

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

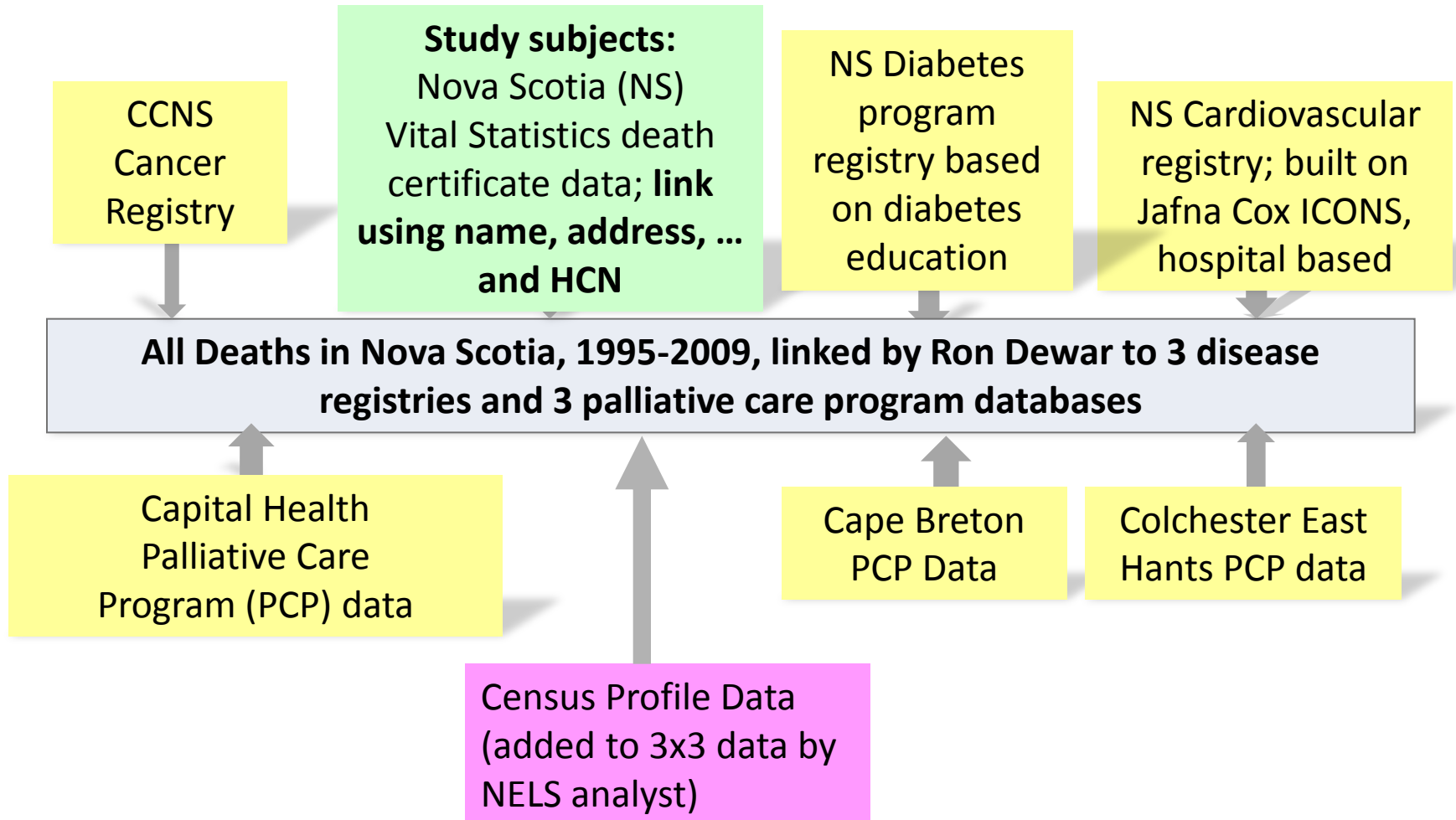
NELS:

1. local, national, and international identify
2. 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
4. scanning environment for new enablers

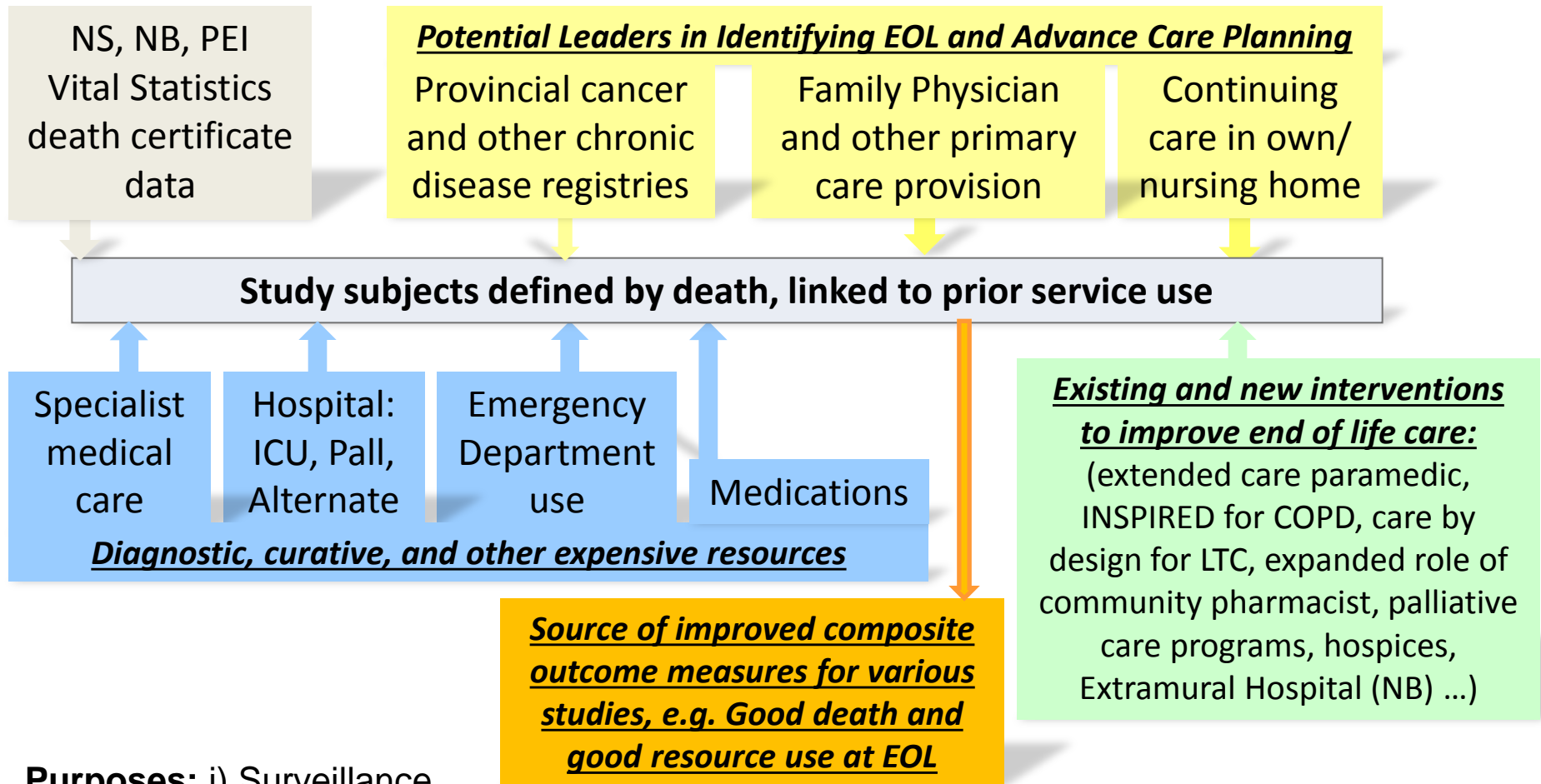
3x3 NELS linked dataset:

1. exists
2. feasible plan to expand 3x3 NELS exists
3. NELS plan for Networked Information System (NIS) is in line with SPOR curated data set
4. 3x3 NELS analyst is Lynn Lethbridge
5. expansion and collaboration would be timely as Grace plan to retire and transition

3x3 NELS linked dataset

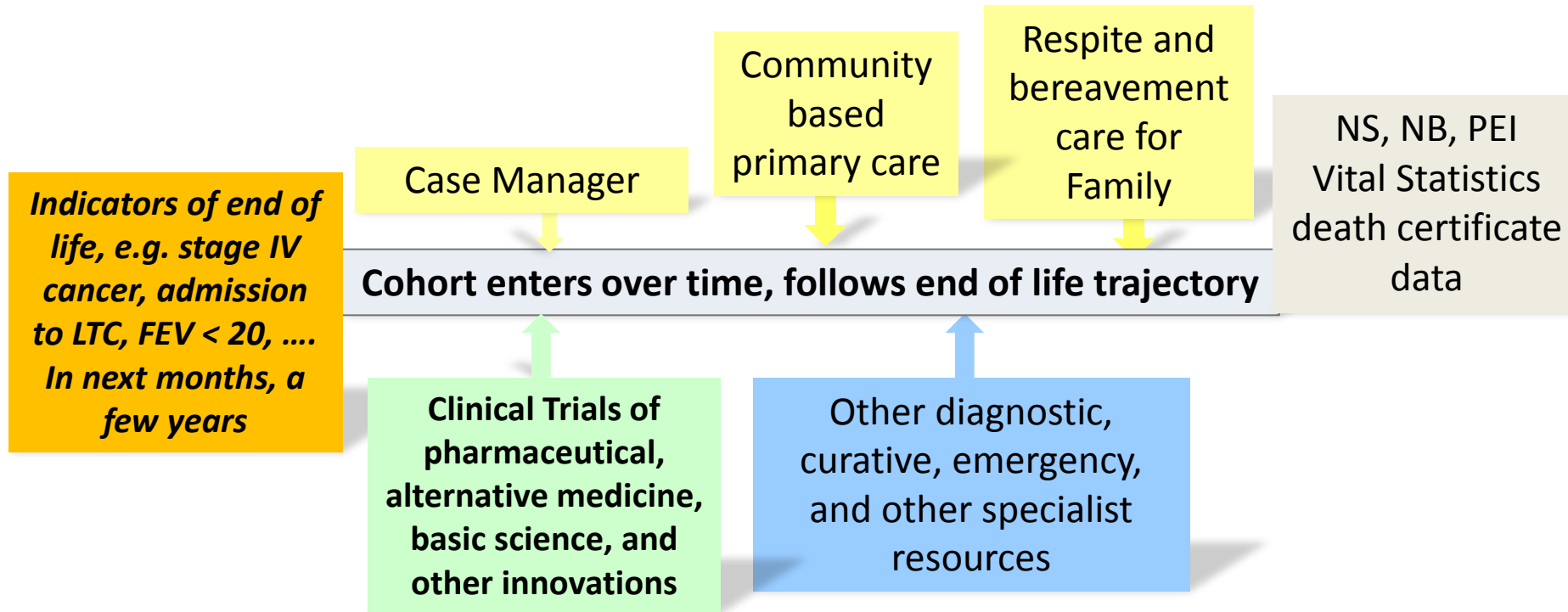


Proposed SPOR Curated Maritime Retrospective (Case-Control) End of Life Dataset



- 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



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
