Primary healthcare needs and service utilisation of people with disability: a data linkage protocol

Jacinta Douglas,1,2 Di Winkler,1,2 Adam McLeod,3 Stacey Oliver,1,2 Karina Gardner,3 Jamie Supple,3 Christopher Pearce3

ABSTRACT

Introduction General practitioners (GPs) play a crucial role in the early management and treatment of the comorbidities and complications experienced by people with disability. However, GPs experience multiple constraints, including limited time and disability-related expertise. Knowledge gaps around the health needs of people with disability as well as the frequency and extent of their engagement with GPs mean evidence to inform practice is limited. Using a linked dataset, this project aims to enhance the knowledge of the GP workforce by describing the health needs of people with disability.

Methods and analysis This project is a retrospective cohort study using general practice health records from the eastern Melbourne region in Victoria, Australia. The research uses Eastern Melbourne Primary Health Network (EMPHN)-owned de-identified primary care data from Outcome Health’s POpulation Level Analysis and Reporting Tool (POLAR). The EMPHN POLAR GP health records have been linked with National Disability Insurance Scheme (NDIS) data. Data analysis will involve comparisons across disability groups and the rest of the population to explore utilisation (eg, frequency of visits), clinical and preventative care (eg, cancer screening, blood pressure readings) and health needs (eg, health conditions, medications). Initial analyses will focus on NDIS participants as a whole and NDIS participants whose condition is either an acquired brain injury, stroke, spinal cord injury, multiple sclerosis or cerebral palsy, as classified by the NDIS.

Ethics and dissemination Ethics approval was obtained from the Eastern Health Human Research Ethics Committee (E20/001/58261), and approval for the general collection, storage and transfer of data was from the Royal Australian College of General Practitioners National Research Ethics and Evaluation Committee (protocol ID: 17-088). Dissemination mechanisms will include the engagement of stakeholders through reference groups and steering committees, as well as the production of research translation resources in parallel with peer-reviewed publications and conference presentations.

INTRODUCTION

In Australia, over 4.4 million people identify as having a disability, who according to the Australian Institute of Health and Welfare (AIHW), are more likely to have poor self-assessed general health and mental health than people without disability.1 Disability refers to the experience of having an impairment (ie, physical, intellectual, cognitive, neurological, visual, hearing or psychosocial) that occurs due to a disease or medical condition and often results in a limitation in activities or a restriction in participation when interacting with their environment.2 The experience of disability is diverse and affected by multiple socioenvironmental factors, including care provided by healthcare services.3 General practitioners (GPs) are important mainstream healthcare providers for the management, treatment and prevention of health complications.4 As GPs are often the first point of contact with the healthcare system, they play a critical role in connecting patients with a wider healthcare team and developing holistic treatment plans to manage ongoing health conditions.5 High-quality care provided by GPs has the potential to avoid unnecessary hospitalisation6 7
and improve the health\(^8\) and well-being\(^9\) of people with disability. Due to multiple competing demands, general practice is often not sufficiently responsive to the needs of people with disability, resulting in a reliance on specialist medical services and hospitals.\(^{10}\) Currently, there is a lack of evidence about how people with disability use general practice and the health needs people with disability present with at general practice.\(^{11}\) Understanding the service use and health needs of this cohort can inform policy, planning and funding and inform interventions to improve the quality of primary healthcare.

In Australia, people with ‘permanent and significant’ disability are eligible to receive funding for disability-related support from the National Disability Insurance Scheme (NDIS). Established in 2013 and gradually rolled out since 2016, the scheme is based on a social insurance model and aims to promote independent living and community participation by providing people with disability greater ‘choice and control’ over their disability support and services.\(^{12}\) In line with aims to increase social inclusion and reduce marginalisation, inclusion in mainstream health services is also a goal of the NDIS\(^{13}\) and comparable international policies.\(^{14}\) Currently, just over 500,000 people with disability are receiving funding through the NDIS.\(^{15}\) People with disability who are eligible for this funding (NDIS ‘participants’) are not an homogeneous group and include different conditions and levels of impairment that impact on their health needs in a variety of ways.

Data pertaining specifically to NDIS participants indicate a need to better understand how the primary care system is operating for people with disability in Australia.\(^{16}\) A recent report found that although 91% of NDIS participants interacted with general practice at least once in 2019–2020 (compared with 87% of the rest of the population), they were less likely to have used pathology collection services, diagnostic imaging and optometry services, which are interventions often associated with preventative care.\(^{17}\) Additionally, NDIS participants access publicly subsidised medicines at higher rates (80%) than the rest of the population (62%) and are almost twice as likely to access a specialist, indicating higher health needs and service use for this cohort.\(^{17}\) However, evidence around this cohort’s specific health needs and service utilisation remains limited. Longitudinal data collected as a part of the NDIS Outcomes Framework survey captured important elements of NDIS participants’ health status and made comparisons with Australian population benchmarks over a 3-year period.\(^{18}\) It was found that NDIS participants had poorer self-rated overall health than the rest of the population and people with an acquired brain injury (ABI), psychosocial disability, cerebral palsy (CP), multiple sclerosis (MS) or ‘other’ disability types were most likely to report a deterioration in health. In terms of health service use, after joining the NDIS, people were more likely to have a regular doctor and are more likely to have received an influenza vaccination or health check in the previous 12 months compared with the rest of the population. However, NDIS participants were found to be over five times more likely to have visited a hospital in the previous 12 months, and less likely to have received complex preventative care interventions, including cervical and prostate cancer screening. Although the NDIS provides funding for the disability support that people with disability in Australia may need to access mainstream healthcare, this cohort remains vulnerable to receiving suboptimal primary care and to experiencing poor health outcomes.\(^{15}\) A greater understanding of the healthcare needs and primary care service use is required to improve the primary care experience and outcomes for people with disability.\(^{11}\)

People with acquired neurological conditions who are eligible for NDIS funding often experience severe or profound levels of core activity limitations due to varying levels of cognitive, communication or physical impairments.\(^{18,19}\) The breadth and severity of these impairments coincide with primary healthcare needs distinct from the rest of the population and increased health challenges that often fall to GPs for initial treatment and management.\(^{11}\) Previous research has found that although people with acquired neurological disability are high users of GP services,\(^{20–22}\) they are less likely to receive comprehensive care,\(^{22,23}\) including low frequency of preventive care practices.\(^{24–27}\) For example, women with traumatic brain injury have reported not receiving care when needed at general practice, particularly for emotional or mental health problems.\(^{25}\) Research of women with advanced MS indicates this group is not receiving a range of screening activities such as pap smears, cancer screening, bone density scans and hypertension monitoring.\(^{26}\) People with spinal cord injury (SCI) have also been found to receive far less preventative care screening than the rest of the population, with particularly low rates for more complex practices that require preparation or special equipment (such as colorectal, cervical and breast cancer screening).\(^{27}\) Furthermore, GPs have expressed difficulties in providing comprehensive care for people with acquired neurological disability due to restrictions in time and complexity of patients’ needs.\(^{27–29}\) People with acquired neurological disability have also expressed frustration and concerns that their GPs do not understand the impact their disability has on their overall health or its health complications.\(^{11}\) Indeed, lack of disability-related expertise is a known barrier to providing high-quality primary care.\(^{30}\) The available evidence regarding the healthcare needs presented at general practice by people with acquired neurological disability lacks sufficient granularity to inform effective treatment strategies that can improve quality of care.\(^{11}\)

Overall, there is a clear need to review how the primary health system, in particular general practice, works for people with disability. Using linked administrative data, this project will first describe the general practice utilisation and health needs presented at general practice for NDIS participants, compared with the rest of the population. These results will serve as an important benchmark.
and allow for meaningful exploration of subsequent cohorts. Because NDIS participants are a diverse group with a range of conditions, functional capacity and susceptibility to secondary and other health conditions, subsequent analysis will look at specific cohorts within the dataset, comparing their GP utilisation with that of the rest of the population. Considering the known vulnerability to incomplete primary care and lack of evidence pertaining to healthcare needs presented at general practice, initial cohorts will be people with acquired neurological disorders as a result of ABI, cerebrovascular accidents (stroke), CP, MS or SCI. This research will provide an important first step to inform targeted areas of intervention that can improve the quality of healthcare provided in general practice for people with disability.

**Aim**

Our study will describe the primary healthcare needs and general practice utilisation for NDIS participants across different disability groups and compare them with the rest of the population.

**Medical care in Australia: overview**

**Health system**

Australian health care operates within a multi-jurisdictional system with medical care delivered primarily through:
1. Primary care—first contact care.
2. Secondary care—medical specialist services.
3. Tertiary care—public or private hospitals.
4. Allied health services.

**National Disability Insurance Scheme**

The NDIS provides individualised funding for support and services to eligible people with disability in Australia. The NDIS is managed and implemented by a government organisation, the National Disability Insurance Agency (NDIA).

Objectives of the scheme outlined in the NDIS Act include:

- Supporting the independence and social and economic participation of people with disability.
- Providing reasonable and necessary support, including early intervention support, for participants.
- Enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their support.
- Facilitating the development of a nationally consistent approach to the access to, and the planning and funding of, support for people with disability.
- Promoting the provision of high-quality and innovative support to people with disability.

**METHODS AND ANALYSIS**

**Project team**

A comprehensive and adequate evaluation of the primary healthcare needs and utilisation of people with disability requires a multifaceted, collaborative approach. In recognition of the complexities which persist around interaction with the health system for this cohort, we have assembled a multidisciplinary project team composed of partners with extensive track records of collaborative research and a strong focus on innovation in their respective fields.

**Summer Foundation**

Summer Foundation is a research and advocacy organisation working to prevent young people with disability from being forced into residential aged care, by helping them to access the funding and support needed to provide them choice and control over their living arrangements. In addition to grassroots work, the organisation contributes to knowledge by researching the issues at each stage of the critical pathways that lead young people into aged care. The organisation has an ongoing research partnership with the Living with Disability Research Centre at La Trobe University.

**Eastern Melbourne Primary Health Network**

Eastern Melbourne Primary Health Network (EMPHN) is 1 of the 31 Primary Health Networks (PHNs) established by the Australian Government to increase the efficiency of medical services, reduce fragmentation of care and improve health outcomes for the local community, and particularly for vulnerable populations. EMPHN contributes to health service coordination for over 1.5 million people in the eastern Melbourne region. EMPHN has data sharing agreements including research with constituent general practices and provides them with a fully subsidised data collection, analysis and reporting service in the areas of clinical, business, accreditation and quality improvement. EMPHN is the owner of the de-identified general practice data collected from general practices. EMPHN provided permission to their contracted data custodian Outcome Health to supply a defined subset of these general practice data to the project through the POpulation Level Analysis and Reporting (POLAR) platform, developed and deployed by Outcome Health. The subset of the de-identified general practice data was sourced from 314 general practices in the EMPHN region and was used to contribute to advancing the evidence base by sharing de-identified, patient-level data for ethics-reviewed, translational research.

**Outcome Health**

Outcome Health is a Melbourne-based not-for-profit organisation working in the primary care space and the developers of the POLAR platform. The platform, deployed in partnership with PHNs, is a cloud-based, comprehensive and secure data management system which allows for near real-time bespoke data insights for general practices, PHNs and other stakeholders. Snapshots of de-identified data are made available for approved research with explicit permission from each PHN. Use of general practice data for this project (originating from 314 eligible general practice clinics) was approved by the EMPHN. Outcome Health operates...
within strict governance structures which ensure adequate data processing systems and appropriate data sharing arrangements.

Eastern Health
Eastern Health is a large metropolitan public health service in Melbourne’s east with services located across 2816 km². Eastern Health operates over 60 sites across 21 locations including three hospital emergency departments. The project partners are operating within geographically aligned areas, increasing the probability of a correct data match and by extension, increasing the sample size and representativeness of the study.

Data sources
Our study will link the NDIS dataset to available general practice data in the eastern region of Melbourne. Because there is no reliable way to detect people with disability within the general practice data, a strength of this data linkage is that it will allow people with disability, as classified by the NDIS, to be flagged in a privacy-preserving way in the general practice data. In this study, the rest of the population refers to people without an NDIS plan who visited a participating general practice clinic and therefore includes people with a disability who are not NDIS participants.

The dataset will be analysed to compare a range of variables, looking at how NDIS participants use general practice (eg, frequency of visits, types of consultations), clinical and preventative care (eg, cancer screening, vaccinations, blood pressure readings) and primary healthcare needs (eg, common diagnoses, chronic health conditions, medications) in general practice records for NDIS participants with different conditions with the rest of the population. Analyses will determine NDIS participants with different medical conditions are more or less likely to have a regular GP. We will also compare the most common diagnoses, chronic health conditions and frequency of preventative care across levels of impairment and with the rest of the population. The second phase of data linkage will add hospital and emergency data.

NDIS data
To identify patients with a disability within the EMPHN dataset, a tailored data request (ref. #76) was made to the implementing government organisation (ie, the NDIA), for data on NDIS participants living in the EMPHN region. The data captured provide some basic data about NDIS participants including medical conditions, demographic data and information about NDIS plans (a list of approved funded supports) and costs. The dataset supplied was based on geographical specifications set by project members for geographical alignment as much as practical with the general practice dataset. The data were supplied to Summer Foundation (in line with project governance, Summer Foundation remains the custodians of this dataset for the life of the project). There were 117,488 records supplied containing participant-level information with the following descriptors:

- Demographic: age, indigenous status, culturally and linguistically diverse status, postcode, local government area, remoteness status.
- Disability: primary disability name, other disabilities.
- NDIS plan information: plan status, plan expiry date, previous plan status, stream type, plan management method.
- Cost data: budget type, budget amount.

General practice data
General practice data are collected from constituent general practice clinics on behalf of EMPHN via the POLAR system. POLAR is a cloud-based, secure, comprehensive end-to-end data analytics platform which extracts, processes and curates de-identified general practice information contained in clinical information systems (CIS) from participating practices. Compatible CIS are: Best Practice, Medical Director and Zedmed. The data collected are processed and agnosticised into a relational database structure containing de-identified data variables. The dataset has been configured to enable curation of datasets for individual research projects.

Data collected from the electronic medical record are longitudinally structured around patient engagement and activity within the practice. General practice data groups analysed for this project include the following.

Patient demographic and activity
This data class captures patient demographic information (de-identified) and activity within the practice. An ‘activity’ is defined as a professional interchange between a patient and a practice team member. Medical software systems record any interaction with the electronic medical record as an activity, regardless of whether the interaction was for clinical or administrative purposes. Activities may be either auto date-stamped by the clinical software or manually entered by the clinician.

Clinical observations and diagnoses
This data class groups observations either recorded about a patient by the clinician at the point of care (such as smoking status) or calculated by Outcome Health from available data fragments collected by the practice (such as cardiovascular risk score based on the Absolute Cardiovascular Disease Risk Calculator32). Diagnosis information is captured during the clinical encounter. The POLAR system applies mapping of free-text diagnosis to the Systematized Nomenclature of Medicine Clinical Terms (SNOMED) terminology. Only coded and mapped values are used in research datasets.

Prescriptions
This data class captures medications prescribed by clinicians. It includes generic drug name, dosage, frequency and number of repeats. POLAR applies mapping to active ingredients information according to the Anatomical Therapeutic Chemical (ATC) Classification developed by
It does not contain information on medication dispensed.

**Referrals**
This data module captures information communicated from the practice to an external provider, requesting specialist services for a patient.

**Pathology**
These data track tests performed by a third-party medical agency on request by clinicians. Information stored contains test name, request date, collection date and result. In some cases, pathology results are sent by pathology laboratories in formats which cannot be read, interpreted or interrogated by the POLAR system.

**Immunisations**
This category includes medicine administered by the practice or elsewhere in the form of vaccines.

**Service**
This refers to general billable service provided to the patients by the practice and usually associated with a Medicare Benefit Schedule (government-subsidised health services) billing activity.

**Radiology**
This category refers to imaging tests performed by an external laboratory which have been requested or ordered by the practice. The dataset is standardised and coded to medical nomenclature.

**Data preparation**

**Linkage**
The NDIS data were linked with data originating from 314 eligible practices within the EMPHN region and with permission from EMPHN.

The linkage was conducted using the ORCA tool, Outcome Health’s proprietary privacy-preserving linkage application. The linkage was conducted using the statistical linkage key (SLK-581) developed by the AIHW. The SLK-581 is a record identifier derived from information that is likely to be:
- Unique to each patient.
- Reliably reported by the patient across multiple care settings.
- Reliably reported by the patient across multiple care settings.

The SLK-581 was generated within the practice environment based on available identifiable data fragments. This process triggered the deployment of the ORCA tool within the practice environment, ensuring that the raw SLK-581 was not visible outside of the practice environment. Privacy and security were further enhanced by ensuring that only the hashed value (***) rather than the raw SLK-581 key, was transferred to Outcome Health.

**Table 1** illustrates the process.

The patient identifier field in the POLAR dataset is a combination of practice ID (*) and patient ID within the practice (**). In table 1, the patient has a record of having attended three practices in the POLAR dataset (ie, practice 145, practice 289 and practice 301).

The ORCA hashing tool was run over the NDIS dataset within the Outcome Health environment (a process which takes place exclusively within the practice environment for general practice data).

The POLAR software applied a complex indexing algorithm over the hashed data values to generate the POLAR_ID (***) which is unique to POLAR and not vulnerable to reverse engineering, therefore ensuring adequate protection of privacy. The common dataset is generated based on the POLAR_ID field. The data were uploaded to Qlik Sense, Outcome Health’s selected analytics platform. Data analysis, visualisation and validation will be performed within Qlik Sense.

Figure 1 illustrates the steps described in table 1.

Applying the steps described in figure 1 generated the study sample dataset described in table 2.

There were 117,488 participant episode records supplied in the NDIS dataset, which resulted in 50,272 unique NDIS participants (ie, a participant may have more than one NDIS plan, leading to multiple ‘episodes’). From the 50,272 unique cohorts, 40,287 patients had a corresponding record in the POLAR dataset. Age discrepancies were resolved as outlined in the next section.

There were 480,815 unique records supplied in the general practice data originating from 314 practices in the EMPHN region. Data linkage performed across the dataset resulted in a total of 40,287 common/matched

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Data processing of linkage key generation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient identifier in each dataset</td>
<td>Raw statistical linkage key</td>
</tr>
<tr>
<td>NDIS dataset</td>
<td>854269374</td>
</tr>
<tr>
<td>General practice dataset</td>
<td>145*−1598767**</td>
</tr>
<tr>
<td></td>
<td>289–8659759</td>
</tr>
<tr>
<td></td>
<td>301–8964253</td>
</tr>
<tr>
<td>POLAR_ID</td>
<td>8014218****</td>
</tr>
</tbody>
</table>

NDIS, National Disability Insurance Scheme; POLAR, POpulation Level Analysis and Reporting Tool.
records. We excluded records where there was a discrepancy in patient age of more than 2 years. Additionally, to omit plans with potential date-stamping errors, we excluded records where the NDIS plan start date was listed as commencing after the plan end date. Following the steps outlined above resulted in a linked cohort of 25,978 patient records.

**Adjusting for patient age data discrepancy**

The NDIS dataset was supplied in static format in January 2020; patient age was locked at the time of extraction. POLAR is a near real-time analytics platform, accurately reflecting patient age at the time of extraction. The general practice data for this study were collected in June 2022. We considered this factor during the process of adjusting for age discrepancy. Given that patient age in the NDIS dataset is locked at the time of extraction (January 2020), we excluded all records where the patient age in the NDIS dataset is at least 1 year less than patient age in the general practice dataset. Additionally, we excluded all records where patient age recorded in the NDIS dataset is

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**Figure 1**  Linkage process summary. NDIS, National Disability Insurance Scheme; POLAR, POpulation Level Analysis and Reporting Tool; SLKs, statistical linkage keys.
compare results across three patient cohorts:

Each of the questions will be framed to address and

Topics of investigation

Each of the questions will be framed to address and compare results across three patient cohorts:

- Patients with MS, ABI, stroke, SCI and CP.

2 or more years higher than age recorded for the linked record in the general practice dataset.

Project analysis plan

People with acquired neurological conditions who are eligible for NDIS support will be the initial focus of the research. Our recent scoping review found that there is a need for studies reporting on the primary healthcare needs and general practice utilisation of people with acquired neurological conditions to enhance the knowledge of the general practice workforce. Therefore, our team will initially focus on the following five acquired neurological conditions, selected because of a gap in the literature pertaining to the utilisation and primary healthcare needs presented at general practice.

<table>
<thead>
<tr>
<th>Condition</th>
<th>Unique patient count (source: NDIS dataset)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acquired brain injury</td>
<td>992</td>
</tr>
<tr>
<td>Multiple sclerosis</td>
<td>872</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>1216</td>
</tr>
<tr>
<td>Stroke</td>
<td>442</td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>285</td>
</tr>
<tr>
<td>NDIS, National Disability Insurance Scheme.</td>
<td></td>
</tr>
</tbody>
</table>

First cut of the linked patient cohort: 39 014 unique patients based on updated GP records

Clean linked patient cohort: 25 978

GP, general practitioner; NDIS, National Disability Insurance Scheme; POLAR, POpulation Level Analysis and Reporting Tool.

For each of these conditions, we will address a series of topics pertinent to the wider disability cohort as well as formulate questions particular to individual conditions:

1. How often do NDIS participants with a specific condition attend general practice?
2. How many NDIS participants attend more than one practice? How does this compare with the rest of the population?
3. What is the rate of comorbidity for NDIS participants?
4. What primary healthcare needs do patients with a specific condition (listed above) present most with? How does this compare with the rest of the population?
5. What is the extent and prevalence of preventative care interventions for patients with one of the conditions listed above and how does it compare with the rest of the population?
6. What are the most common medications prescribed for patients with one of the conditions listed above and how do they compare with the rest of the population?
7. What is the rate of GP management plans, team care arrangements and plan reviews for NDIS participants compared with the rest of the population?

The second phase of the project will involve incorporating the hospital perspective by linking with Victorian Emergency Minimum Dataset supplied by Eastern Health.

Statistical analysis plan

All relevant general practice data will be extracted from the POLAR database and imported into statistical software for data management and analysis. As POLAR is a live database, a snapshot of the data will be extracted and stored (sandboxed) to capture a point in time. To prevent the comparison of duplicate data, the rest of the population dataset will be limited to non-NDIS participants. Therefore, comparisons will be made between NDIS participants and the rest of the population.

To preserve privacy and in accordance with the POLAR governance framework, the system processes and displays data in 5-year age groups. To reduce potential age confounding factors, both datasets will be limited to patients aged 20–64 years. For each cohort of interest, the NDIS dataset will be limited to the primary condition as classified by the NDIS (ie, ABI, stroke, CP, MS, SCI).

Descriptive demographic statistics will be presented for NDIS participants and the rest of the population who attended a participating general practice clinic between January 2020 and June 2022.

Percentages and descriptive statistics for general practice utilisation, preventative care practices and prescribed medications will be compared between NDIS participants and the rest of the population. Preliminary analysis of service utilisation will include between-groups comparisons of the number of consultations recorded across general practice clinics per year, the number of clinics visited per patient per year, the number of Care Plans and Mental Health Care Reviews completed per patient per year, the number of visits to emergency departments per patient per year and the number of medications prescribed per patient per year.
Health Plans issued per year and the number of health assessments conducted per year. Preliminary preventative care analysis will include comparing the number of blood pressure readings, bone density scans, influenza vaccinations and mental illness screens conducted per patient, as well as the number of cervical screens and breast screens conducted per eligible patients. In the ATC Classification system used by POLAR, prescribed medications are divided into different groups according to the organs or system in which they act. Medications are also classified in a hierarchy with three different levels that are divided into chemical, pharmacological or therapeutic groups. We will present the system that prescribed medications have previously been grouped by Outcome Health into high-level categories that reflect the primary problem description or diagnosis. These high-level categories include but are not limited to: alcohol and other drugs, chronic kidney disease, cancer, cardiovascular, dementia/Alzheimer’s, diabetes, mental health, musculoskeletal, oral and respiratory. Each high level then drills down to the GP-entered diagnosis (eg, the high-level category of musculoskeletal drills down to the GP-entered diagnosis of osteoarthritis). The prevalence of high-level chronic disease diagnoses and the most prevalent GP-entered diagnoses will be presented for each NDIS participant subgroup and compared with the rest of the population. Additionally, we will present known condition-specific diagnoses (eg, autonomic dysreflexia, pressure areas, fatigue, insomnia) that are not captured in the high-level groupings. The number of active diagnoses and number of chronic health conditions will be compared between groups using percentages, descriptive statistics and CIs.

**Patient and public involvement**
People with disability and primary healthcare professionals will be involved in the project in one or more of the following ways: coauthors, consultants, reference group or steering committee members. It is anticipated that these service users will provide a sophisticated understanding of the clinical data and context of the setting in which care is delivered, which may guide subsequent data analysis and knowledge translation processes. A steering committee comprising primary healthcare professionals informed the development of the protocol.

**ETHICS AND DISSEMINATION**
The POLAR system has ethics clearance for the collection, storage and transfer of data (Royal Australian College of General Practitioners National Research Ethics and Evaluation Committee (protocol ID: 17-088)). Ethics approval for the current project was obtained from the Eastern Health Human Research Ethics Committee (E20/001/58261).

Dissemination mechanisms will include the engagement of stakeholders through reference groups and steering committees, as well as the production of research translation resources in parallel with peer-reviewed publications and presentations at national and international conferences. Findings will be reported to PHNs and will guide subsequent co-designed resources.

The impact and scope of linkages between disability support funding data and healthcare activity are poorly explored and understood. The objectives of this project have been designed to address a persistent knowledge gap around the frequency and extent of primary care engagement of people with disability. The incorporation of service users and GPs will allow for an in-depth understanding of the data and enhance knowledge translation. The analysis of this linked dataset will provide a unique and rich evidence base for working with stakeholders to co-design potential solutions to improve the primary care experience and outcomes for people with disability.

**Contributors**
JD contributed to the design of the study, provided domain knowledge expertise and contributed to the technical design. DW conceptualised the project, provided domain knowledge expertise and contributed to the technical design. AM conceptualised the project, provided domain knowledge expertise and contributed to the technical design. SD contributed substantially to the writing and design of the final study protocol, and had a part in the technical design. KG contributed substantially to the writing and design of the final study protocol, and had a part in the technical design. JS contributed substantially to the technical implementation and conceptualisation of the technical design. CP provided domain knowledge expertise and contributed to the technical design. All authors read and approved the final manuscript.

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**Competing interests**
None declared.

**Patient and public involvement**
Patients and/or the public were involved in the design, conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication**
Not required.

**Provenance and peer review**
Not commissioned; externally peer reviewed.

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**ORCID iD**
Stacey Oliver http://orcid.org/0000-0003-0841-0795

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