National Stroke Registry Data Linkage Program: essential infrastructure to inform health care policy and practice

<u>Dr Monique Kilkenny</u>[1,2], Dr Nadine Andrew[1,3], Dr Joosup Kim[1,2], Prof Vijaya Sundararajan[4], Prof Amanda Thrift[1], Dr Judy Katzenellenbogen[5], Dr Frank Sanfilippo[5], Dr Felicity Flack[6], A/Prof James Boyd[4], Dr Phil Anderson[7,8], Mr Sam Shehata[2], Ms Sharon Williams[9], Dr Trisha Johnston[10], Dr Steve Faux[11,12], A/Prof Natasha Lannin[13,14], Prof Craig Anderson[15,16], Prof Dominique Cadilhac[1,2]

[1]School of Clinical Sciences at Monash Health, Monash University, Clayton, Australia, [2]Stroke Division, Florey Institute of Neuroscience & Mental Health, Heidelberg, Australia, [3]Peninsula Clinical School, Monash University, Frankston, Australia, [4]College of Science, Health & Engineering, La Trobe University, Bundoora, Australia, [5]School of Population and Global Health, The University of Western Australia, Crawley, Australia, [6]Centre for Data Linkage, Population Health Research, Perth, Australia, [7]Data Linkage Unit, Australian Institute of Health and Welfare, Canberra, Australia, [8]University of Canberra, Canberra, Australia, [9]Centre for Victorian Data Linkage, Department of Health and Human Services, Melbourne, Australia, [10]Queensland Department of Health, Brisbane, Australia, [11]St Vincent's Hospital, Sydney, Australia, [12]University Of New South Wales, Sydney, Australia, [13]Faculty of Health Sciences, La Trobe University, Clayton, Australia, [14]Occupational Therapy Department, Alfred Health, Melbourne, Australia, [15]The George Institute for Global Health, University of New South Wales, Sydney, Australia, [16]Royal Prince Alfred Hospital, Sydney, Australia

Parallel Session 2B, Grand Ballroom 5, November 20, 2019, 11:00 - 12:30

Abstract Title National Stroke Registry Data Linkage Program: essential infrastructure to inform health care policy and practice

***Kilkenny, M**[1,2], Andrew, N[1,3], Kim J[1,2], Sundararajan, V[4], Thrift A[1], Katzenellenbogen, J[5], Sanfilippo, F[5], Flack, F[6], Boyd, J[4], Anderson, P [7,8], Shehata, S[2], Williams, S[9], Johnston, T[10], Faux, S[11,12], Lannin, N[13,14], Anderson, C[15,16], Cadilhac, D[1,2] on behalf of the Stroke123 investigators and National Stroke Data Linkage Interest Group*

Affiliations
[1] School of Clinical Sciences at Monash Health, Monash University, Clayton, VIC
[2] Stroke Division, Florey Institute of Neuroscience and Mental Health, Heidelberg, VIC
[3] Peninsula Clinical School, Monash University, Frankston, VIC
[4] College of Science, Health & Engineering La Trobe University, Bundoora, VIC.
[5] School of Population and Global Health, The University of Western Australia, Crawley, WA
[6] Centre for Data Linkage, Population Health Research, Perth, WA
[7] Data Linkage Unit, Australian Institute of Health and Welfare, Canberra, ACT
[8] University of Canberra, Canberra, ACT
[9] Centre for Victorian Data Linkage, Department of Health and Human Services, Melbourne, VIC
[10] Queensland Department of Health, Brisbane, QLD
[11] St Vincent's Hospital, Sydney, NSW
[12] University Of New South Wales, Sydney, NSW
[13] Faculty of Health Sciences, La Trobe University, Bundoora, VIC
[14] Occupational Therapy Department, Alfred Health, Melbourne, VIC
[15] The George Institute for Global Health, University of New South Wales, Sydney, NSW
[16] Royal Prince Alfred Hospital, Sydney, NSW

Oral and poster abstract text (Arial, size 10 font, left aligned, maximum 250 words)

Background
Stroke is a leading cause of death and disability. Our innovative data-linkage program, initiated in 2012, has enabled the successful linkage of data from the Australian Stroke Clinical Registry (AuSCR) with other state-based and national datasets to investigate the continuum of stroke care.

Objectives

To describe the opportunities, progress and challenges in developing a National Stroke Registry Data Linkage Program.

Method
We used a range of iterative and innovative projects linking the AuSCR, used now in >80 public hospitals across Australia with follow-up survey of patients between 90-180 days, with various government-held administrative datasets. These included: National Death Index (NDI), inpatient admissions and emergency presentations, Pharmaceutical Benefits Scheme(PBS), Medicare Benefits Schedule(MBS), Aged Care services, Ambulance Victoria and the Australian Rehabilitation Outcomes Centre(AROC).

Results
Stroke123(NHMRC:#1034415): impact of quality of acute care on admission/emergency presentations and survival; MBS/PBS linkages: adherence to secondary prevention medications and GP care following stroke. Current projects: PRECISE (NHMRC:#1141848) linkages with PBS/MBS, aged care services and admissions/emergency data to evaluate primary care models; ambulance to describe pre-hospital care and AROC to describe rehabilitation care. Challenges: Delays in ethics and data custodian approvals, as well as costs (e.g. SURE and linkage fees) and limited access to data.

Conclusions
The program has been visionary and remains highly contemporary in the field of linked data and its use in reforming health policy. There is active participation of clinicians and policy-makers to ensure the results generated from specific research questions have direct benefits accelerating change in practice and translating into policy.