Might there be a win-win between SPOR and 3x3 NELS?

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Meeting with SPOR Leaders:
Adrian Levy, David Anderson,
Bill Gardner, Emily Edwards

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

Network for End of Life Studies (NELS)

Program of palliative and end of life care research

- > commenced in mid 1990's
- ➤ by Dr. Grace Johnston, School of Health Administration and Dr. Fred Burge, Department of Family Medicine, in collaboration with Surveillance and Epidemiology Unit of Cancer Care Nova Scotia, and Director of the Capital Health palliative care program
- based on retrospective studies using linked health administrative databases for Nova Scotia
- ➤ expanded from 2006 to current through an CIHR Interdisciplinary Capacity Enhancement (ICE) grant, hence NELS ICE
- > part of NELS ICE is a linked dataset called 3x3 NELS



Potential SPOR Benefits of working with NELS and/or 3x3 NELS

NELS:

- local, national, and international identify
- valued 'brand'
- 3. proven track record of
- research productivity,
- collaboration,
- relevance to policy and practice,
- enabling innovation in delivery of community based care,
- KT,
- trainees
- scanning environment for new enablers

3x3 NELS linked dataset:

- 1. exists
- feasible plan to expand3x3 NELS exists
- NELS plan for Networked Information System (NIS) is in line with SPOR curated data set
- 3x3 NELS analyst is Lynn Lethbridge
- expansion and collaboration would be timely as Grace plan to retire and transition



3x3 NELS linked dataset

CCNS Cancer Registry

Study subjects:

Nova Scotia (NS)
Vital Statistics death
certificate data; link
using name, address, ...
and HCN

NS Diabetes
program
registry based
on diabetes
education

NS Cardiovascular registry; built on Jafna Cox ICONS, hospital based

All Deaths in Nova Scotia, 1995-2009, linked by Ron Dewar to 3 disease registries and 3 palliative care program databases

Capital Health
Palliative Care
Program (PCP) data

Cape Breton PCP Data

Colchester East Hants PCP data

Census Profile Data (added to 3x3 data by NELS analyst)



Proposed SPOR Curated Maritime Retrospective (Case-Control) End of Life Dataset

NS, NB, PEI
Vital Statistics
death certificate
data

Potential Leaders in Identifying EOL and Advance Care Planning

Provincial cancer and other chronic disease registries

Family Physician and other primary care provision

Continuing care in own/ nursing home

Study subjects defined by death, linked to prior service use

Specialist medical care Hospital: ICU, Pall, Alternate

Emergency Department use

Medications

Diagnostic, curative, and other expensive resources

Source of improved composite
outcome measures for various
studies, e.g. Good death and
good resource use at EOL

Existing and new interventions to improve end of life care:

(extended care paramedic, INSPIRED for COPD, care by design for LTC, expanded role of community pharmacist, palliative care programs, hospices, Extramural Hospital (NB) ...)

Purposes: i) Surveillance,

- ii) Evaluation of innovations and forms of care at end of life, and
- iii) Development of new measures of a "good" (versus "bad") death, estimating survival algorithm



Plus, Proposed SPOR Maritime Prospective (Cohort) End of Life Care Registry

Indicators of end of life, e.g. stage IV cancer, admission to LTC, FEV < 20, In next months, a few years Community based primary care Respite and bereavement care for Family

NS, NB, PEI
Vital Statistics
death certificate
data

Cohort enters over time, follows end of life trajectory

Clinical Trials of pharmaceutical, alternative medicine, basic science, and other innovations

Case Manager

Other diagnostic, curative, emergency, and other specialist resources

Purposes:

- i) **Enabling coordinated, comprehensive clinical care** through case management and advance care planning,
- ii) Provision of data/registry 'platform' for recruiting for Randomized and other cohort Clinical Trials at end of life



Might SPOR help NELS and/or 3x3 NELS?

NELS

3x3 NELS

Potential Benefits

'home' for NELS, e.g. NELS website, NELS News, enable collaborations beyond 3x3 NELS, e.g. with CLSA to add end of life focus

at least five years and ideally longer for further 3x3 NELS development and use

Challenges

depends upon collaboration and negotiation among Grace, Fred, and SPOR leaders in association with NELS and SPOR partners is required for use of NELS 'brand' depends upon developing a good working relationship among various parties, e.g., Grace, Lynn, SPOR leaders, DOHW, data providers, and REBs, and others such as maybe Fred and Bev



Discussion









