



Using big data to better understand health and wellbeing

Part A: Primary healthcare for young people on the autism spectrum

Final report

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole-of-life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people on the autism spectrum.

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1. Projects and publications

The Autism CRC project '*Using big data to better understand health and wellbeing*' has two primary overarching objectives:

- Part A : To investigate reasons for encounters, problems managed, referrals being made and medications prescribed by Australian GPs to young autistic people in comparison with those without an autism diagnosis.
- Part B: To use the existing New South Wales state-based linked administrative data infrastructure to explore the potential of an existing autism flag or identifier to examine mortality, cause of death and health outcomes for autistic Australians and compare these to the non-autistic population.

The findings from Part A have been published in the following peer-reviewed papers:

Birch RC, Foley K-R, Pollack A, et al. (2017) Problems managed and medications prescribed during encounters with people with autism spectrum disorder in Australian general practice. *Autism*: 136236131771458. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/28914073>

Foley K-R, Pollock AJ, Britt HC, et al. (2017) General practice encounters for young patients with autism spectrum disorder in Australia. *Autism*. doi: 10.1177/1362361317702560

2. Introduction

People on the autism spectrum experience many more co-occurring medical conditions than those in the general population, including sleep problems, epilepsy and psychiatric conditions (Mannion & Leader, 2013). Health service delivery in the primary health care sector is thus important for this population (Carbone, 2013). Addressing this issue adheres to the human rights obligation to ensure equity of access to quality health care for persons with disabilities (Tomlinson et al., 2014). There is limited research available on this topic. Existing evidence regarding children on the spectrum suggests that parents find difficulties in accessing appropriate services and that GPs feel underprepared in dealing with children diagnosed with Autism Spectrum Disorder (ASD) (Carbone et al., 2013).

Autistic adults also experience difficulties in primary health care, such as having higher unmet physical and mental healthcare needs, lower satisfaction with patient-provider communication and lower self-reported rates of preventive health care such as tetanus vaccination when compared to non-autistic people (Nicolaidis et al., 2012).

Another issue of concern is the lack of research exploring prescription of psychotropic medications to those on the spectrum. While there is evidence that prescription rates are high (Esbensen, Greenberg, Seltzer, & Aman, 2009), and taking psychotropic medications has important health implications, there is very little known about clinical and prescribing practices. This is particularly concerning in the face of a recent report stating that antipsychotic drugs were prescribed to those with learning disabilities and/or autism without a diagnosis of the condition the drug is designed to treat (Public Health England, 2015).

This project involved two studies with the overall aim of investigating the reasons for encounters, problems managed and medications prescribed by Australian General Practitioners (GPs) to young people on the spectrum in comparison to those not on the spectrum. Study 1 investigated whether GP services and patterns of practice differed for young people on the spectrum, compared to those not on the spectrum. This was examined in terms of the reason for encounters with GP services and/or problem managed. It also considered differences in patient characteristics, reasons for presentation and problems managed. Study 2 describes the problems managed and medications prescribed by GPs in Australia during encounters where an ASD was recorded.

3. Research design and methods

Data

This project utilised data from the Bettering the Evaluation and Care of Health (BEACH) program. The BEACH program continuously collects information about the clinical activities in general practice in Australia. Each year the program recruits a random sample of about 1,000 GPs, each of whom collects data on 100 consecutive consultations. The BEACH program collected information on: GP and patient characteristics, the reasons that people seek medical care ('reasons for encounter (RFEs)'), the problems managed during the encounter, medications, clinical treatments, procedures, referrals and tests ordered. Data collected from March 2000 to April 2014 were analysed. A more detailed description of the BEACH program is available elsewhere (Britt et al., 2014).

Sample

For both studies, data from encounters with patients aged less than 25 years were analysed in two groups: 'ASD' and 'non-ASD'. The 'ASD' group was defined as encounters at which ASD was recorded as a reason for encounter and/or problem managed using the International Classification of Primary Care (ICPC-2 PLUS) classification. Four codes (P99010 – Asperger's Syndrome; P99005 - Autism; P99006 – Autism, child; P99013 – Disorder, Autism Spectrum) were used. The 'non-ASD' group was defined as all other encounters. A total of 282,052 encounters were identified, of which 579 had an ASD-associated code recorded and 281,473 did not.

Larger proportions of patients on the spectrum were male and were Commonwealth Health Care/Benefits Card holders. Refer to Table 1 for patient demographics. Chi square tests found no significant differences existed in the two groups regarding English speaking background status or identifying as Aboriginal or Torres Strait Islander. There were significant differences in the age distributions of the patients, with fewer individuals on the spectrum in the youngest (0-4) and older (15-24) age groups and more being between 5-14 years old. For the 579 encounters that were recorded as being with an individual on the spectrum, the patient was twice as likely to be male and hold a Commonwealth health care/benefits card than those not on the spectrum.

Table 1. Patient demographics

		'ASD' group patients		'Non-ASD group patients		Chi Sq	P=value	Odds Ratio OR (95% CI)
		n	%(95%CI)	n	%(95%CI)			
Total Encounters		579		281473				
Sex	Male	476	82.2 (79.1–85.3)	124990	44.4 (44.2–44.7)	341.6	<0.0001	5.8 (4.7–7.1)
	Female	103	17.8 (14.7–20.9)	156483	55.6 (55.3–55.8)	—	—	—
Age-group (years)	0-4	129	22.3 (18.7–25.8)	86656	30.8 (30.5–31.1)	376.3	<0.0001	—
	5-9	230	39.7 (35.7–43.8)	39278	14.0 (13.8–14.1)	—	—	—
	10-14	109	18.8 (15.5–22.1)	34469	12.2 (12.1–12.4)	—	—	—
	15-19	77	13.3 (10.5–16.1)	52360	18.6 (18.4–18.8)	—	—	—
	20-24	34	5.9 (3.9–7.9)	68710	24.4 (24.1–24.7)	—	—	—
CHCC	Yes	357	66.4 (61.5–71.2)	74589	31.1 (30.6–31.6)	214.8	<0.0001	4.4 (3.5–5.4)
	No	181	33.6 (28.8–38.5)	165229	68.9 (68.4–69.4)	—	—	—
	Missing	41	—	41655	—	—	—	—
NESB	Yes	31	5.8 (3.8–7.7)	19956	7.9 (7.6–8.3)	3.5	0.06	0.7 (0.5–1.0)
	No	506	94.2 (92.3–96.2)	231239	92.1 (91.7–92.4)	—	—	—
	Missing	42	—	30278	—	—	—	—
ATSI	Yes	9	1.7 (0.5–2.9)	6767	3.0 (2.7–3.2)	2.4	0.13	0.6 (0.3–1.2)
	No	516	98.3 (97.1–99.5)	222336	97.0 (96.8–97.3)	—	—	—
	Missing	54	—	52370	—	—	—	—

CHCC = Commonwealth Health Care/Benefits Card holder

NESB = Non-English Speaking Background, defined as patients who speak a language other than English as their primary language at home (self-reported)

ATSI = Aboriginal and Torres Strait Islander (self-identified)

Analysis

Study 1

This study explored RFEs in patients aged up to 25 years for the 'ASD' and 'non-ASD' groups. Data for the ASD group was standardised to the age-sex distribution of the non-ASD group in order to allow comparison. Also examined was patient demographic data, including: sex; age; Commonwealth Health Concession/Benefits Card (CHCC) status; non-English speaking background (NESB) (defined as “a language other than English is primarily spoken at home”); and, self-identified Aboriginal and Torres Strait Islander (ATSI) status.

Analyses included exploration of the annual frequency of encounters with the GP for those in the ASD group and comparison of the rates of the different RFEs between the ASD and non-ASD groups using chi square statistics and odds ratios. All analyses were adjusted for clustering in SAS® 9.3 statistical software (SAS Institute Inc, Cary, NC, USA).

Study 2

This study explored the rates that different problems were managed, the rates that medications were prescribed, the top ten medication subgroups and top ten generic medications prescribed for each group. Analyses performed included Chi square statistics to compare the ASD and non-ASD group on: demographics (same factors as Study 1), rates of problems managed per 100 counters, rates of prescribed medications, the top ten medication groups as well as top ten generic medications that were prescribed.

Ethics

The BEACH program is approved by the University of Sydney Human Research Ethics Committee, (HREC 2012/130) with ethical approval allowing this study.

4. Findings

Study 1

The annual frequency of GP encounters for the ASD group increased significantly over the study period, from 2000-2001 (46 per 100,000 encounters) to 2013-2014 (386 per 100,000 encounters). This may reflect the increased numbers of those diagnosed in recent years.

Overall, the ASD group had more RFEs than the non-ASD group. This means they had higher numbers of reasons for seeing GPs. Rates of RFEs were higher for 'psychological', 'general and unspecified' and 'social' related reasons and lower for 'respiratory' and 'skin' related reasons.

Those in the ASD group had different RFEs to those in the non-ASD group. Eight of the top ten RFEs for the two groups were different. Only 'general check up' and 'preventive immunisation/vaccination/meds –all' were in the top ten for both groups. The top ten RFEs for the non-ASD group were largely symptoms of preventive care, while the RFEs in the standardised ASD group top ten were largely related to psychological conditions or requests for services such as

referrals. Detailed analysis of these findings have been published (Foley, Pollack, Britt, Lennox & Trollor, 2017).

Table 2: Comparison of 'ASD' group encounters with 'Non-ASD' group encounters:

Rates of RFEs, classified by ICPC-2 chapter

	'ASD' group encounters	'ASD' group encounters: age-sex standardised	'Non-ASD' group encounters
RFEs classified by ICPC-2 chapter	n	Rate per 100 encounters (95% CI)	Rate per 100 encounters (95% CI)
All RFEs [^]	904	156.1 (150.1–162.1)	156.4 (144.0–168.8)
Psychological [^]	406	70.1 (63.0–77.2)	71.8 (61.0–82.5)
General & unspecified [^]	248	42.8 (37.3–48.4)	43.7 (35.2–52.3)
Respiratory [^]	60	10.4 (7.6–13.1)	9.0 (5.1–13.0)
Social [^]	38	6.6 (4.5–8.6)	4.8 (2.7–7.0)
Digestive	35	6.0 (3.8–8.3)	6.7 (1.2–12.2)
Skin [^]	33	5.7 (3.8–7.6)	6.3 (1.0–11.6)
Ear	29	5.0 (3.2–6.9)	5.6 (2.7–8.6)
Neurological	17	2.9 (1.6–4.3)	3.2 (1.1–5.2)
Endocrine & metabolic	10	1.7 (0.5–3.0)	1.8 (0.2–3.4)
Musculoskeletal	9	1.6 (0.5–2.6)	0.7 (0.0–1.5)
Urology	9	1.6 (0.6–2.5)	0.9 (0.2–1.5)
Male genital system	3	0.5 (0.0–1.1)	0.1 (.–)
Eye	2	0.3 (.–)	0.1 (.–)
Circulatory	2	0.3 (.–)	0.4 (.–)
Pregnancy & family planning	1	0.2 (.–)	0.6 (0.0–1.8)
Female genital system	1	0.2 (.–)	0.6 (0.0–1.8)
Blood	1	0.2 (.–)	0.0 (.–)

[^] Significant difference between age-sex standardised 'ASD' and 'non ASD' groups
ICPC-2 = International Classification of Primary Care

Table 3: Comparison of 'ASD' encounters with 'Non-ASD' encounters:

Top ten RFEs ranked by frequency

RFE rank#	'ASD' group encounters	'ASD' group encounters: age-sex standardised	'Non ASD' group encounters
1	Psychological disorders, other	Psychological disorders, other	Cough
2	Administrative procedure NOS	Administrative procedure NOS	Preventive immun/vacc/meds-all
3	Child behaviour symptom/complaint	Other referrals NEC NOS	Throat symptom/complaint
4	Other referrals NEC NOS	Anxiety	Fever
5	Prescription all	Child behaviour symptom/complaint	Rash
6	Refer physician/specialist/clinic/hosp NOS	Refer oth provid/nurse/thera/social wkr psychological	Upper respiratory infection, acute
7	Other preventive procedures psychological	General check-up	Pain, ear/earache
8	Cough	Prescription all	General check-up
9	Administrative procedure social	Refer physician/specialist/clinic/hosp NOS	Sneezing/nasal congestion
10	Anxiety	Preventive immun/vacc/meds-all	Test results

Study 2

GPs managed more problems (164.8 per 100 encounters), at ASD encounters than at non-ASD encounters (123.9 per 100 encounters). Further, significantly higher rates of old and chronic problems were managed during ASD encounters (123.9 and 113.2 per 100 encounters, respectively) than during non-ASD encounters (53.8 and 14.9 per 100 encounters, respectively).

Overall, prescribed medication rates per 100 encounters were similar at ASD and non-ASD encounters; however, the rate of psychological medication prescription was significantly higher at encounters where an ASD was recorded. The most common medication subgroups prescribed at ASD encounters were antipsychotics and antidepressants. In contrast, no psychotropic medications were listed in the top ten medications prescribed at the 'non-ASD' encounters. Overall these findings are consistent with existing evidence of high rates of psychological problems and psychotropic medications prescribed in children and young adults on the spectrum. Detailed analysis of these findings have been published (Foley, Birch, Pollack, Britt & Trollor, in press).

Table 4. Comparison of ‘ASD’ group with ‘Non-ASD’ group: Top ten medication subgroups prescribed

Top ten medication subgroups prescribed

Medication rank	‘ASD’ group encounters*	‘ASD’ group encounters: age-sex standardised	‘Non ASD’ group encounters
1	Antipsychotics	Antipsychotics	Broad spectrum penicillins
2	Antidepressants	Antidepressants	Penicillins/Cephalosporins
3	Broad spectrum penicillins	Other antibiotics	Immunization
4	Penicillins/Cephalosporins	Tetracyclines	Other antibiotics
5	Central nervous system stimulants	Topical steroids	Contraceptives oral/systemic
6	Bronchodilators/Spasm relaxants	Sulphonamides	Topical steroids
7	Asthma preventives	Broad spectrum penicillins	Bronchodilators/Spasm relaxants
8	Antimigraine	Penicillins/Cephalosporins	Simple analgesics
9	Other hormones	Sex/Anabolic hormones	Asthma preventives
10	Immunization	Immunization	Anti-infectives eye

5. Limitations

There is the possibility that some encounters in the non-ASD group included patients who had seen the GP for other health problems and where ASD was not recorded. This limits the generalisability of our results. Also, due to small sample numbers of people on the spectrum who have an intellectual disability, it was not possible to separate encounters for those in the ‘ASD’ group with and without intellectual disability. For Study 2, comparisons of patterns of generic medication data prescribed in this sample should be interpreted with caution due to the small number of prescriptions for each medication in the ‘ASD’ group.

6. Implications for research and practice

The rise in consultations where an ASD was recorded since 2000 highlights the urgent need to upskill GPs and healthcare providers in best practice healthcare management for young people on the spectrum. The development of tools to facilitate the successful interaction between GPs and

individuals on the spectrum will only become more important in the future as the number of GPs managing individuals on the spectrum increases.

Given the high numbers of physical and mental health concerns documented for young people on the spectrum relative to those not on the spectrum, it will be important for primary healthcare providers to be adequately equipped to identify and manage such concerns among individuals on the spectrum. There are examples of programs, strategies and initiatives which have been developed to support GPs in their practice with individuals on the spectrum and with developmental disability more broadly such as the Comprehensive Health Assessment Program - Autism (CHAP-A) tool which is under development through the Autism CRC. GPs and specialists should be aware of current clinical guidelines for best treatment practices and consider adverse outcomes when considering pharmacotherapy for patients on the spectrum.

7. Key recommendations

1. The high complexity of needs reported in RFEs for the ASD group highlights the need for primary health care services to be equipped to meet the specific needs of younger people on the spectrum.
2. The rise in consultations where an ASD was recorded since 2000 highlights the urgent need to upskill GPs and healthcare providers in best practice healthcare management for young people on the spectrum.
3. The rate of psychological RFEs in the ASD group was seven times that of the non-ASD group. Effective management of psychological conditions and social issues in patients diagnosed with ASD presents a challenge to GPs and requires specific support through continuing education, and development of tailored tools.
4. In light of the high rates of psychological RFEs and higher rate of psychological medications prescribed to this group, GPs and specialists should be aware of current clinical guidelines for best treatment practices, which recommend use of first-line psychosocial (e.g. behavioural, speech-language and educational) interventions to manage core symptoms of ASD in children and adults.

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