

APPLICATION FOR USE OF PRIMARY SENSE DATA FOR SECONDARY PURPOSES

Gold Coast Primary Sense Clinical Advisory Group

Name / organisation of applicant: Jerneja Sveticic (GCPHN)

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Research Team	
<p>Who is involved in the research project?</p> <p><i>List all personnel and their role e.g., lead investigator, co-investigator and include:</i></p> <p><i>Title and Name</i></p> <p><i>Institution/Organisation</i></p> <p><i>Role on project</i></p> <p><i>Please identify GP and/or primary care researchers</i></p>	<p>Gold Coast Primary Health Network (GCPHN) Dr Jerneja Sveticic, Health Intelligence and Research Manager Dr Alyson Ross, Executive Director, Digital Insights and Performance Brandon Ibbotson, Business Intelligence Systems and Data Support Officer</p> <p>Australian Institute of Health and Welfare (AIHW) Primary Health Care Data Development Unit</p>
Project Details	
<p>Project title</p>	<p>General practice data demonstration project: Dementia</p>
<p>Project funding - what control does the funder have on the research or dissemination?</p>	<p>There is no funding for this project.</p>
<p>What is the primary care/PHN priority that your research addresses? <i>(max 200 words)</i></p>	<p>Dementia is a significant and growing health and aged care issue and is most commonly diagnosed, treated and managed in the community. A lack of national data on the diagnosis and management of dementia by primary healthcare providers is a significant data gap affecting our understanding of dementia in Australia.</p> <p>Dementia was chosen as the first in a range of small-scale data demonstration projects conducted by the AIHW, with the aim of generating a better understanding of the general practice data landscape which will ultimately inform a National Primary Health Care Data Collection (NPHCDC).</p>

<p>How will your project benefit patients and/or staff in general practice? (<i>max 200 words</i>)</p>	<p>The AIHW is requesting aggregated general practice data on dementia from all participating PHNs, to develop a consolidated snapshot of general practice data specific to dementia prevalence and management.</p> <p>Outputs from this project will strengthen the evidence base on the prevalence of dementia among the local population, which can assist GCPHN and general practices in the region in informing program implementation, support service delivery and resource allocation.</p>
<p>What is involved for GPs? (<i>max 200 words</i>)</p>	<p>Data used in this project will be drawn from the routinely collected general practice data, therefore no direct involvement of GPs or other general practice staff will be required.</p>
<p>What is involved for other practice and/or PHN staff? <i>Please be specific and provide details including, if applicable:</i></p> <ul style="list-style-type: none"> • <i>assist in data collection (specify number or participants, data collection method and tools)</i> • <i>recruitment (specify recruitment strategies)</i> • <i>surveys</i> • <i>organising focus groups</i> <p><i>Max 200 words.</i></p>	<p>GCPHN will extract a defined dataset of 19 data items, relevant to dementia prevalence and care, from the general practice dataset accessed through Primary Sense. Data points will include, for example:</p> <ul style="list-style-type: none"> • Count of active patients • Count of active patients aged 30 years and over with dementia listed as a current diagnosis • Count of active patients aged less than 30 years with dementia listed as a current diagnosis • Measure 3: Count of active patients aged 30 years and over with dementia listed as a current diagnosis by dementia type • Count of active patients aged 30 years and over with dementia listed as a current diagnosis with coronary heart disease (CHD) also listed as a current or past diagnosis • Count of active patients aged 30 years and over with dementia listed as a current diagnosis with chronic obstructive pulmonary disease (COPD) also listed as a current or past diagnosis • Count of active patients aged 30 years and over with dementia listed as a current diagnosis with diabetes also listed as a current or past diagnosis <p>All data used in this project will be de-identified and shared with AIHW in an aggregate format. Data will be aggregated for the region, and will not allow for identification of individual practices. Cell suppression rules will apply for low data counts.</p> <p>Data will be supplied to the AIHW via the Primary Health Insight platform, utilising a mechanism that securely transfers the data between the PHN's lockbox and AIHW's lockbox.</p>
<p>Will there be any technical changes required to Primary Sense functionality?</p>	<p>No.</p>

What is involved for patients? <i>(max 200 words)</i>	Data used in this project will be drawn from the routinely collected general practice data, and no direct involvement of patients will be required.
How will participants' contribution to your research be acknowledged and/or honoured?	Unknown at this stage, as the outputs will be prepared by AIHW.
Ethics approval?	
Has this research received ethical approval? <i>(yes/no/exemption)</i>	Yes
Which ethics committee/s?	AIHW's Ethics Committee. The project has received support from the PHN National Data Governance Committee and the PHN Steering Committee.
PS CAG involvement	
What are you asking the PHN or Primary Sense Clinical Advisory Committee to do for you? Please provide detail including wording for any email invitation, if appropriate.	Primary Sense Clinical Advisory Committee is asked to provide endorsement for secondary use of Primary Sense data, required for completion of this project. GCPHN staff will ensure all general practices using Primary Sense are notified of this project and given an option to opt out of their data being included in the analysis. This is an established process within GCPHN that has been successfully implemented with previous research studies.
Dissemination of research findings	
How will findings from your research be disseminated? Please provide as much detail as possible, e.g., target journals, conference names etc.	Expected outputs by AIHW include: <ul style="list-style-type: none"> • GCPHN access to compiled extract/s of data in PHI • Possible data visualisations for PHNs • Collaboration between AIHW and PHNs that supports the vision of a NPHCDC GCPHN will be consulted if any additional analytical outputs and outputs will be considered at the conclusion of the project.
How will you report back to Primary Sense Clinical Advisory Committee?	PS CAG will be informed of the progress with this project in subsequent meetings.