Highlighting NELS ICE Successes

2006 - 2011

Grace Johnston, PI
Thursday, September 8, 2011
Network for End of Life Studies (NELS)

- Long term (10+ years) series of projects by Halifax based researchers to investigate end of life care

- Interdisciplinary team of researchers and clinicians from Dalhousie University, Capital Health District and IWK Health Centre in Halifax, Nova Scotia (NS)
Interdisciplinary Capacity Enhancement (ICE)

- 5-year (2006-2011)
- $820,000
- Canadian Institutes for Health Research (CIHR) ICE grant: “Reducing Health Disparities and Promoting Equity for Vulnerable Populations”

**Vision:** To enhance interdisciplinary research capacity through collaborations aimed to identify disparities and inequities in quality end of life care; explicate end of life care vulnerabilities; and develop and test ways to overcome inadequacies in publicly funded end of life care for persons at end of life with chronic disease.
Goals of NELS ICE

1. Create an interdisciplinary team
2. Develop surveillance to identify vulnerable populations
3. Design and conduct pilot studies
4. Engage in knowledge translation
success: Interdisciplinary team

- Grace Johnston, PhD, Principal Investigator
- Fred Burge, MD FCFP MSc, Co-PI
- Yukiko Asada, PhD
- Trevor Dummer, PhD
- Gerri Frager, MD FRCPC
- Eva Grunfield, MD FCFP DPhil
- Beverley Lawson, MSc
- Victor Maddalena, BN MHSA PhD
- Paul McIntyre, MD FCFP
- Graeme Rocker, DM FRCP FRCPC MHSc

ICE Investigators - 2006
success: Expanded interdisciplinary team

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<th>Trainees</th>
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<td>New Investigators</td>
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**success: Expanded interdisciplinary team**

### New Investigators

<table>
<thead>
<tr>
<th>Name</th>
<th>Project Details</th>
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<tr>
<td>Melissa Andrew</td>
<td>ICE New Investigator recipient (NI), Project 6, LTC geriatric assessment</td>
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<tr>
<td>Yukiko Asada</td>
<td>ICE Co-investigator, ’05-’08 learn research team development/management</td>
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<tr>
<td>Alix Carter</td>
<td>NI, Project 3, pediatric advanced care directives</td>
</tr>
<tr>
<td>Heather Castleden</td>
<td>NI, Project 4, aboriginal peoples at end of life</td>
</tr>
<tr>
<td>Anne Frances D’intino</td>
<td>NI, Project 8, informal caregiving</td>
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<tr>
<td>Rebecca Earle</td>
<td>NI, Project 3, pediatric advanced care directives</td>
</tr>
<tr>
<td>Jan Jensen</td>
<td>NI, Project 6, novel paramedic-long term care</td>
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<tr>
<td>Sue Korol</td>
<td>NI, Project 8, informal caregiving</td>
</tr>
<tr>
<td>Monique Lanoix</td>
<td>’08 develop ICE literature data base; now tenure track Asst Prof</td>
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<tr>
<td>Emily Marshall</td>
<td>NI, Project 5, LTC geriatric assessment</td>
</tr>
<tr>
<td>Delores Mullings</td>
<td>NI, Project 4, social work role in support of informal caregivers</td>
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<tr>
<td>Andrew Travers</td>
<td>NI, Project 6, novel paramedic-long term care</td>
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<tr>
<td>Gail Wideman</td>
<td>NI, Project 4, social work role in support of informal caregivers</td>
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<tr>
<td>Yoko Yoshida</td>
<td>’08-’10, develop equity measurement</td>
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</tbody>
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**success: Expanded interdisciplinary team**

### Post Doctoral Fellows

- **Judith Fisher** - Post Doctoral Fellow, ’09-’10, in ‘08 PhD student in Pharmacy at U of Toronto
- **Victor Maddalena** - Post Doctoral Fellow ’06-’07, in ‘08 tenure track Assistant Professor at MUN

### PhD Students

- **Dorothy Barnard** - PhD candidate, ‘06-’07 knowledge translation literature review for ICE
- **Rebecca Earle** - PhD candidate
- **Cathy Simpson** - PhD candidate
- **Robin Urquhart** - NET Coordinator, PhD candidate, ‘07-’09 ICE knowledge exchange

### Clinical/Admin.

- **Christine Beck** - Family Medicine Resident, ’08-’09 ICE Project 6 qualitative, nursing home
- **Nicole McQuinn** - ICE Research Coordinator, BA graduate, ‘09-’11 management/KE trainee
- **Dorianne Rheauem** - Radiation Oncologist, ’08 sabbatical, equity in palliative radiotherapy
- **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
## success: Expanded interdisciplinary team

### Masters & Recent Grads

<table>
<thead>
<tr>
<th>Name</th>
<th>Degree &amp; Year</th>
<th>ICE Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jennifer Barnes</td>
<td>MN '10</td>
<td>3 on end of life care in pediatric ICU</td>
</tr>
<tr>
<td>Shawn Chhabra</td>
<td>MHA '11</td>
<td>4</td>
</tr>
<tr>
<td>Jessica Dooley</td>
<td>CHE MSc '07</td>
<td>3</td>
</tr>
<tr>
<td>Jun Gao</td>
<td></td>
<td>‘06–’11, develop NELS ICE surveillance, reporting, measures</td>
</tr>
<tr>
<td>Jenn Gillis</td>
<td>MHA ‘09</td>
<td></td>
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<tr>
<td>Farhana Kant</td>
<td>MHSA ‘08</td>
<td>4 Immigrants; now Policy Analyst, NS DOH</td>
</tr>
<tr>
<td>Junaid Kapra</td>
<td>MHI ‘06</td>
<td>palliative program data review</td>
</tr>
<tr>
<td>Ruth Lavergne</td>
<td>CHE MSc ‘07</td>
<td>2; ’08-09 develop Surveillance measures</td>
</tr>
<tr>
<td>Andre Madison</td>
<td>CHE MSc ‘09</td>
<td>Equity measures for ICE Project 2, ICE Project 9 literature review</td>
</tr>
<tr>
<td>Suha Masalmeh</td>
<td>MHSA ‘08</td>
<td>8 Review of Family Caregiver Policy</td>
</tr>
<tr>
<td>Shauna McVorran</td>
<td>MHSA ‘07</td>
<td>develop Surveillance report</td>
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<tr>
<td>Patricia Murray</td>
<td>MHSA ‘08</td>
<td>3 Documentation of End of Life Pediatric care</td>
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<tr>
<td>Sarbjeet Singh</td>
<td>MHA ‘09</td>
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<tr>
<td>Dorothy Wang</td>
<td>MHA ‘11</td>
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<tr>
<td>Hao Wu</td>
<td>MSc candidate ‘13</td>
<td>ICE Project 4 Chinese Immigrant Population</td>
</tr>
<tr>
<td>Alison Zwaagstra</td>
<td>MHI ‘07</td>
<td>develop Vulnerable Population Surveillance system</td>
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success: NIS / surveillance

Network Information

- Cancer Registry (includes death information from Vital Statistics)
- Halifax and Cape Breton Palliative Care Program Data
- Hospital discharge data from Canadian Discharge Abstract database
- Family and specialist physician billings data
- Continuing care (home care and nursing)
- Palliative radiotherapy and medical oncology
- Medication data
- Colchester Palliative Care Program data
- Death certificate information from Vital Statistics for all chronic conditions
- Cardiovascular and Diabetes disease registries

Dataset for Cancer and Other Chronic Conditions with an End of Life Care Phase

Previous cancer database analysis
3x3 NELS in progress
Medications in progress
success: Beyond cancer surveillance systems

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
5. Mortality Follow-Back Study from Death Certificates
6. Elderly in Nursing Homes
7. Community Care for COPD
8. Policies to Support Family Caregivers
9. Medication Use at End of Life
**success:** New grants

<table>
<thead>
<tr>
<th>Additional grants received, related to NELS ICE research, by NELS ICE investigators since 2006</th>
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<tr>
<td>Total number of grants: 25</td>
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<td>Total dollar value of grants: $10,905,100</td>
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success: New grants

Some examples:

<table>
<thead>
<tr>
<th>PI</th>
<th>Award (years)</th>
<th>Amount</th>
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<tbody>
<tr>
<td>Yukiko Asada</td>
<td>CIHR New Investigator Award (2008)</td>
<td>$300,000</td>
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</table>
| Fred Burge and Bev Lawson               | *Mortality Follow Back study*  
CIHR Operating Grant (2008-12)                                                                                                                                                                           | $432,188     |
| Eva Grunfeld                            | *Towards measuring and improving access to quality cancer services in Nova Scotia*  
CIHR NET ACCESS Grant (2007-12)                                                                                                                                                                           | $1,598,660   |
| Graeme Rocker                           | *Palliation of dyspnea in advanced COPD: Patient and caregiver experiences opioid therapy*  
CIHR Regional Partnership Grant (2009-10)                                                                                                                                                             | $130,000     |
| Serge Dumont with P.McIntyre, G.Johnston, F.Burge, M.Scales and others | *Palliative care in Canada II: The economic perspective* - Capital District and Colchester East Hants Health Authorities  
CIHR (2008-10)                                                                                                                                                                                                 | $876,330     |
success: Knowledge translation

NELS News

• Issues highlight events and features completed and ongoing studies by ICE project streams.

• More issues to be released in 2011
success: Knowledge translation

Events

- Work-in-Progress Sessions
- Management Meetings
- 2009 Local Poster Event
- 2010 NELS Reception at the 18th International Congress on Palliative Care
- 2011 Highlighting NELS ICE Successes

Visiting Scholars

2007 - Harvey Chochinov, Craig Earle, Dan Hausman
2008 - Scott Murray, Serge Dumont, Konrad Fassbender
2009 - David Kuhl, R. Sean Morrison
2010 - Vickie Baracos, Allan Kellehear, Kevin Brazil
2011 - Mary Lou Kelley, Maxine Hancock
success: Knowledge translation

Reports

- Surveillance and Stakeholder Reports
- Project reports (nels.dal.ca/ice.html)
- Department of Health adapting NELS ICE report for district palliative care programs
- Special topic, end of life with cancer, in Canadian Cancer Statistics 2010

Collaborators

- **Julie Lachance**, Health Canada (2005-11)
- **Gail Page**, Canadian and Nova Scotia Hospice Palliative Care Associations (CHPCA, NSHPCA) (2005-09)
- **Ann McKim**, CHPCA and NSHPCA (2009-11)
success: Knowledge translation

- 65+ publications
- 170+ presentations
Upcoming ICE events

• African Nova Scotians at end of life KT workshop
  • Friday, October 14, 2011, AM – Rm 544 Bethune

• Visiting Scholar Maxine Hancock
  • 2012
Projects beyond ICE

- Supportive care for women with advanced breast cancer
- GoldHELP

New initiative
- CIHR Community based grant
Questions?