis
3. End of Life Care for Children and Youth
4. Palliative Care for African Nova Scotians and other Populations: Deaf, SE Asian Immigrants, Aboriginal; qualitative, participatory
5. Mortality Follow-Back Study from Death Certificates
6. Elderly in Nursing Homes
7. Community Care for Chronic Obstructive Pulmonary Disease
8. Policies to Support Family Caregivers



NELS ICE Research Framework

Knowledge Exchange:

2007 Visiting Scholars

Dan Hausman, Philosopher: *Equity and Justice*,
University of Wisconsin-Madison, USA

Craig Earle, Clinical Research: *Quality Indicators*
Previously at Dana Farber, Boston, USA

Harvey Chochinov, Palliative Medicine: *Dignity*,
University of Manitoba, Winnipeg, Canada

Knowledge Exchange:

2008 Visiting Scholars

Serge Dumont, Social Work: *Costing Palliative Care*
University of Laval, Quebec City, Canada

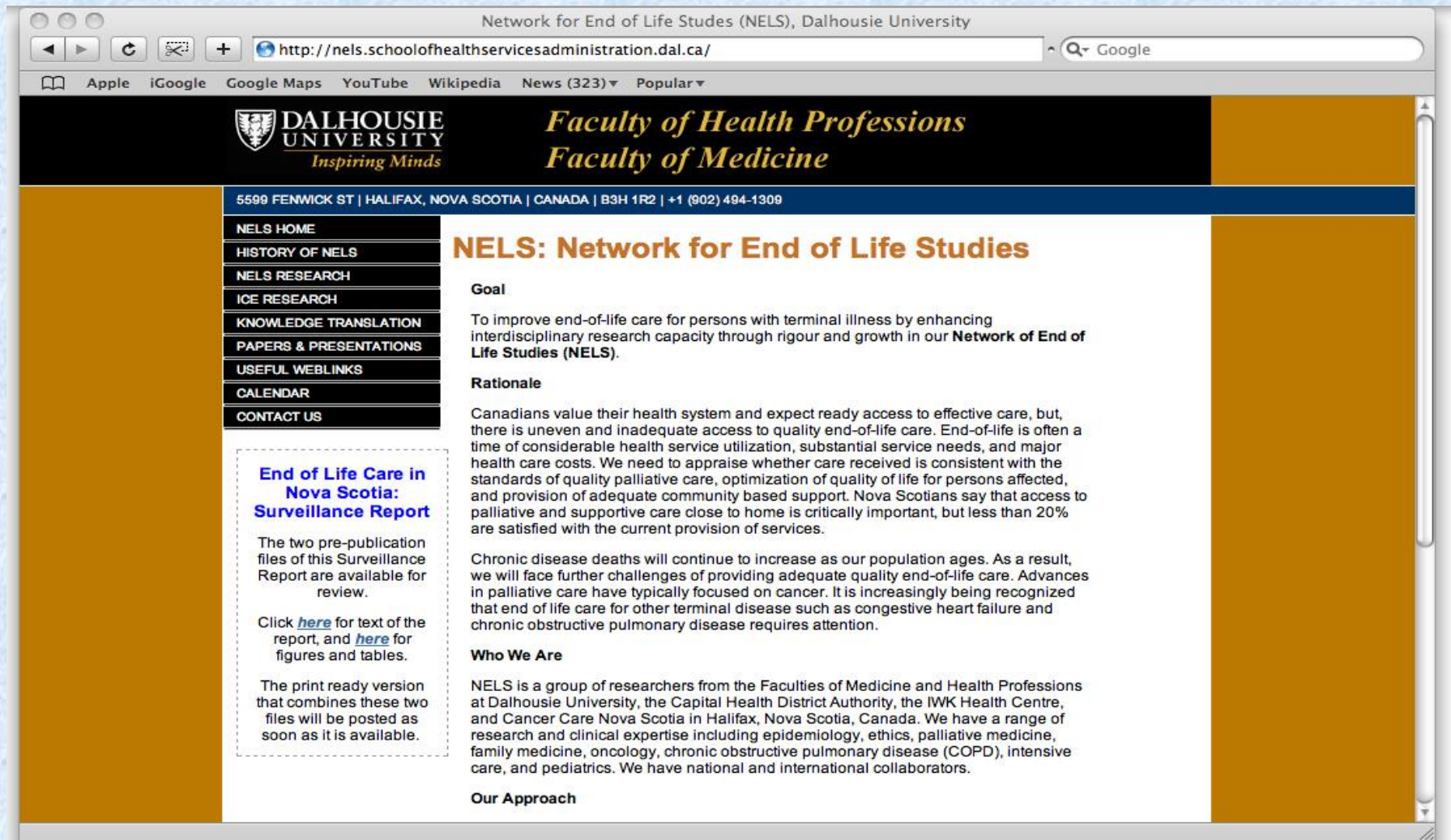
Scott Murray, Family Medicine: *UK Gold Standards*,
University of Edinburgh, Scotland

Konrad Fassbender – Economist: *Economic Analyses*,
University of Alberta, Edmonton, Canada

plus

work-in-progress sessions, conferences, website,

NELS ICE Website: www.nels.dal.ca



Questions after Presentation on:

- Consumer Representation
- Vulnerable Populations and Equity
- UK Gold Standards
- Research Team Development