ACT Government
Health

ACT Population Health Bulletin

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Upcoming Events

- Health Promotion Innovation Fund - opening soon - http://www.health.act.gov.au/healthy-living/health-promotion-grants-program
- Your guide to Summer Safety - http://www.health.act.gov.au/healthy-living/summer-safety

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Introduction

A message from the ACT Chief Health Officer

Data is the stethoscope of the public health practitioner, and this Issue of the Bulletin describes the way in which data, from multiple sources, is used in the ACT to inform population health policies and programs to prevent disease and to promote and protect health.

The World Federation of Public Health Associations Charter places information (along with governance, advocacy and capacity) as one of the key supporting pillars for public health action.[1] The United States Centres for Disease Control and Prevention put data and its analysis central to their definition of the public health approach, that is, to "define and monitor the [health] problem, identify risk and protective factors, develop and test prevention strategies, and assure the widespread adoption of proven strategies ... and public policy."[2] Here it is important to consider the data-information-knowledge-practice pathway to public health action. *Datum* (or data in the plural) is a Latin word for something which is given. Information also has a Latin origin in the word *informare*, which means to give form to. *Information* therefore is data which has been processed, organised and structured within a given context to assign meaning and to improve the reliability and utility of that data. Knowledge is the result of further interpretation of the information by the public, policy makers and practitioners to guide action.

In this Issue of the Bulletin, a range of topics are covered, highlighting how this information for action is derived by the detailed and careful analysis of data, which are generated or accessed from a variety of sources. The journey of a piece of data to information and eventually to knowledge can be long and tortuous, with numerous pitfalls along the way. Surveys, routinely collected health and other service data, various legislatively governed registers and specific research-generated data can all be used to inform policy and programs and to provide information to the public. The art and the science of population health are crucial to carefully meld these different data sources in a systematic way into a coherent resource for information for knowledge generation. This is an exciting era for Population Health informatics with whole of government policies led by the ACT Chief Digital Officer that encourage the strategic use of and, within the constraints of privacy and other considerations, open access to data held by the ACT government. Population Health Protection and Prevention has been leading in both of these initiatives through our data linkage platform and the *HealthStats ACT* website. Thanks to guest editor Bridget O'Connor and all contributors to this Issue.

Dr Paul Kelly
ACT Chief Health Officer
November 2016

References:

1. Lomazzi M. A Global Charter for the Public's Health-the public health system: role, functions, competencies and education requirements. *Eur J Public Health*. 2016 Apr;26(2):210-2.
2. Centers for Disease Control and Prevention. (2014) The Public Health Approach to Violence Prevention. http://www.cdc.gov/violenceprevention/overview/publichealthapproach.html (accessed 22 Nov, 2016)

Breaking News

ACT's smoke-free areas extended

Smoke-free areas are an effective tool to reduce tobacco related harms to the community. Legislated smoke-free areas reduce the community's exposure to harmful second-hand tobacco smoke, make smoking less socially acceptable, and support those trying to quit or who have quit smoking.

All public playgrounds and play spaces in the ACT were declared smoke-free on 7 September 2016. The declaration was the first to be made by the ACT Government under the Smoke-Free Public Places Amendment Bill 2016, which was passed in the Legislative Assembly in March on this year. The Bill enabled the Chief Minister and responsible Minister to jointly declare new smoke-free areas in the ACT under the Smoke-Free Public Places Act 2003. Previously new smoke-free areas were declared by primary legislation, which proved to be a cumbersome and resource intensive process.

Playgrounds and play spaces where children congregate were selected, as children are particularly susceptible to second hand smoke. Children regularly exposed to second hand smoke have a higher risk of health conditions, such as middle ear infections, upper and lower respiratory infections, asthma, chronic cough and developmental delays.

Consultation undertaken by the Health Protection Service (HPS) in July showed overwhelming community support for the proposal, with 98 per cent of 307 complete submissions received in favour of restricting smoking at public playgrounds and play spaces.

Under the declaration smoking is now prohibited within 10 metres of play equipment at ACT Government-managed playgrounds and play spaces. 'No Smoking' signage is currently being installed across playground sites across the ACT. Under the declaration fines apply for smoking in a declared smoke-free play space, with ACT Policing and Access Canberra City Rangers authorised to enforce smoking restrictions.

The HPS is now working to consult the community on further smoke-free areas in the ACT, including public transport hubs.

For more information visit http://www.health.act.gov.au/public-information/public-health/tobacco-and-smoke-free

The ACT Government responds to community consultation on food and drink marketing with a range of actions to help keep Canberra healthy.

A range of measures to increase the availability of healthier choices and change the way unhealthy food and drink is marketed, particularly towards children, will be implemented in the ACT following extensive community consultation. The actions will focus on sporting clubs, businesses and ACT venues and events to help keep Canberra healthy.

In late 2015 the Government sought community views on ways to increase the availability and promotion of healthy food and drink choices and reduce the marketing of unhealthy food and drinks. The consultation was part of the Government's commitment to halt the growing rates of obesity and overweight in our community through the Healthy Weight Initiative. The results showed that Canberrans support the Government taking steps to reduce the marketing of unhealthy food and drinks, especially when aimed at children.

In response to the consultation, the Government has announced a range of measures aimed at working with industry and young people to change behaviour and address unhealthy food and drink marketing. The measures will be backed by $755,000 in funding under the Healthy Weight Initiative.

The measures to be implemented include:

- Expanding the successful Choose Healthier program to reduce unhealthy food and drink marketing in local Canberra businesses and make healthier choices easier for consumers.
- Establishing a project to find innovative ways to provide healthier food and drink at sporting club canteens, and help sporting clubs to broker 'healthy' sponsorships.
- Partnering with business to install additional drinking water stations across the ACT, and develop a Water Friendly Cafe campaign to encourage and support food businesses to supply drinking water for free to patrons and passers-by.
- Reviewing the costs and benefits of supplying and promoting healthy food and drink at ACT venues and events, with a view to introducing mandatory requirements.
- Initiating a competition to design healthy food and drink marketing that could be displayed in ACT Government settings.
- Engaging with children and young people to get their views on strategies to reduce unhealthy marketing and increase healthier choices.
- Continuing to advocate at a national level for a collaborative approach to reduce unhealthy food and drink marketing.

Drawing on the Australian Dietary Guidelines, the Government will develop definitions of 'healthy' and 'unhealthy' food and drink marketing to give industry some guidance about what healthy food and drink looks like. The Australian Dietary Guidelines give advice on eating for health and wellbeing. Based on the latest scientific evidence, they describe the best approach to eating for a long and healthy life.

Collectively, these additional measures are designed to make it easier for Canberra families to stay healthy and take pressure off our health system. The ACT Government will work collaboratively with stakeholders, including businesses, sporting clubs and event organisers, in taking these measures forward. The actions proposed are predominantly voluntary in nature, but other approaches may be considered.

Acronyms

Acronyms

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
ACTCR	ACT Cancer Registry
ACTGHS	ACT General Health Survey
ACT MPDC	ACT Maternal and Perinatal Data Collection
ANU	Australian National University
ACTPANS	ACT Year 6 Physical Activity and Nutrition Survey
AHMAC	Australian Health Ministers' Advisory Council
AIHW	Australian Institute of Health and Welfare
APC	Admitted Patient Care data collection
ACR	Australian Coordinating Registry
ASSAD	Australian Secondary School Alcohol and Drug survey
BMI	Body Mass Index
BRFSS	Behavioural Risk Factor Surveillance System
CATI	Computer assisted telephone interviewing
CDC	Communicable Disease Control
CDNA	Communicable Disease Network Australia
CHeReL	Centre for Health Record Linkage
CHO	Chief Health Officer
CINSW	Cancer Institute New South Wales
COD URF	Cause of Death Unit Record File
CRAHW	Centre for Research on Ageing, Health and Wellbeing
CSP	Cervical Screening Program
ED	Emergency Department
EDIS	Emergency Department Information System
ENM	Endocrine, nutritional and metabolic (diseases)
ERA	Enhanced Reporting of Aboriginality
ES	Epidemiology Section
GP	General Practitioner
HIB	Health Improvement Branch
HPS	Health Protection Service
HPV	Human papillomavirus
ICD10	International Classification of Diseases
IRSAD	Index of Relative Socioeconomic Advantage and Disadvantage
MBS	Medical Benefits Scheme
MLA	Member of the Legislative Assembly
NATSIHS	National Aboriginal and Torres Straight Islander Health Survey
NCD	Non-communicable disease
NDI	National Death Index
NHS	National Health Survey
NNDSS	National Notifiable Disease Surveillance System
NSW	New South Wales
NSWCR	New South Wales Cancer Registry
NT	Northern Territory
PATH	Personality and Total Health through Life project
PBS	Pharmaceutical Benefits Scheme
PCR	Nucleic Acid Test
SEIFA	Socio-Economic Indexes for Areas
STaR	Stage, Treatment and Recurrence
TNM	Tumour, Node and Metastasis
TRIP-DPH	Translating research into practice - dementia and population health
USA	United States of America

Resources

Resources

- *HealthStats ACT* - http://stats.health.act.gov.au/
- *Healthy Canberra*: ACT Chief Health Offier's Report 2016 - http://www.health.act.gov.au/datapublications/reports/chief-health-officers-report-2016
- Data ACT - www.data.act.gov.au
- ACT General Health Survey - http://health.gky.com.au/about-us/act-general-health-survey
- Towards Zero Growth: Healthy Weight Action Plan - http://www.health.act.gov.au/sites/default/files/Towards%20Zero%20Growth%20Healthy%20Weight%20Action%20Plan.pdf
- ACT Road Crash Report - http://www.pedalpower.org.au/wp-content/uploads/2016/09/Crash-report.pdf
- Smoke-free public places - http://www.health.act.gov.au/public-information/public-health/tobacco-and-smoke-free
- Cervical Screening - http://www.health.act.gov.au/healthy-living/cervical-screening
- A Picture of Children and Young Persons Report - http://www.children.act.gov.au/documents/PDF/A%20Picture%20of%20ACT's%20Children%20and%20Young%20People%202014.pdf
- Australian Institute of Health and Welfare - http://www.aihw.gov.au/
- Australian Bureau of Statistics - www.abs.gov.au
- Aboriginal and Torres Strait Islander Health Performance Framework 2014 - https://www.dpmc.gov.au/sites/default/files/publications/indigenous/Health-Performance-Framework-2014/
- National Notifiable Diseases Surveillance System - http://www.health.gov.au/internet/main/publishing.nsf/Content/cda-surveil-nndss-nndssintro.htm
- Zika Virus - http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-zika-health-practitioners.htm
- Personality and Total Health through Life Project - http://crahw.anu.edu.au/research/projects/personality-total-health-path-through-life
- Cancer Australia - https://canceraustralia.gov.au/research-data/cancer-data/improving-cancer-data
- NSW Cancer Registry - https://www.cancerinstitute.org.au/data-research/data-held-by-cinsw/nsw-cancer-registry
- Lab test online - www.labtestsonline.org.au/understanding/reading-your-results
- Walk Score® - https://www.walkscore.com/AU-ACT/Canberra

Journey of a piece of data

Dr Alison Oakleigh, Rosalind Sexton, Elizabeth Chalker & Bridget O'Connor, Epidemiology Section, Population Health Protection and Prevention

> ***"The truth of the story lies in the details."***
> **— Paul Auster, The Brooklyn Follies**
>
> ***"It is a capital mistake to theorize before one has data."***
> **— Sherlock Holmes, A Study in Scarlett, Arthur Conan Doyle**

Data and evidence should underpin much of what we do in ACT Health. The recently released Chief Health Officer's Report (CHO Report) is a good example of how data becomes evidence to inform our practices. But where does this data come from? What journey does it undertake as it moves from its origin to its application?

ACT Health is responsible for gathering, storing, analysing and reporting a wide range of data about the health of Canberrans. To make its journey from recording to reporting, each piece of data typically moves through three key stages: capture; processing (including cleaning and storage); and analysis and reporting. While each piece of data takes a slightly different route on this journey, the stages remain the same. What follows are three examples of the journey of a piece of data.

The journey of Maternal and Perinatal Data: from a pregnant woman's first contact with the health system to the CHO Report and the Smoking in Pregnancy program

1: CAPTURE

When a woman in the ACT suspects she is pregnant, she will often book in to see her GP, to have the pregnancy verified with a blood test and to receive a referral to antenatal care. She'll often make several visits to see a midwife or obstetrician in the process of receiving antenatal/prenatal care, and at some stage in this process her health care provider will make a record of her information. This information will include items collected at prenatal visits and at the baby's birth such as the number of weeks pregnant when she first received prenatal care, current smoking status, age when she gave birth and the weight of her baby at birth. Not only will this information be noted in a booklet that the woman will usually keep with her, it will also be entered into an electronic records system.

This information helps us to know about how to best support women in Canberra who access health services, and to measure the quality of our maternal health services in the ACT. For example, there are national indicators and benchmarks about when a woman should have her first interaction with health care when she's pregnant – under the assumption that this is a good proxy measurement of the quality of the health care system.

Image: Newborn baby. FreeDigitalPhotos.net

2: PROCESSING

Routinely, every month, it is the role of a data manager from the Epidemiology Section (Health Improvement Branch, Population Health Protection and Prevention Division) to contact the maternal and perinatal electronic records system managers and to request an "extract" of the data from the previous month. This data extracted includes all the birth and related records for the period, which are then stored in the secure database within Epidemiology.

To double-check the accuracy of this data, the data manager runs 30 standard formula-based queries to validate the data. These queries check elements of the data such as missing or atypical fields. The data manager's list of clarifications goes back to the source (i.e. the hospital) where the data is checked and confirmed to be correct.

As a part of this process, the data will also be matched to other data such as admitted patient care data and perinatal deaths data. This may generate further queries, for example, one woman's entry states she gave birth at a particular location, however if there is no corresponding admitted patient data about the mother, then the data manager will ask the hospital to check the entry is accurate. This process of checking and "cleaning" the data can take some time and is vital to ensure the data is accurate.

Pregnant women and smoking

- From 2009 to 2014, self-reported data showed a decrease in women who smoked during pregnancy from 11% to 7%, but teenage mothers still smoke more than older women.

- Smoking in pregnancy has a negative impact on both the mother's and baby's health.
- The birth weight for babies of women who smoked during pregnancy was significantly lower than for the babies of women who did not smoke.
- The number of cigarettes smoked per day contributed to lower birth weight.

Pregnant women and smoking

Women's age group	Percent who reported smoking at first antenatal visit 2009–2014
Under the age of 20	42%
20-34 years	9%
Over 35 years	5%

- Aboriginal and Torres Strait Islander women were 6 times more likely to smoke during pregnancy (48%) than their non-Aboriginal and Torres Strait Islander counterparts (8%).

Image: *Healthy Canberra*: ACT Chief Health Officer's Report

Journey of a piece of data *(continued)*

3: ANALYSIS & REPORTING

The data manager is also responsible for preparing the data set for analysis. Analysis might occur in a range of ways. For example, when a whole calendar year's worth of data is ready, the data manager will put it together in a package and send it securely to the Australian Institute of Health and Welfare (AIHW). At the AIHW it will be tested and validated again before being analysed and included in the annual Australia's Mothers and Babies Report.

Another way this data about mothers and babies will be analysed and reported is in the biennial ACT CHO Report. For example, a section of the 2016 CHO Report reported on the rates of women who report they smoke during pregnancy. This involved bringing together information about the women whose records indicate they were smoking, calculating percentages of pregnant women who smoke and seeing if this percentage has changed over the years. Another analysis can explore if there are specific characteristics of these women that can help us understand more about their situation. In this instance, the analysis uncovered that the percentage of women who report they smoke at their first antenatal visit has decreased over the past five years, however it is much higher for women aged less than 20 years.

In this particular instance, these findings have led to the development of two health promotion programs about quitting smoking while pregnant, one aimed at supporting young women and another aimed at Aboriginal and Torres Strait Islander women.

2: PROCESSING

When ACT Health receives these notifications, it sends them to the Cancer Institute NSW to be scanned, coded and entered into the NSW/ACT Cancer Registry by an expert cancer coder. The process of transforming the piece of paper from a laboratory, with all its technical details, listed as numbers and measurements, into a useful set of data in the Cancer Registry is a complex process, guided by standard operating procedures. The experts responsible for coding the data have undergone specific training to ensure they code the information accurately. There is even a specialist pathologist on staff to support the coding team in complex situations.

The coding process might also involve a back-and-forth interaction between the Cancer Institute and the laboratory that performed the test. Also information may be added from ACT death certificates and the national Cause of Death files that are coded by the Australian Bureau of Statistics. This process can take up to 18 months to complete.

Each piece of data will also undergo many other processes during this time. One example is that the data is sent to the AIHW every year to be linked to the National Death Index to ensure that the information in the Cancer Registry is updated if someone has subsequently died interstate. The data is also sent to AIHW each year for inclusion in the Australian Cancer Database.

The journey of a piece of Cancer Data: from a laboratory to the ACT Cancer Registry

1: CAPTURE

There are many paths on which a piece of cancer data might travel. The "capture" moment typically occurs when a specimen or sample has been sent to a laboratory and tests reveal the presence of cancer. Another pathway is through hospitals and aged care facilities when they identify a patient or resident with cancer. In other instances cancer might be discovered only after a person has died, in which case data will most likely be "captured" on a person's death certificate. Once this piece of data is captured, legislation across Australia requires that the event is notified to the appropriate authority– in this case, ACT Health. This occurs either by secure, courier-delivered reports from laboratories to the Epidemiology Section at ACT Health or electronic notifications from hospitals to the Cancer Institute NSW (CINSW) via their secure Cancer Notification Portal. The ACT Cancer Registry registers all new cases of cancer diagnosed in ACT residents. Therefore some sorting is required between NSW and ACT registries to correctly register people who may be diagnosed in the ACT but live interstate.

ACE PATHOLOGY

Requesting Doctor	Patient
Dr Peter Green	SMITH, Alicia
Brown St Medical Centre	21 Riverton Road
233 Brown Street	WHITEVILLE, NSW
WHITEVILLE, NSW	DOB: 2/Feb/1997 Sex: Female
	Phone:

Date: 23/Jul/2014

			Latest Results		
Collection date:	15/Apr/14	18/May/14	23/Jul/14	Reference	Units
Collection Time:	09:00	09:30	09:30		
Request No:	H123278	H123344	H123456		
Haematology					
Haemoglobin	118 L	132 L	146	(135-175)	g/L
Haematocrit	0.35 L	0.40	0.47	(0.40-0.54)	
RCC	2.9 L	4.1 L	4.8	(4.5-6.5)	10^12/L
MCV	70 L	75 L	97	(80-100)	fL
WCC	6.0	9.0	4.2	(3.5-10.0)	10^9/L
Neutrophils	4.56	4.96	2.72	(1.5-6.5)	10^9/L
Lymphocytes	1.14	2.27	0.99 L	(1.0-4.0)	10^9/L
Monocytes	0.13	1.0 H	0.36	(0-0.9)	10^9/L
Eosinophils	0.10	0.50	0.13	(0-0.6)	10^9/L
Basophils	0.03	0.05	0.03	(0-0.15)	10^9/L
Platelets	251	356	178	(150-400)	10^9/L

Image: Sample pathology result. Source www.labtestsonline.org.au/understanding/reading-your-results

3: ANALYSIS & REPORTING

Once the coding is complete, ACT Health receives data files that the Epidemiologists analyse using specialised statistical software. Analysis involves a series of routine investigations, identifying, for example, the rates of incidence and mortality for the different types of cancer. Reporting then occurs through a range of products such as the CHO Report, specific incidence and mortality reports, survival reports and projections, as well as in the Epidemiology Focus On reports and on the HealthStats ACT website.

Researchers both in Australia and overseas also work with this data. There are many ongoing research projects, some which retrospectively analyse the cancer data, and others which track particular groups over time to see if they have higher or lower rates of cancer incidence or mortality. The process for researchers accessing cancer data can be complex and requires thorough ethical and administrative consideration. ACT Health has a close working relationship with Cancer Institute NSW. At all times, the ACT Chief Health Officer (CHO) remains accountable and responsible for the way the data is used. This means that ACT Health carefully considers each and every request for cancer data, and seeks the CHO's approval each and every time the data is released. For example, the AIHW regularly publishes reports about Cancer in Australia as well as reports on the various screening programs (which typically include cancer incidence data) and the annual Report on Government Services. Each of these requests is considered, processed and approved every year by ACT Health.

Journey of a piece of data *(continued)*

1: CAPTURE

The journey of a piece of survey data: from the telephone to the Healthy Weight Initiative Report

Once a year, a group of randomly selected ACT residents – a different group each year – receive a telephone call, either on a fixed line or a mobile phone, with an invitation to participate in the annual ACT General Health Survey, which has been operating since 2007. These phone calls are made by a social research company where their trained staff are sitting in front of a computer in a call-centre. There is usually a short introductory conversation involved, in which the interviewer identifies if the person being interviewed (the respondent) is the right person to talk to – for example that the respondent is an adult and an ACT resident. The interviewer will then spend the next half hour or so asking the respondent questions about themselves and possibly also about children in the house.

The interviewer might ask all sorts of things about the respondents health. An example question might be "how many cups of milk have you (or your child) drunk today (or this week)?" Or perhaps "how many serves of fruit or vegetables have you (or your child) had today (or this week)?" The interviewer then enters the respondents responses into a computer and moves on to the next question until the survey is finished and they call the next person on their list of randomly selected individuals. It might take the team of interviewers a couple of weeks to conduct enough surveys to reach their target number of between 1,500 and 2,000 people, including specific targets for certain groups of people such as certain age groups to ensure the sample is representative of the population of the ACT.

Image: Call centre worker. FreeDigitalPhotos.net

2: PROCESSING

When the collection phase is complete, the company sends a file with all the data to NSW Health (who administer the survey contract on ACT Health's behalf), who then check the data for accuracy and missing elements. At this stage NSW Health also do some calculations to "weight" the data – to adjust it to consider the people who are and are not in the sample. It is important to weight the data so that we can draw population estimates from this sample. NSW Health also process some of the answers in order to provide us with more meaningful information – for example taking a person's self-reported height and weight to calculate the body mass index score and category. Another example of this initial processing is that a whole set of questions about physical activity are processed together at this early stage to determine if a respondent is meeting their age group's physical activity guidelines or not.

Following this initial processing stage, NSW Health securely sends the data to the ACT Health Epidemiology Section who runs its own logic checks to test the data's accuracy and joins this year's data to previous year's data to generate larger datasets and information over time.

3: ANALYSIS & REPORTING

Epidemiology run a series of data management steps to check the quality of the survey data, the calculation of key variables and their consistency over the data time series. Epidemiology then uses specific statistical software packages to analyse the survey data and report it in a range of different places and products. There is a core group of measures such as a person's weight status, nutrition, physical activity, smoking status, alcohol consumption, mental health which are reported in products like the CHO Report or the Healthy Weight Initiative Progress Report. Other survey data is reported in regular reports such as the annual Picture of the ACT's Children and Young People, prepared by the ACT Community Services Directorate.

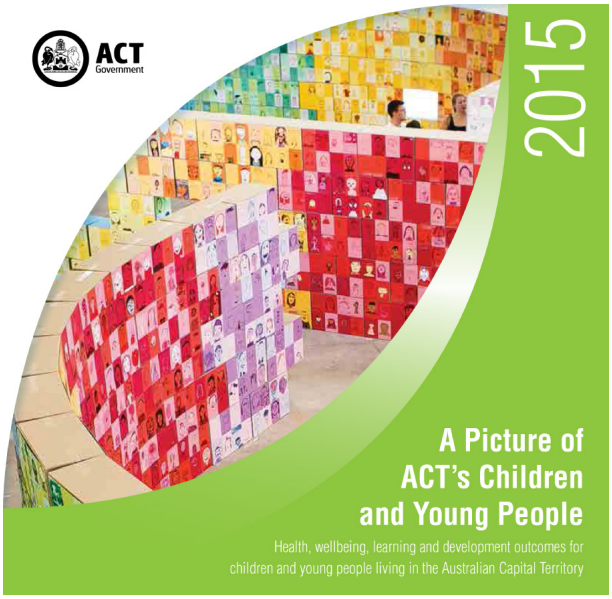

Image: A Picture of ACT's Children and Young People. ACT Government

The Epidemiology Section might also receive requests for data from various parts of ACT Health, the ACT Government or Legislative Assembly. For example a Member of the Legislative Assembly (MLA) might ask a question in the Assembly, such as "is mental health of our young people improving or getting worse?" The process of responding to this question involves extensive clarification with parameters such as "how to define a young person – some data refers to people aged 15 to 24, other datasets classify young people as 12 to 17. Other parameters for clarifying in this instance include "what do you mean by getting worse?" as there is a dataset about the extent to which people access mental health services; and there is another dataset about people self-reporting they have had a diagnosis in the previous year/week. In the absence of opportunities to clarify, the Epidemiology Section must provide enough information to build a picture that helps the Minister to respond meaningfully.

In the Health Improvement Branch we are especially interested in trends over time, such as how many people do enough exercise and has that changed over time? This can assist in monitoring this outcome as well as creating statistical models that predict which factors are associated with better physical activity outcomes. These results feed into health promotion programs that target improving physical activity.

These three examples demonstrate the types of pathways taken for public health information to be created and used. Each type of data collection will have its individual nuances and understanding the methods of collection is imperative for its usefulness.

A roadmap of health datasets

Rebekah Smith & Wayne Anderson, Epidemiology Section, Population Health Protection & Prevention

The following article is a summary of data sources held or accessible to the Health Improvement Branch of ACT Health. The article outlines general descriptions of the datasets and their use in forming health policy and research activities. The datasets cover a wide variety of health related topics, including diseases, births and deaths, hospital services utilisation, youth and children, and general health. The data produced from these sources are used for internal policy, briefs or reports, external reports such as the Chief Health Officer's Report, the *HealthStats ACT* website, and data requests from external researchers.

The Health Improvement Branch (HIB) of ACT Health has a number of health datasets at its disposal for research, analysis, and to assist with ongoing health policy and planning within the ACT. The Cervical Screening Program (CSP) Section holds a register of ACT women's Pap test results called the ACT Cervical Screening Register. The Epidemiology Section manages the ACT Cancer Registry and the ACT Maternal Perinatal Data Collection, and administers a collection of surveys to monitor the health of ACT residents, including the ACT General Health Survey, the Australian Secondary Schools Alcohol and Drug Survey, and the ACT Physical Activity and Nutrition Survey.[1]

The Epidemiology Section also has access to several other collections of ACT Health data,[1] including the Notifiable Diseases Management System, Cause of Death Unit Record File, and other State and Federal datasets, for example the Australian Bureau of Statistics Population datasets (which includes but is not limited to cause of death, life expectancy, and estimated resident populations).[2] The Section also has access to clinical datasets, including the Admitted Patient Care and the Emergency Department Information System datasets that are used from a population health perspective, and to fulfil the statatory responsibilities of the Chief Health Officer. A full list of population health datasets is outlined in Table 1 on page 9.

The Epidemiology Section contributes data to the Centre for Health Record Linkage (CHeReL)[3] for the purpose of research data linkage. Data linkage is the process of creating links within and between data sources so that information that is related to a particular person, place or event can be connected for analysis. Consequently, it can be possible to construct a record of sequential health events for individuals. Combined, these individual 'stories' can create a larger story about the health of people in the ACT. CHeReL complies with best practice in preserving privacy/confidentiality, adopting the Kelman, Bass and Holman (2002) approach.[4] CHeReL holds and links personal identifiers only and uses a system of numbered "keys" to exchange information with data custodians. CHeReL does not provide linked records directly to researchers, as they do not hold health information. Data custodians retain control of the information that is provided to CHeReL for linkage and for provision of de-identified linked records to researchers, subject to strict conditions including the independent oversight of the ACT Human Research Ethics Committee.

Diseases

HIB has access to the following disease specific datasets that help provide information related to the incidence of these diseases in the ACT. The Epidemiology Section maintains the ACT Cancer Registry, which is a legislated data collection of all cancer diagnoses (except non-melanoma skin cancers i.e. basal cell carcinomas and squamous cell carcinomas) within the ACT. The dataset includes information relating to demographics, topography (site), morphology (classification of cancer tissue), incidence, and mortality. The data is collected from hospital records, pathology laboratories, day surgeries, hospices and nursing homes, and is used to monitor and examine cancer incidence and trends in the ACT for the estimation of burden of disease.

The Epidemiology Section also has access to data contained in the Notifiable Diseases Management System, which is held by the Communicable Disease Control Section of the Health Protection Service within ACT Health. This system is a register of diagnoses of infectious diseases which are notifiable under the *Public Health Act 1997*,[5] notified to ACT Health by laboratories, hospitals, and medical practitioners in the ACT. For a condition to be notified, a patient must seek medical help, be diagnosed with the condition, have the appropriate laboratory tests (where applicable), and then the diagnosis must be reported to ACT Health.

The Cervical Screening Program Section holds a register of ACT women's Pap test results called the ACT Cervical Screening Register. Women have a choice as to whether their results are stored on the Register. The Register plays a role in reducing cervical cancer, as a considerable number of women who develop cervical cancer have been screened infrequently. The Register records all results and generates reminders when tests are overdue. It is a list of information about the patient including name, date of birth, Aboriginal and Torres Strait Islander status, postal address, date of test, histology (type of cancer), and cytology (examination of tissue sample) and human papillomavirus (HPV) test results. It also includes practitioner details, and follow-up instructions for the patient. De-identified data from the Registry can be used for prevention, strategic or research purposes under strict guidelines outlined in Part 3 of the ACT Public Health Regulation 2000, including data custodian approval.

Image: Cervical Screening poster. ACT Health

Births and deaths

The Epidemiology Section also maintains, or has access to, datasets focused on births and deaths within the ACT. The Section collates and manages the Maternal Perinatal Data Collection (ACT MPDC), which contains information on all hospital and home births that occur in the ACT. The ACT MPDC encompasses all live births, and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight. For every birth, data is provided from public and private maternity units and home birth midwives. This data includes demographic, medical and obstetric information on the mother, and information on the labour, delivery and condition of the baby. The information is sent to ACT Health where it is checked and compiled into one territory-wide dataset. A record is submitted for each baby, even in the case of a multiple birth. The Section uses the data for national reporting and it is used by the Australian Institute of Health and Welfare to produce the Australia's Mothers and Babies report annually.[6]

The Epidemiology Section receives coded cause of death data from the Australian Coordinating Registry (ACR) on behalf of the Australian Registries of Births, Deaths and Marriages, Australian Coroners and the National Coronial Information System, for the Cause of Death Unit Record File (COD URF). The COD URF includes information about an individual's cause of death (using standardised coding and classifications) and is used to examine the incidence of avoidable and/or premature deaths.

A roadmap of health datasets *(continued)*

Hospital services utilisation

The Epidemiology Section also has access to the ACT Admitted Patient Care (APC) and the ACT Emergency Department Information System (EDIS) datasets. These datasets allow for analyses of trends in hospital admissions and the use of hospital services in the ACT.

More specifically, the APC dataset records all inpatient hospital separations (where an inpatient is discharged from hospital or is transferred to a different unit) within the ACT and collects admission details, diagnosis (reason for admission), the procedures undertaken during the patient's hospital stay, as well as discharge and other administrative details. Public hospital APC data are recorded in terms of episodes of care, which are recorded when the patient ends a period of stay in hospital (e.g. by discharge, transfer or death), or becomes a different 'type' of patient within the same period of stay. For private hospitals, each APC record represents a completed hospital stay. APC data are based on the date of separation (discharge) from hospital.

The EDIS dataset records all ACT emergency department presentations and includes reason for attendance. The purpose of this dataset is to assist clinicians in the management of patients, and enables comparisons of outcomes in respect to access to services, quality clinical outcomes, patient management, customer satisfaction, and cost effectiveness. Each record in the EDIS represents a single presentation to the emergency department at either the Canberra Public Hospital or the Calvary Public Hospital.

Health of children and youth

The Epidemiology Section administers two survey datasets of the young ACT resident population – the ACT Year 6 Physical Activity and Nutrition Survey (ACTPANS), and the Australian Secondary School Alcohol and Drug survey (ASSAD).

Since 2006, ACTPANS has been conducted every three years in primary schools within the ACT, where a sample of Year 6 students completes a questionnaire on a range of topics such as their physical activity, dietary, and lifestyle behaviours. In addition, physical measurements of height and weight are undertaken to calculate Body Mass Index (BMI). ACTPANS allows ACT Health to report against national guidelines on fruit and vegetable consumption, physical activity, and electronic screen time. It also provides important indicators for weight status, participation in active travel, organised sport and consumption of healthy and discretionary foods.

The ASSAD survey focuses on students aged between 12 and 17 years in a sample of ACT secondary schools every three years. Students complete a survey on their attitudes to, and use of, tobacco, alcohol and illicit drugs, as well as other health related behaviours such as physical activity, screen time, and diet. It is part of a national survey conducted every three years, and the national results are reported to the National Drug Strategy. The survey is funded by the Cancer Council Victoria Centre for Behavioural Research in Cancer, State and Territory health departments, State and Territory cancer councils, and the Australian Government Department of Health. It is coordinated nationally by the Cancer Council Victoria with each of the States and Territories managing the survey within their own jurisdiction. The Section has had access to ACT data produced from this report since it began in 1996.

General Health

The ACT General Health Survey (ACTGHS), is one of the main instruments with which ACT Health monitors population health indicators. It is conducted as a computer assisted telephone interviewing (CATI) survey. The Survey has been administered by the NSW Ministry of Health since 2007. A third party, McNair Ingenuity, collected the data for the Survey in 2015 and 2016. The Survey covers all residents of the ACT living in private households, and in 2012 mobile phones were incorporated into the survey sample. Its objectives are to:

- monitor changes over time in self-reported health behaviours, health status, health service use, satisfaction with health services, and other factors that influence health;
- support the planning, implementation, and evaluation of health services;
- collect health information that is not available from other sources;
- be responsive to emerging needs for health information; and
- promote research.

Other publicly available data

In order to maximise the effectiveness and usefulness of the data maintained by ACT Health, internal data is complemented by other sources to provide completeness and allow for further analysis. Primarily, this involves use of data collected by the Australian Bureau of Statistics (including the results of the Australian Health Survey), the Australian Institute of Health and Welfare, and the Australian Department of Health. For example, measured Body Mass Index (BMI) can be used from the Australian Health Survey to complement the self-reported BMI in the ACT General Health Survey.

Conclusion

Data maintained or accessed by HIB are mainly used for the Chief Health Officer's report,[7] other external reports[8], the *HealthStats ACT* website, internal policy briefs or reports, and data requests from external researchers. The release of data related to any of the datasets maintained or accessible by HIB is subject to internal standard operating procedures, ACT Health Human Research Ethics Committee approval (where required), data custodian approval, and must comply with the requirements of the ACT Health Data Release Policy 2007. For more information, email healthinfo@act.gov.au

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A roadmap of health datasets *(continued)*

DATASET	ESTABLISHED	DESCRIPTION	DATA CUSTODIAN	VARIABLE EXAMPLES	Included in CHeReL
ACT Cancer Registry	1994	Legislated data collection of cancer diagnoses in the ACT.	Chief Health Officer, ACT Health	Clinical details about the cancer, information about the notifying institution and doctor.	Yes
ACT Maternal Perinatal Data Collection	1997	Population based surveillance system covering all births in the ACT public hospitals and homebirths	Chief Health Officer, ACT Health	Details on mother, hospital of birth, smoking during pregnancy, details about the labour and delivery, details about the baby e.g. weight.	Yes
ACT General Health Survey	2005	Computer assisted telephone survey to monitor population health issues in the ACT	Chief Health Officer, ACT Health	Health status, health behaviours, health services use, satisfaction with health services.	No*
The Australian Secondary Schools Alcohol and Drug Survey	1996	Survey of students aged 12 and 17 in the ACT on their attitudes and use of tobacco, alcohol and illicit drugs	Chief Health Officer, ACT Health	Smoking status, use of screen-based equipment, amount of exercise.	No*
ACT Physical Activity and Nutrition Survey	2006	A survey of a sample of Year 6 students on a range of topics such as physical activity, dietary and lifestyle behaviours.	Chief Health Officer, ACT Health	School type, attitude to physical activity, daily serves of fruit and vegetables, usual consumption of fast food.	No*
Notifiable Diseases Management System	Early 1990's	A collection of records of notifiable diseases.	Chief Health Officer, ACT Health	Disease name, type name, diagnosis method, recorded date, specimen date, hospitalised	Yes
Cause of Death Unit Record File	2006	Coded cause of death data	Chief Health Officer, ACT Health as Delegate Deputy Registrar General (from ACT Births, Deaths and Marriages)	Cause of death	Yes
Admitted Patient Care	2004/5	A record of all inpatient separations (discharges, transfers and deaths) from all public hospitals in the ACT.	Chief Executive Officer, Calvary Health Care; Director-General, Canberra Hospital	Hospital, date of admission, length of stay, diagnosis, procedures, insurance status, separation mode.	Yes
Emergency Department Information System	2000	A record of all ACT emergency department presentations.	Chief Executive Officer, Calvary Health Care; Director-General, Canberra Hospital	Hospital identifier, arrival details, type of visit, diagnosis, departure details.	Available from 2005
ACT Cervical Screening Register	1995	A central and confidential list of ACT women's Pap test results. Women have a choice as to whether their results are stored on the register.	Chief Health Officer, ACT Health	Name, date of birth, postal address, date of test, cytology, histology, HPV test results, practitioner details, follow-up details and Aboriginal Torres Strait Islander status.	No

Table 1. Population health datasets in use by Health Improvement Branch

***Anonymous data collection and therefore unable to be linked**

Looking at the feasibility of adding clinical data to the population-based ACT Cancer Registry: where are we up to?

Elizabeth Chalker, Epidemiology Section and Dr Sonia McCarthy, Office of the Chief Health Officer, Population Health Protection & Prevention

Background

State and territory cancer registries in Australia currently collect information on cancer incidence and mortality for the purposes of monitoring population-level trends, evaluating cancer control and screening programs, and providing information for prevention and healthcare service planning. This is only part of the story though. In order to better assess differences in outcomes, there is a need to collect clinical information, particularly on the stage of the cancer at the time of diagnosis, treatment and cancer recurrence.[1] There is presently a strong focus in Australia to supplement population-based registries with this clinical data.

Cancer Australia's Stage, Treatment and Recurrence (STaR) Project

Cancer Australia, in collaboration with all Australian state and territory cancer registries, is undertaking a multi-phased Stage, Treatment and Recurrence (STaR) Project to collect, collate and report this data at the national level. This will enhance our understanding of:

- Variability in cancer stage at diagnosis across tumour types, population groups and geographical locations;
- Treatments received compared to best-practice care recommendations; and
- Patterns of cancer recurrence.[1]

It is expected that this will contribute to improved outcomes for Australians with cancer.

So far, Cancer Australia has worked with Cancer Council Victoria to develop business rules to derive TNM (Tumour, Node and Metastasis) stage at diagnosis for the top five incident cancers (prostate, breast, lung, bowel, melanoma) from data sources already held by population-based registries. Cancer Australia has also worked with the Cancer Council Queensland to develop business rules for the derivation of stage at diagnosis for paediatric cancers. It is hoped that this stage at diagnosis data will be incorporated into a national database in the future through the Australian Institute of Health and Welfare which currently manages the Australian Cancer Database.[1]

Cancer Australia is currently working to develop a core Cancer Clinical Treatment Dataset through linkage to existing data sources such as the Medical Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS) and national hospitalisation databases.[1]

Where are we up to in the ACT?

The ACT is currently developing a proof of concept for enhancement of the ACT Cancer Registry (ACTCR), to include clinical data collection. This is an extensive process involving literature reviews (to compare international examples) as well as consultations with existing clinical cancer registries in Australia and other key stakeholders, including clinicians.

Potential benefits of incorporating clinical data into the ACTCR include:

- the ability to analyse cancer treatment and outcomes in different population groups for selected cancers in the ACT;
- providing information to healthcare providers and government on the variance in treatments and outcomes for different cancers; and
- the ability to improve quality healthcare by encouraging best practice and consistency in treatment, as well as to enable improved outcomes across providers.

It is anticipated that by the end of the project, a comprehensive mapping of the legislative, notification and infrastructure environment will be available, along with issues for consideration when developing a clinical reporting framework for the ACTCR. The findings will also be used to inform future policy decisions about the ACTCR.

Collaboration with Cancer Institute NSW

The ACTCR and Cancer Institute NSW (CINSW) have benefitted from a close working relationship. Data for the ACTCR is coded alongside NSW Cancer Registry (NSWCR) data by CINSW, under a Services Agreement.

The NSWCR is the first population-based Australian cancer registry to begin including data on stage, treatment and quality of care.[2] Although the ACT context is different to NSW, relevant lessons learned from NSWCR will be applied. Discussions with NSWCR, along with a site visit, have enabled ACTCR staff to better understand the processes involved in the collection of clinical data.

Ideally, clinical data collection for the ACT would be undertaken by CINSW under a new Services Agreement. This is particularly important as the ACT is an island within NSW and there are many cross-border issues associated with ACT patients who are treated in NSW and vice versa. These cross-border issues could be easily managed by having all the NSW and ACT coding done by CINSW.

The shared experience and continued close collaboration will be an advantage for both cancer registries and the information obtained is likely to result in improved cancer treatment outcomes for patients.

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Case Study

Linking data for better outcomes

Leah Newman, Epidemiology Section, Population Health Protection & Prevention

Introduction

The Data Linkage Unit in the Epidemiology Section of Population Health Prevention & Protection of ACT Health provides a data linkage service to research and government organisations. It is a partner with the Centre for Health Record Linkage (CHeReL) which provides the infrastructure to conduct data linkage. The ACT Data Linkage Unit has a program of data linkage projects.

This article describes two current collaborative projects that will provide new information on health service utilisation, treatments and patient outcomes. These data linkage projects also assist in identifying inequities and opportunities for improvement in health services and population health outcomes in the ACT.

Cancer Performance Outcomes Data Linkage Project NSW and ACT

ACT Health is collaborating with the Cancer Institute New South Wales (CINSW) on the Cancer Performance Outcomes Data Linkage Project. The project aims to:

- Further develop a program of health system performance reporting against quality and outcome indicators for health service performance and planning for the NSW and ACT Cancer Registry Program;
- Investigate, monitor and evaluate outcomes of healthcare for people with cancer;
- Determine patterns of care particularly where emergency departments and hospitals have been utilised;
- Monitor patterns of care for people treated for cancer in NSW and the ACT; and
- Evaluate the impact of patient, disease, treatment and socio-demographic factors on cancer incidence and outcomes.

The project will link the records of people diagnosed with cancer from the ACT and NSW Cancer Registries with hospital and death records. The linkage to hospital records will provide information on emergency department visits and admissions for cancer surgery and care. The death records will provide information about the people with cancer who die and their cause of death.

Cancer registry records will also be linked to the notifiable conditions data collection to investigate the association between hepatitis B and C and liver cancer, and to cervical and breast cancer screening programs to investigate screening practices and behaviours, and outcomes. Part of the project involves assessing the feasibility of linking cancer cases to the Medicare Benefits Scheme (MBS) and Pharmaceutical Benefits Schemes (PBS) to access information on radiotherapy and systemic therapies.

The linkage of the cancer registry records to ACT and NSW hospital and death records will be conducted at CHeReL. Linkages with the MBS, PBS and the National Death Index (NDI) will be conducted at the Australian Institute of Health and Welfare's (AIHW) Data Linkage Unit. At the time of writing, this project was awaiting results of the linkage by CHeReL.

CHeReL and the AIHW Data Linkage Unit comply with privacy legislation and operate according to privacy preserving principles and best practices for data management and governance. The AIHW Data Linkage Unit is an Accredited Integrating Authority for linkage of Commonwealth data. The project has appropriate approvals from relevant Human Research Ethics Committees and data custodians.

The analysis will provide evidence for the ACT on the following:

- cross-border utilisation of health services between ACT and NSW and patient outcomes;
- patterns of care for people with cancer covering diagnosis, treatment and outcomes by cancer type, health care type and patient characteristics;
- diagnosis and treatment compliance against clinical guidelines;
- outcomes for people who have a diagnosis of hepatitis B or C and a subsequent diagnosis of liver cancer; and
- outcomes for screening verses non-screening detected cancers.

The results will provide opportunities to improve cancer services, as well as cancer control programs and policy for people in the ACT and patients from NSW who access ACT health services. The findings are expected to be available in the next two years.

Acknowledgements

Cancer Institute NSW

Bureau of Health Information NSW

Better Cardiac Care Collaborative Data Linkage Project for NSW and the ACT

Aboriginal and Torres Strait Islander Peoples have higher rates of cardiac conditions, and poorer access to health services that prevent and treat cardiac conditions than other Australians.[1] It also had been reported that, among Aboriginal and Torres Strait Islander Peoples, circulatory disease accounts for 17 percent of the burden of disease and 25 percent of mortality.[2]

The Better Cardiac Care collaborative data linkage project between NSW and the ACT (and Queensland) will provide new information that will assist in 'closing the gap' on mortality and morbidity from cardiac conditions in Aboriginal and Torres Strait Islander Peoples.

The project objectives are to:

- provide information on primary and secondary preventive care activities, access to services, and referral patterns;
- determine the effectiveness of the proposed data in understanding processes of care and identifying differentials in care provision; and
- explore opportunities to enhance and develop the agreed national measures for the Australian Health Ministers' Advisory Council (AHMAC) as part of the Better Cardiac Care for Aboriginal and Torres Strait Islander Peoples project.

Linking data for better outcomes *(continued)*

Study questions:

1. Do Aboriginal and Torres Strait Islander Peoples receive appropriate and equitable rates of multidisciplinary chronic disease service compared to other Australians?
2. Is there equity in access to cardiac revascularisation procedures for Aboriginal and Torres Strait Islander Peoples compared to other Australians?
3. Is there equity in access to specialist diagnostic procedures and specialist physician review for Aboriginal and Torres Strait Islander Peoples compared to other Australians?
4. Do Aboriginal and Torres Strait Islander Peoples receive appropriate and equitable rates of primary health care and specialist physician follow-up after discharge from hospital compared to other Australians?

The project intends to link people with cardiac conditions, including acute rhematic fever to hospital admitted patient care (APC) and emergency department (ED) data collections, to death registrations and to relevant items claimed through the Medicare Benefit Scheme (MBS). Without linkage each of these data collections can only be analysed separately. Completion of linkage enables patients with cardiac diseases to be followed from diagnosis and treatment, through to their health outcomes. This enables the analysis of patterns of care.

The project provides an opportunity for the ACT to improve its completeness of Aboriginal and Torres Strait Islander Peoples identification in its study cohort (for the purposes of this project) by having NSW's Enhanced Reporting of Aboriginality (ERA) algorithm[3] applied to the ACT datasets using data linkage techniques. This would assist in more accurate reporting of the experience of cardiac disease care among this population in the ACT.

CHeReL will conduct the linkage of jurisdictional hospital and death records, and the AIHW Data Linkage Unit will link patients to the relevant MBS items. At the time of writing, the linkage was being completed and the resulting datasets were expected to soon be made available for analysis by authorised project investigators through the Secure Unified Research Environment at the Sax Institute.

The project will have an Aboriginal Advisory Group that will provide advice on the data analysis to be undertaken, contribute to the interpretation of results, and provide advice on practice and policy implications, as well as publication and dissemination of findings.

The analysis will compare access, treatment and outcomes for Aboriginal and Torres Strait Islander Peoples with cardiac conditions with other people in the ACT and NSW. The findings, which will be interpreted through engagement with stakeholders, may improve local health service delivery for cardiac disease, identify differences in access, and may improve the coordination of care between primary and specialist service providers, as well as the quality and safety of that care.

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ACT Health and the Australian National University collaborate to address chronic disease

Prof. Kaarin J. Anstey & Dr. Kimberly Ashby-Mitchell, Centre for Research on Ageing, Health and Wellbeing, The Australian National University

ACT Health and the Australian National University (ANU) have entered into a new partnership agreement where they will be focusing on addressing chronic disease. This collaboration builds on a long-term relationship between the Epidemiology Section and the Centre for Research on Ageing, Health and Wellbeing (CRAHW). As part of the present initiative, two projects are in train. The first examines the prevalence of chronic disease and patterns of comorbidity using data from the CRAHW-administered Personality and Total Health Through Life Project. The second project seeks to examine the health impacts of vulnerability.

Outputs of these projects include the joint development of published materials for use by the general public, policymakers and scientists. In addition, joint seminars will be conducted for ACT Health staff, researchers and students at the Research School of Population Health, ANU.

In February 2016, the Epidemiology Section in Population Health Protection & Prevention, ACT Health and the Centre for Research on Ageing, Health and Wellbeing (CRAWH) based at the Australian National University (ANU) began working on two joint projects. These projects build on a long-term collaboration between the two groups.

Having developed a joint report based on results of the Personality and Total Health through Life Project[1] (PATH) in 2011, and the subsequent completion of the Translating Research into Practice – Dementia and Population Health (TRIP-DPH) project this year, both parties were keen to collaborate further. The availability of PATH data (developed and administered by CRAHW) presented an opportunity to do so. PATH has collected data from ACT and Queanbeyan (in New South Wales) residents for over 12 years including information on health risk factors, chronic disease and health service use. Queanbeyan was included at the study inception in 1999 to provide a broader representation of the Australian population. (further details about PATH are presented in Box 1 below).

Information available from PATH, particularly relating to chronic disease and the socio-economic determinants of health, are useful to policymakers as they not only identify longitudinal trends in disease and service use but also help to determine the implications of these on prevention and management approaches, clinical practice and policy development.

Project 1: Examining patterns of comorbidity in the ACT and Queanbeyan

This first project focuses on older adults (aged 60 years and over) who participated in baseline PATH data collection and its aims are three-fold. Firstly, we aim to examine prevalence of key risk factors for chronic diseases of interest to ACT Health (heart disease, cancer, arthritis, cataracts, asthma, diabetes mellitus, stroke, hypertension, depression, anxiety, overweight/obesity and cognitive impairment). Secondly, we seek to examine patterns of comorbidity. Finally, we want to examine this prevalence and disease pattern data within the context of age, gender and socio-economic group.

Image: Older adults. FreeDigitalPhotos.net

This work is important since chronic disease and comorbidity in Australia is reportedly high,[2] presents challenges to health service provision,[3] and there is a need to better evaluate chronic disease status in the ACT and the effectiveness of past and present strategies for managing patients with comorbidities. Preliminary findings of this research are presented in Box 2 on page 14.

Box 1: The Personality and Total Health through Life Project (PATH)

The PATH Through Life project is a 20 year longitudinal cohort study of 7,485 young (aged 20–24 at baseline), midlife (aged 40–44 at baseline) and older (aged 60–64 at baseline) adults randomly sampled from the electoral roll of the Australian Capital Territory and the nearby city of Queanbeyan.

The original aims of the project are outlined below:

- To delineate the course of depression, anxiety, substance use and cognitive ability with increasing age across the adult life span;
- To identify environmental risk, genetic risk and protective factors influencing individual differences in the course of these characteristics; and
- To investigate interrelationships over time between the three domains of: depression and anxiety, substance use, and cognitive ability and dementia.

Several design features of the PATH project contribute to its unique standing among population based longitudinal cohort studies:

- Obtaining measures of genetic, biological (including Magnetic Resonance Imaging), psychosocial and lifestyle risk and protective factors for mental health and wellbeing;
- Use of a narrow age cohort design with longitudinal follow ups as an optimal means of separating age and cohort effects;
- Assessment of participants across the full adult lifespan, permitting investigation of developmentally significant, but understudied periods such as midlife; and
- Recruitment and follow up of a population ranging from early to late adulthood, providing important pre-clinical data for studying the development of age related changes in memory and cognition.

ACT Health and the Australian National University collaborate to address chronic disease *(continued)*

Box 2: Preliminary findings of Project 1 – Examining patterns of comorbidity in the ACT and Queanbeyan among adults ≥60 years

- The majority of the sample (aged 60 years and over) was recorded as having two or more diseases (93.0 percent);
- Overall, the highest disease prevalence was recorded for arthritis (35.6 percent), hypertension (63.6 percent), overweight/obesity (67.5 percent) and cognitive impairment (23.9 percent);
- Several chronic diseases were found to occur together. As such, several distinct disease patterns including a 'Psychological', 'Metabolic', 'Vascular and neurodegenerative' and 'Inflammatory' disease pattern were identified.

Project 2: Joint Development of a Partnership Protocol for studying health impacts of vulnerability

The second project focuses on vulnerable groups in the ACT and methods of recruitment for PATH sample follow-up. Vulnerability can result from low socio-economic status, social isolation, physical disability, cognitive impairment, mental disorder or a combination of factors that reduce the capacity to access services and increase the risk of poor health outcomes and hospitalization. This project is significant since, unlike most other jurisdictions, the ACT has been purposely designed to reduce area disadvantage through relatively equal distribution of public housing and other community services targeting low income groups across the region. As a consequence, census and administrative data based on area significantly underestimates the prevalence of socio-economic disadvantage in the ACT.[4] This lack of accurate data on disadvantage has implications for health service planning that effectively targets such groups, particularly for older residents who are the greatest consumers of health care and represent a growing sector.[5]

Image: Older adults. FreeDigitalPhotos.net

Where to from here?

The findings of PATH studies are regularly published in scientific journals and these can provide useful information for policymakers and other health professionals. In addition, through collaboration with ACT Health, there are now mechanisms in place to promote the dissemination of PATH scientific findings to those who may benefit. A comprehensive list of papers published using PATH research is available online at http://crahw.anu.edu.au/research/publications.

As part of these current initiatives, Dr. Kimberly Ashby-Mitchell, a Postdoctoral Fellow at CRAHW has been based at the Epidemiology Section one day per week. She is supervised by Dr. Hai Phung (Senior Manager, Epidemiology Section) and Professor Kaarin Anstey (Director of CRAHW, ANU). An advisory group consisting of representatives from other units including Health Promotion and the Australian Bureau of Statistics has also been convened since the issues being addressed require a multi-factorial approach.

Outputs of these projects include contributing to the development of ACT Health 'Focus On' publications which highlight health issues, scientific manuscripts for journal submission, development of an NHMRC Partnership grant, and the organisation of a series of research seminars by Dr. Kim Kieley, a Postdoctoral fellow based at CRAHW. These seminars will be held for ACT Health staff, researchers and students at the Research School of Population Health, ANU.

Further plans are also being discussed for additional projects involving the ACT Health Epidemiology and Health Promotion Sections and CRAHW. This partnership will benefit ACT Health through access to study samples, infrastructure and expertise, and benefit the ANU through research activities with high policy impact and translational capacity.

CENTRE FOR RESEARCH ON AGEING, HEALTH AND WELLBEING (CRAHW)

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Using multiple data sources for population health outcomes: the influence of neighbourhood on hospital admission rates for non-communicable diseases in the Australian Capital Territory

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This article demonstrates the use of population health data in its spatial form. By mapping hospitalisation rates and overlaying built environment features, this analysis allows the researcher to explore geographical clusters of hospitalisations and determine any associations between high or low areas of hospitalisations and potential neighbourhood effects. This study highlights research from a working paper developed by the Centre for Research and Action in Public Health at the University of Canberra investigating the relationship of the built environment on health outcomes such as hospital admissions from NCDs in addition to health behaviours.[1]

Introduction

The recent Australian Burden of Disease Study demonstrates unequivocally the dominance of non-communicable diseases (NCDs) in the overall burden of disease in Australia.[2] However, understanding the underlying factors contributing to this burden or where best local governments should allocate limited resources to alleviate these health problems remains to be fully understood. There is a need for a better understanding of the local or 'neighbourhood' factors that contribute to lifestyle behaviours that may be beneficial or harmful to future health. Most Canberrans enjoy a relatively high standard of living. However, as noted in the Chief Health Officer's Report 2014, an estimated 18.4 percent of the population in 2011-12 had a disease of the circulatory system, compared with 16.9 percent for Australia as a whole.[3] Additionally, disparities in health exist between geographical areas, sometimes in very close proximity as small pockets of 'disadvantage' hidden within 'advantaged' areas.[4] It is well recognised that residents of neighbourhoods that: have good access to local services and amenities; are designed and built to encourage regular physical activity; have residential density that supports public transport services and mixed land use; preserve and protect the natural environment; and are socially connected, are likely to enjoy good health.[5,6,7]

In this article we describe an example of how population heath data from multiple sources can be used to support an ecological study of the relationship between hospitalisation for NCDs and selected neighbourhood factors.

The study of neighbourhood and hospitalisation of non-communicable diseases

The study examined lifestyle-related NCD hospital admission data including circulatory diseases; endocrine, nutritional and metabolic disorders; respiratory diseases and selected cancers. The study aimed to understand whether types of NCD hospitalisations were concentrated in particular geographic areas (i.e. areas of high rates of NCDs or NCD hot spots) or other consistent hospitalisation clustering patterns across suburbs of Canberra could be discerned.

Methods

In this study, multiple data sources were used. Hospital admission data were used for four NCDs that are among the chronic conditions contributing the greatest burden to hospital costs in ACT and Australia.[8] The hospitalisation data, including demographics, were combined with indicators of health-related behaviours and measures of the built environment to allow for further exploratory mapping within small areas with statistical modelling undertaken to detect potential neighbourhood effects on health outcomes.

Population Health Data

Public hospital admissions covering the period between 1 January 2007 and 31 December 2013 from the ACT Admitted Patient Care data collection (APC) were included for the International Classification of Diseases (ICD10) chapters on selected cancers, endocrine, nutritional and metabolic (ENM) diseases, diseases of circulatory system (with a subset of myocardial infarction) and all diseases of the respiratory system. Rates of hospitalisation per 100 000 population were mapped by suburb of residence of person hospitalised. Other population health data included in the study was ACT General Health Survey data on the health risk behaviour for the ACT population.

Spatial Data

A range of indicators of the built environment were developed based on spatial data obtained from the ACT Government using Geographical Information Systems software. Indicators developed included: street connectivity, population density, residential density, land use mix, traffic volume exposure, access to off license alcohol outlets and GP clinic density. Walk Score®, a planning metric and validated measure of walkability was obtained for suburbs of Canberra.[9]

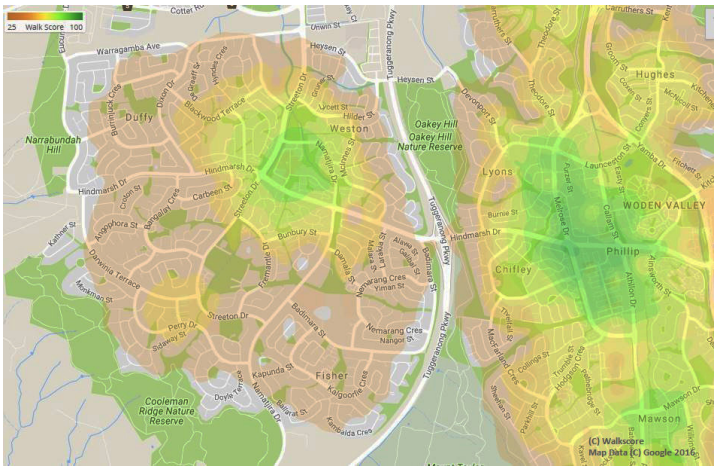

Figure 1. Walk score heat map showing contrast across suburbs. The suburb of Phillip has a walk score of 85 indicating good walkable access to local destinations. Weston is considered somewhat walkable with a score of 50, whereas Duffy has a walk score of 34 indicating most destinations require a car.

Data analysis and modelling

Two major types of analysis were undertaken for this study:

1. spatial cluster analysis of variation in rates of hospital admissions using SaTScan™ software.[10] This analysis allows the risk of hospitalisation for that geographical area to be determined relative to the risk in the rest of the ACT.
2. multilevel modelling of hospital admissions using indicators of the built environment characteristics at suburb level (or below in some instances) and individual level demographic variables age, sex and health insurance status.

This research was approved by the ACT Health Human Research Ethics Committee (Ref.: ETH.11.14.310) following approval by the University of Canberra Human Research Ethics Committee (Ref.: 13-112).

Using multiple data sources for population health outcomes: the influence of neighbourhood on hospital admission rates for non-communicable diseases in the Australian Capital Territory *(continued)*

Results

Analysis of spatial variation of hospital admissions across ACT

There was good quality evidence of significant spatial variation in rates of NCD-related hospitalisations across the ACT. The following general patterns of hospitalisation rates were observed:

- Circulatory diseases – significantly lower than the ACT age and gender standardised average in inner suburbs and higher in the outer suburbs;
- Endocrine, nutrition and metabolic diseases – broadly similar to circulatory diseases, though less marked;
- Respiratory diseases – broadly similar to circulatory diseases but different in detail of locations of the clusters;
- Primary myocardial infarction – showed three clusters with significantly higher rates and five clusters with significantly lower rates.
- Neoplasms –spatial patterns across small regions suggest risks may vary at suburb level.

The incidences of hospitalisations for circulatory and respiratory-disease-related events were such that significant differences in sex and age-adjusted rates could be detected using small areas (Statistical Area 1, or SA1).

Analysis of hospital admissions with built environment characteristics.

Walk Score®, traffic exposure and Index of Relative Socioeconomic Advantage and Disadvantage (IRSAD) were significantly correlated with NCD-related hospitalisations.

Assessment of available data sources

The ACT General Health Survey, whilst providing an adequate snapshot of the ACT for national reporting, lacked the precision required for the sub-regional level analyses conducted here.

Data ACT, an open data initiative launched in late 2012, enables the public to access a range of spatial and non-spatial data. The ACT data portal requires regular maintenance and updates in order to be an effective method of providing spatial data to the public. For this project the majority of spatial data could not be sourced directly from the portal either because data were out-of-date or unavailable. Thus for this study spatial data were obtained directly from ACT Directorates with the first point of contact being the Access Canberra website. Key to effective provision of spatial data to the public, the ACT data portal requires a transparent approach to data, detailing what data is available for access, even if at a particular point in time it is not available for download, or a cost is associated with its extraction. Furthermore, there is still considerable potential for owners of non-spatial data to assign spatial attributes. This would increase the potential for spatial analysis and allow further insights to be gained from routinely collected data.

Conclusions

Maximising the use of routinely collected datasets both within the health sector and beyond with advanced statistical and research methodology can help translate research into healthier policy and practice.

Local health interventions that engage sectors outside of health particularly in areas of environment, planning and transportation are critical to creating active, healthy neighbourhoods that encourage and support healthy lifestyle behaviours. This study demonstrates that routinely collected administrative data can be used to improve local population surveillance and monitoring. This can advance our understanding of health disparities within smaller areas, however opportunities still remain for using small area data to improve targeting of health interventions.

Acknowledgements

We would like to thank the ACT Health Directorate for funding this research and providing both the ACT General Health Survey data and the hospitalisation data from the ACT Admitted Patients Data Collection. We are grateful to both the Health Improvement Branch and Epidemiology Section for providing expert advice during the course of this research project. Spatial data were sourced from a variety of ACT Government Directorates (including Environment and Planning, Territory and Municipal Services and Justice and Community Safety) and we are very grateful for Directorate staff assistance with regards to data access and technical advice which made this research project possible.

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The Chief Health Officer's Report 2016 – knowledge translation in action

Deborah Schaler, Louise Freebairn, Paula Sutton and Dr Alison Oakleigh, Epidemiology Section, Population Health Prevention & Protection

The ACT Chief Health Officer's Report (CHO Report) is published every two years as a requirement of the *Public Health Act 1997*. The report provides an account of the health and wellbeing of the ACT population and covers a range of topics including potential public health risks, trends and indicators in health status, morbidity and mortality, harm minimisation activities and notifiable conditions.

The population health data and the information reported provide a vital platform for looking forward and anticipating future health challenges and opportunities. The target audience for the report is very broad and includes policy makers both inside and outside government, health service planners, and health researchers. It is intended that provision of local population health data and interpretation of population health trends will provide an evidence base to inform policy and service planning decisions aimed at improving the health and wellbeing of the Canberra community.

Evidence informed policy decisions are essential to ensure that health policies, intervention programs and service plans are likely to be effective and offer value for money. However barriers to the use of evidence to inform decision making remain[1] and the use of published research to inform policy development is often limited.[2] To address this, evidence provided to policy makers needs to be in a form that is useful to them.[3,4,5]

Policy makers require synthesised and localised data that:

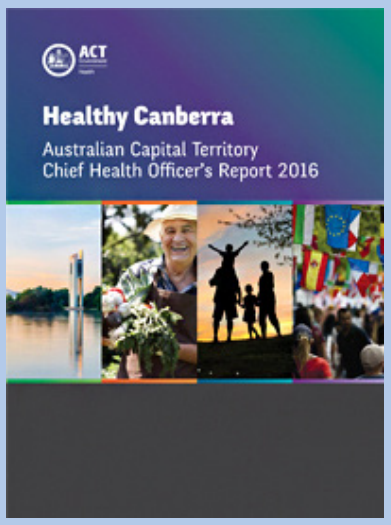
- contrasts and prioritises policy options
- demonstrates effectiveness of interventions, the need for a policy response, and the cost effectiveness of actions
- reflects the level of public support for a particular issue; and
- personalises the problem.[5, 6]

The information presented to policy makers also needs to be accessible in terms of readability and this can be a challenge when presenting information derived from complex data which is often presented in scientific report format.

The Health Outcomes & Knowledge Translation team in the Epidemiology Section of Population Health Protection & Prevention was formed with the intent to use a range of knowledge translation strategies to improve health outcomes rather than simply reporting health data. The term knowledge translation is used to refer to a range of active approaches deployed to encourage the creation and sharing of research-informed knowledge.[7] The number of terms used to describe knowledge translation activities is large[8] and have been widely debated. These terms include knowledge mobilisation, knowledge transfer, knowledge to action, knowledge exchange, knowledge interaction, and so on. This multiplicity of terms can be a barrier to clear communication in this field.[8] The Epidemiology Section has adopted the term Knowledge Translation to refer to our work in this area.

The ACT Chief Health Officer, Dr Paul Kelly, requested that the small team produce a new format and highly accessible CHO Report in 2016 to replace the previous scientific report format. The aim of the new format was to increase the relevance of ACT population health data to health policy and practice. Dr Kelly's brief to the team was that the report should be short, report on a number of priority population health topics, include policy content and analysis, advise on future directions, and report progress against population health targets and indicators where they exist. Drawing on examples that Dr Kelly brought back from his study tour to New York in late 2015, his design brief for the report was to maximise the use of info-graphics and other design features to improve accessibility of the data.

The result was the CHO Report 2016 *Healthy Canberra* which was launched by the then Assistant Minister for Health in June 2016. To cover legislative requirements for the public reporting of a range of population health indicators, the project to produce the new format report had a complementary project to develop a local population health statistics website *HealthStats ACT*. The website was launched at the same time as the *Healthy Canberra* report. See page 19 for more information on *HealthStats ACT.* While the CHO Report is a biennial publication, the data presented on the website are updated regularly thus improving access to timely ACT data by researchers, policy makers, health service planners and the general public.



The Chief Health Officer's Report 2016 – knowledge translation in action *(continued)*

Healthy Canberra was the 20th anniversary edition and the data in the 2016 report were presented in a way which departed significantly from the format used in the previous scientific reports. Information and advice to inform the report was provided by policy makers, health promotion, clinical and other services across ACT Health. *Healthy Canberra* focused on priority health issues that cause the greatest burden of disease, are preventable and are fundamental to good health. Topics were presented under four themed chapters – Healthy City, Healthy Weight, Healthy Lifestyle, and Healthy People – representing the influence of our environment and lifestyle on our health. The report compared some statistics published in the very first report from 20 years ago to show where the ACT has made some significant progress in improving the health of our community (smoking and immunisation rates) along with our challenges (adult obesity and mental health). A further broad picture of Canberra's health was presented as a snapshot of our healthy city.

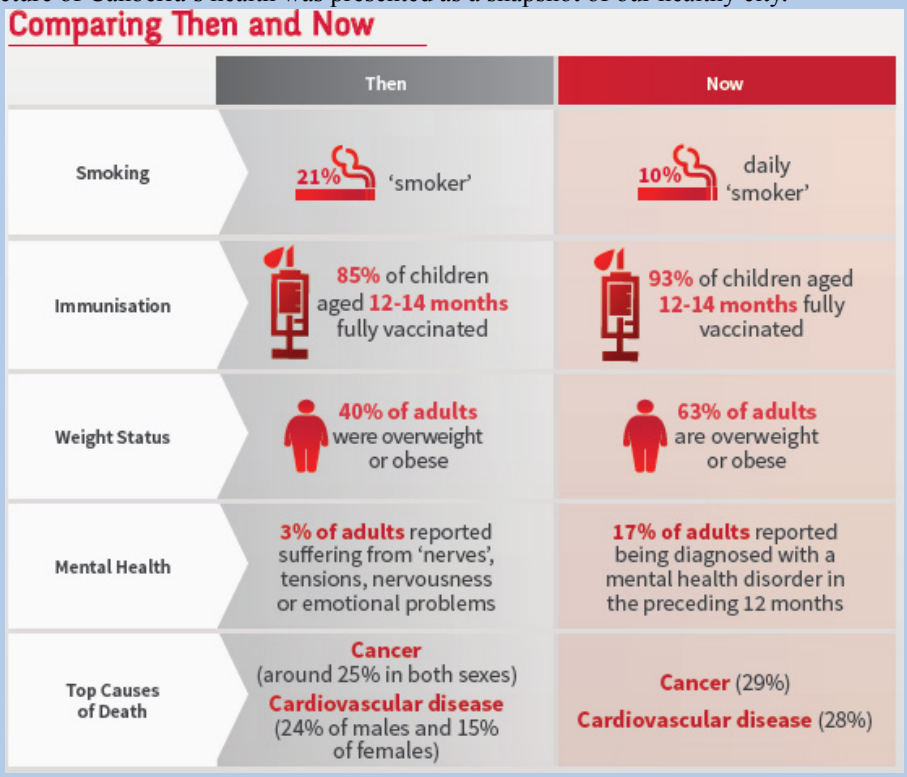


Image: Excerpt from ACT Chief Health Officer's Report 2016

A significant change to previous reports was the inclusion of two new sections Looking to the future – what does the data tell us? and What does this mean? These sections highlighted for policy makers, health service planners and others where we have achieved population health gains but also where the challenges and opportunities lie and the major implications to guide our path toward an even healthier Canberra in future. Trends against health targets were reported where they were available, for example the ACT Government Healthy Weight Initiative targets. Anecdotal feedback on the new report format has been very positive.

In further striving to improve the use of data and other evidence in health policy and practice, the Health Outcomes and Knowledge Translation team is taking on a knowledge brokering role by building or strengthening strategic partnerships across research and policy areas and undertaking collaborative research projects with academic partners. The team is producing new tools to build policy capacity including Focus On (short health topic) reports as part of a broader knowledge translation focus in the Epidemiology Section.

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ACT population health data now showing

Epidemiology Section, Population Health Protection & Prevention

HealthStats ACT has been developed in response to the increasing demand for health-related information to be: in real-time; to include linkages with clinical and community data; to be available to policy makers, planners, clinicians and the public; and for there to be capability for limited online data analysis for the public and clinicians.

There is an expectation of having health data accessible quickly and easily, and increasingly consumers engage in health information seeking via the internet.[1]

HealthStats ACT has been developed by the Epidemiology Section. The Epidemiology Section provides population health monitoring and reporting for the ACT population. *HealthStats ACT* is part of the wider ACT Government DataACT open data initiative, which enables the ACT community to access, explore and build upon datasets in new and innovative ways. *HealthStats ACT* data can be accessed at any time by anyone who is interested in accessing population health information. It works towards transparent and open government utilising digitised data.

HealthStats ACT delivers the most up-to-date information on a broad range of ACT population health topics, ranging from cancer statistics to the number of babies born each year. *HealthStats ACT* presents aggregated data about the health of the population and the website provides information in a number of formats including "Focus on" health topic reports and interactive health indicator presentations utilising the dataACT platform.

By increasing the availability of health data, *HealthStats ACT* supports the use of evidence for decision making on the government priorities of improving people's health outcomes.

HealthStats ACT is available at http://stats.health.act.gov.au/.

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A little introduction to big data

Dr Oscar Yang, Epidemiology Section, Population Health Protection & Prevention

What is big data?

As information technology advances at a remarkable pace, the corresponding growth in data generation is overwhelming. In modern health care, a tremendous amount of digital health information comes from a variety of sources including electronic health records, clinical trials, insurance claims, mobile applications, and social media.[1] As traditional technologies and techniques are inadequate, if not impossible, to store and process large volumes of data, new solutions are required. This has led to the emergence of the concept of big data. Big data is a term that describes the large collection of structured and unstructured data which is beyond the ability of traditional tools to process and analyse. Big data is not only massive in volume but also remarkable in terms of variety, complexity and velocity of real-time data processing.

Why is big data a big deal?

For organisations which have realised the value of increasing amounts of information, insights from big data have enabled them to optimise operations, prevent threats, and reduce costs. In healthcare, big data is being used to predict epidemics, develop prevention strategies, improve diagnosis, and make clinical decisions.[2] With recent advances in data collection and analytic techniques, effective use of big data could help substantially reduce the soaring cost in healthcare and improve care quality.[2] The following are a few examples of how the potential of big data can be realised to improve healthcare.

As individual health information is organised into big data, patterns related to disease development can be detected, leading to better predictive models. If signs of serious problems can be identified at early stages, treatments are simpler and less expensive. Insights gained from integrating data from various sources for patients are increasingly being used to identify patients at high-risk. This is essential for developing prevention strategies that target the right patients and subgroups.[3]

Big data from linking gene sequences, health records, environmental influences and treatment outcomes enhances providers' ability to make precise clinical decisions. Based on knowledge extracted from the large volumes of collected data (linking patients' genetic, clinical and environmental characteristics), many areas of healthcare, such as radiation oncology and cancer care, are moving towards personalised diagnoses and tailored treatments for individual patients.[4]

Another major promise of big data use is to help develop faster, cheaper and more reliable methods for new drug discovery, especially at the molecular identification and validation phases. Advances in chemistry, biology and laboratory automation have led to the creation of large collections of molecules available for drug discovery. In combination with clinical data, gene sequencing and expression data, and protein structure and interaction data, better predictive models can be defined to determine which chemical compounds will be the most promising drug candidate for effective treatment of a variety of diseases.[4] Progress in identification of new genes and biomarkers specific to disease subtypes, combining with an individual's genetic data and environmental information, have also made the design of personalised medicines possible.[5]

Are we ready for the big data revolution?

Big data is so large and complex that traditional data processing applications are inadequate.[2] To benefit from the power of big data, fundamentally new approaches to infrastructure, tools and practices are required. Healthcare data have diverse types and are often maintained in multiple different systems. It is a compelling challenge to extract, link, transform and protect these data for operational need. New kinds of infrastructure and data warehouses are needed to store and process the exponentially growing volume of structured and unstructured data in real-time. To reveal meaningful insights and extract value from big data, advanced analytic techniques (such as artificial intelligence, machine learning and predictive analytics) must be used. It is evident that big data provides us with both opportunities and challenges. For big data initiatives to succeed, the government, leading companies, and research institutions must undergo some fundamental changes and develop the capacities to manage and use big data for maximum benefit to the health of the population.

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Case Study

Statistical modelling in population health research

Dr Oscar Yang, Epidemiology Section, Population Health Protection & Prevention

Introduction

Many population health studies use quantitative methods. Statistics play an important role in all steps of a population health investigation, which may include identifying problems related to health, measuring their magnitude, understanding the key determinants, developing intervention strategies, and evaluating the effect of interventions. There are various factors at different levels influencing population health. To explore the nature, strength and interactions among multiple factors simultaneously, researchers need to use statistical modelling as quantitative thinking tools for theory building and testing. This article briefly describes three applications of statistical modelling commonly used in population health research.

1) Statistical models can provide theoretical frameworks to understand the association between study variables and the outcome, and generate hypotheses for causality

Population health studies seeking to investigate the statistical association between exposures (study variables) and the health outcomes are susceptible to the effects of chance, bias and confounding. Failing to consider these effects at the design and analysis stages can lead researchers to conclude the existence of an association that does in reality not exist or the absence of an association that is actually present. At the data analysis stage, statistical modelling is commonly used to control for multiple confounding factors, which help us make judgements about the separate effects of individual attributes.[1] For example, adjusting for background variables such as age, sex and baseline measures are often required when evaluating the association between the exposures and outcome.

2) Multilevel modelling to handle clustered hierarchical data

Individuals in populations interact with the social contexts to which they belong. In a hierarchical system of individuals nested within social groups, people within particular social groups may share certain properties. This leads to hierarchical data structure with variables characterising individuals and variables characterising groups. The multilevel modelling (also known as hierarchical or mixed-effects modelling) approach provides researchers a framework to incorporate social contexts while attempting to understand the true effects of both individual-level and group-level attributes on the outcome of interest.[2,3] For example, multilevel models can be defined to estimate how personal, area and school characteristics influence the risk of being overweight and obese for school children (Figure1).

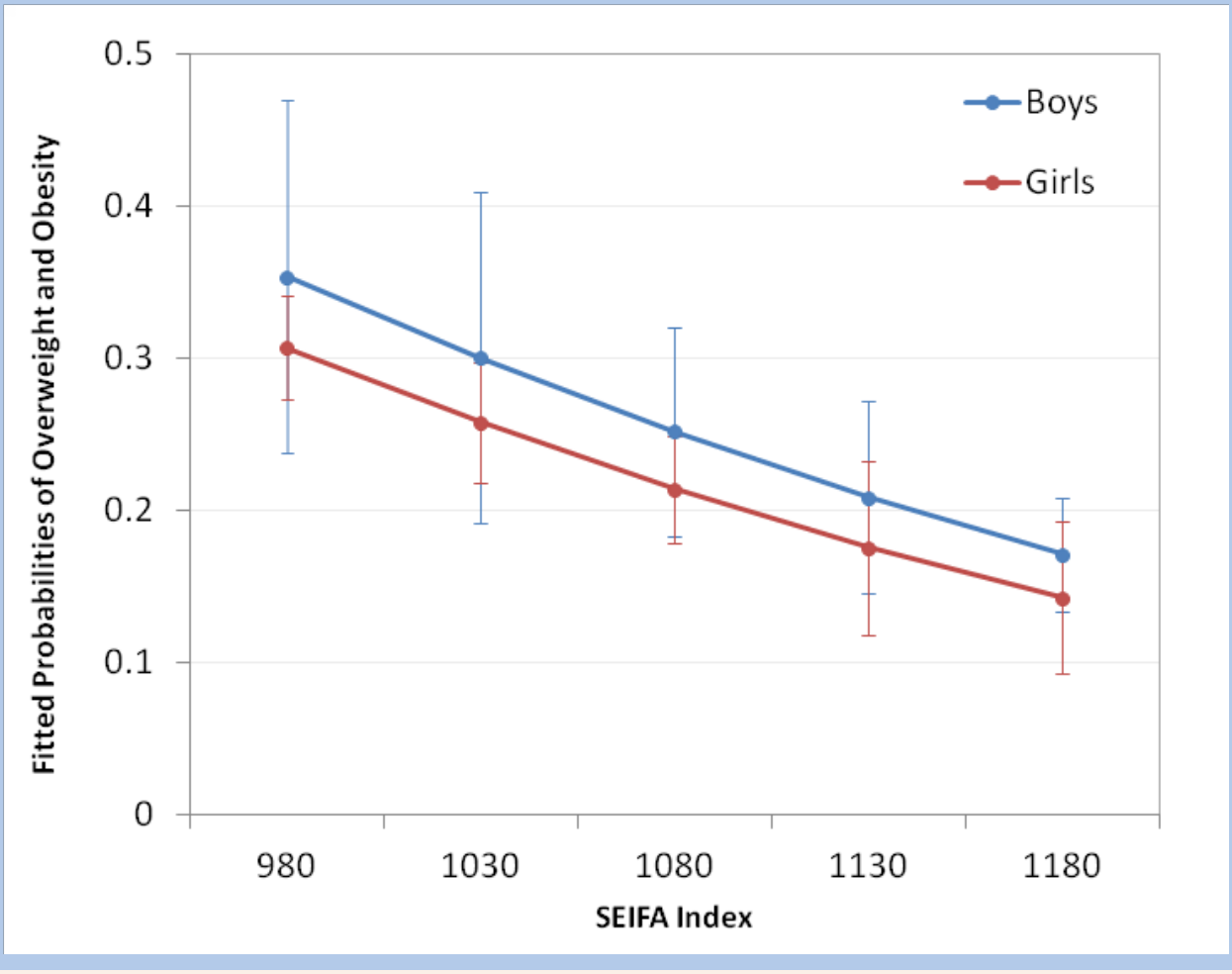

Figure 1. Fitted probability of overweight and obesity in relation to increasing Socio-economic Indexes for Areas (SEIFA) index.

In addition to personal physical activity and nutritional factors, the SEIFA index of the school's suburb is associated with the risk of being overweight and obese for year six children in ACT. The school suburb's SEIFA values can explain a large proportion of the difference among schools in the prevalence of overweight and obesity. Low SEIFA index reflects relative disadvantage in socioeconomic measures. Data Source: ACT Physical Activity and Nutrition Survey (ACTPANS) 2012.

Statistical modelling in population health research

3) Models can be built upon available data from the past in order to predict the future

Predictive modelling is rapidly developing and widely applied in population health. Understanding how trends in the past will unfold in the future helps policy makers to evaluate future priorities and to make planning decisions. For example, using ACT Cancer Registry data from 1984 to 2013, we have conducted a cancer incidence and mortality projection in the ACT for the next 20 years. Projections over the long term require a complex model to incorporate the effect of age, time period, birth cohort, and the extent to which the past trend is likely to continue into the future.[4] In this cancer projection study, incidence trend estimation was performed using an age-period-cohort model, and then the estimated trend was extrapolated out to 2033 and applied to the projected ACT populations (Figure 2). Projections of cancer incidence are important for setting priorities for prevention and planning future health services.

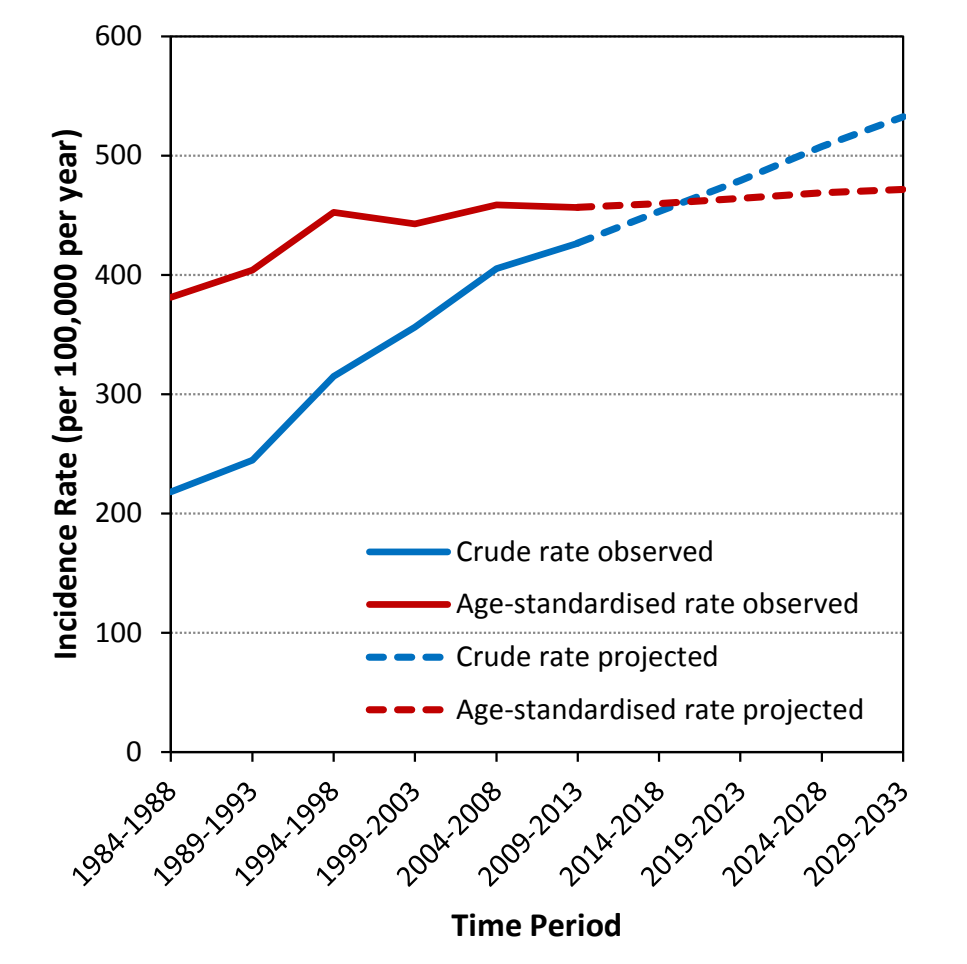

Figure 2. Cancer incidence projection in the ACT up to 2033.

For all cancer combined, the incidence rate in the ACT is expected to reach approximately 530 per 100,000 population per year during the 2029-2033 time period. However the main driver for this increase in incidence rate is the change in age profile of the population. The age standardised incidence rates are likely to remain similar. Data Source: ACT Cancer Registry

Implication Technology and data on statistical modelling

The development of inexpensive, powerful computers and modern statistical software has allowed researchers to perform statistical analysis without the need to understand the very sophisticated mathematics that underlies modern statistics.[5] However, in order to formulate statistical models to answer the questions of interest, researchers need to know how to apply model-building strategies and interpret the results correctly. It is also important to understand that, for each modelling method, there are assumptions that need to be adequately met for the data. Availability of good quality data is one of the major limitations for reliable modelling. Great effort has been made by researchers to improve data availability and usefulness through various data linkage projects. As data quality, quantity and complexity increase, statistical modelling will play an increasingly important role in population health research.

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Future of health surveys in Australia

Dr Margo Barr, Study Director 45 and Up Study, Sax Institute; Dr Hai Phung, Lindy Fritsche, Bridget O'Connor, Epidemiology Section, Population Health Protection & Prevention; Prof. David Steel, National Institute for Applied Statistics Research Australia, University of Wollongong

Household sample surveys designed to monitor health risk behaviours are considered an important component of any health information system. This article covers a brief history of health surveys in Australia and their role in meeting population health needs in the changing world of data. ACT Health is currently undertaking a review of their health information systems to identify data needs, gaps and methodological issues.

Introduction

There is no universal formula for a precise combination of data sources in a health information system necessary for sound public health decision-making. The Health Metrics Network was a global health partnership established in 2005 to develop a framework and standards for countries to deliver timely and accurate health information systems.[1] During the technical discussions underpinning its development, there was consensus that all countries should aspire to a mix of data-generation approaches, which include:

1. A population-wide census every ten years;
2. Continuous monitoring of births and deaths, with certification of cause of death;
3. A surveillance and response system focused on epidemic and vaccine-preventable diseases;
4. A programme of household sample surveys designed to measure use of health care services and important household or individual behaviours;
5. A system of service-generated data derived from facilities and patient–provider interactions covering important variables, such as conditions, care offered, quality of care and treatments administered;
6. Mapping of public health facilities and services at national and district levels;
7. Behavioural surveillance, focusing especially on risk factors such as smoking, unsafe sex and malnutrition;
8. National health accounts i.e. health expenditure data for the country;
9. Financial and management information i.e. how health expenditure is spent;
10. Modelling, estimates and projections; and
11. Health research, including clinical, health systems and operations research.[1]

Although there are large amounts of data generated in health service administration (e.g. hospitalisations) that also includes information on particular diseases and conditions, it is often difficult to use this data for reliable population level estimates of common conditions and risk factors for these conditions.[2,3] This is because people with conditions such as asthma, influenza and diabetes do not always attend a hospital for their condition and therefore hospitalisation data will only reflect the severe spectrum of the condition or disease. Also these administrative data sources do not routinely collect data on relevant health behaviours and/or social determinants of health (e.g. socioeconomic status). Therefore, it is not always possible to reliably use these datasets to examine relationships between diseases of interest, health behaviours and social determinants of health to inform policies and programs to improve the health of the population.[4]

Consequently, a programme of household sample surveys has been historically identified as an important component of any health information system. These surveys are designed to measure use of health care services, important household or individual behaviours and behavioural surveillance, focusing on risk factors such as smoking, unsafe sex and poor nutrition.

Health surveys in Australia

In Australia, household sample surveys are undertaken principally by the Australian Bureau of Statistics (ABS) and the Australian Institute of Health and Welfare at a national level. States and territories also implement Computer Assisted Telephone Interviewing (CATI) health surveys in their respective jurisdictions.

Regular interval health surveys of the Australian population have been conducted through the:

- National Health Survey (NHS)
- National Aboriginal and Torres Strait Islander Health Survey (NATSIHS)
- General Social Survey
- National Aboriginal and Torres Strait Islander Social Survey
- Survey of Disability, Ageing and Carers
- Survey of Mental Health and Wellbeing
- Community Housing Infrastructure Needs Survey
- National Drug Strategy Household Survey, and the
- Australian Secondary Schools Alcohol and Drug Survey.[5-7]

Computer Assisted Telephone Interview (CATI) Health Surveys in Australia

In the 1990s, three Australian states established state-based CATI health surveys arising from a perceived need for ongoing behavioural risk factor monitoring (that was not being routinely collected through the NHS). These surveys were modelled on the Behavioural Risk Factor Surveillance System (BRFSS) in the United States of America (USA).[8] Between 1993 and 2001, five states - New South Wales (NSW), Victoria, Queensland, Western Australia and South Australia - introduced regular state-based survey programs to conduct surveillance of the health behaviours of their populations.[9-12] These five states represented almost 95 percent of the Australian population. The states used varying models and methods to undertake the surveys.

In 2002, there was a movement across the states to maintain repeated surveys using consistent data collection methods. In 2004, in order to obtain a complete set of CATI health survey data for Australia, behavioural data was also collected in the ACT, Queensland, Northern Territory (NT) and Tasmania through the 'Filling the Gaps' survey initiative commissioned by the Australian Government Department of Health and Ageing. In 2007, the ACT Government initiated the ACT General Health Survey (ACTGHS) in collaboration with the NSW Health Survey Program.[13] Over the years, the Department of Health in the NT and the Department of Health and Human Services in Tasmania have conducted their own CATI surveys and/or collaborated with other jurisdictions.

Future of health surveys in Australia *(continued)*

The role of population health surveys in meeting health information needs.

In 2002 and 2008, the Population Health Information Development Unit located at Torrens University in Adelaide undertook two audits of Australian chronic disease and associated risk factor data collections.[14,15] In 2008, they concluded that although there were substantial improvements from 2002, there were still substantial gaps, deficiencies and concerns.

These concerns included:

- The continuing lack of a dedicated national monitoring system on chronic disease and associated risk factors and determinants;
- Ongoing gaps in integrated data on nutrition, physical activity, and physical and biomedical measurements; and
- Limitations in the representativeness of the population for state-based CATI health surveys due to significant changes in telecommunications, which impacted both sampling and access to participants.

In 2009, the Centre for Statistical and Survey Methodology at the University of Wollongong evaluated the survey methodologies used by the NSW Health Survey Program and provided options to address the methodological issues impacting on the quality of surveys undertaken by the Program. The report made recommendations on: sample design, data collection processes and instruments, survey quality measures, weighting and analysis, and reporting. The outcomes of the review's recommendations include the addition of a mobile phone component and a method to increase the number of child participants.[16]

In 2010, Mokdad and Remington[17] examined how health behaviours in populations were measured in the USA, including strengths, limitations and challenges into the future. They concluded that data from surveys of health behaviours across populations will continue to play a role in public health efforts at the national, state, and local levels. They also stated that telephone surveys had become a standard approach to collecting information from adults and children; however, as response rates were declining and costs increasing, other methods for collecting these data needed to be considered.

In 2016, ACT Health is undertaking a review of their health information systems to identify data needs, gaps and methodological issues. Specifically, the ACT Health Information System review is designed to:

- examine ACT Health's population health information needs;
- explore existing and alternative sources of information (including their strengths and weaknesses);
- provide a best practice solution for the organisation that is cost effective; and
- encourage broader use of the information for ACT Health and its partners.

Data collections included in the review are the ACT GHS, ACT Year 6 Physical Activity and Nutrition Survey, ACT Secondary School Alcohol and Drug Survey, ACT Cancer Registry, and the ACT Maternal Perinatal Data Collection.[18] Outcomes will include an information system plan that includes cost-effective improvements to data collection, data quality, the range of methods and necessary skill sets employed in small area analysis, and survey methodology to enable ACT Health to more easily meet reporting and epidemiological needs.

Role of population health surveys in the big data environment

Traditionally, the three most common ways to collect data for population sample surveys are through the mail, by phone or face-to-face. More recently, the internet and email are also being used to collect data. Multi-mode approaches are also employed, which include a combination of collection methods.[19-21] Internet surveys rely on a person having access to the web and, as with mail surveys, rely on the respondent being motivated to complete the survey. Without reasonable coverage of the general population by people volunteering to participate in internet surveys, the estimated population results derived from internet surveys can be biased.[22]

In the current environment of big data (see article on page X), an individual's internet browsing behaviour is monitored by various internet companies. Additionally, there are countless smartphone applications that monitor an individual's movements and personal networks and connections. With the increasing availability of big data, there is a question mark over whether there is still a need for government departments to continue to collect information about the population through sample surveys.[23-25]

Nuti et.al[26], in a recent systematic review of the use of Google Trends in healthcare research, concluded that Google Trends holds potential as a free, easily accessible means to access large population-level internet search data to derive meaningful insights about population behaviour and links to health and health care. However, to be reliably used as a research tool, methods must be elucidated to enable confirmation of the findings. This would greatly increase the trustworthiness of the results and applicability for healthcare research. To handle the challenge of big data, new and advanced analytic tools will need to be developed. Testing and validation are required before these tools can be applied for making real world decisions.[27]

In 2015, both the ABS and the American Association for Public Opinion Research considered the use of big data. Although both organisations concluded that there is great potential in big data, they highlighted several fundamental challenges (as outlined above) that must be resolved before its full potential can be realised.[28-29]

Thus, sampled population health surveys with their current limitations (including lower response rates and lack of accessible mobile phone lists for sampling purposes) are still the most cost-effective way to obtain accurate population prevalence estimates for health behaviours and health status. Until there are reliable population inference methods that can be applied to big data and/or we are able to collect the data accurately on all of the population, then the use of sampled population health surveys are likely to continue in some form.

Future of health surveys in Australia *(continued)*

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Bicycle crash injuries in the Australian Capital Territory: a data blind spot?

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Bicycle crashes are an important cause of injury in the ACT and are underreported in routinely collected data sources. This makes it difficult to target, and evaluate, injury prevention initiatives. This article outlines the issue, describes some of the challenges around data collection on injury resulting from bicycle crashes in the ACT, and proposes avenues for exploration to improve our injury surveillance system.

Introduction

Pedal cyclists (referred to in this article as cyclists) are vulnerable road users and are overrepresented in injury statistics.[1] In the ACT, we have a particularly high rate of serious injuries for cyclists in comparison to the rest of Australia. In 2010, the annual injury rate for high threat to life injuries for cyclists* was close to 7 per 100,000 people, more than double the rate in any other states.[2] The ACT has had significantly higher rates of serious injuries for cyclists than the rest of Australia since around 2007, and over the ten year period between 2000-01 and 2008-09, this rate has increased almost 20 percent.[2] Canberra has a high cycling participation rate relative to other Australian jurisdictions, and this is almost certainly a contributing factor.[3] This fact emphasises the need to both reduce the number and severity of injuries sustained by cyclists, whilst at the same time increasing the number of people who cycle for transport and recreation. These actions will deliver important benefits to individuals, society and government by increasing physical activity levels, as well as reducing traffic congestion, pollution and carbon emissions. Of importance, fear of injury is a known deterrent for potential cyclists, which discourages people from choosing active forms of travel and contributes to the burden of physical inactivity. This is an issue given that only half of our adult population undertakes sufficient physical activity to achieve health benefits, and as such, a key priority of the ACT Government is to help people integrate more movement into their daily life.[4]

Understanding the trends behind injuries is important in order to both prevent them and to evaluate the effectiveness of injury prevention strategies initiated by governments. Examples of this might include identifying crash 'hotspots', evaluating the effectiveness of specific infrastructure such as separated bicycle lanes, or singling out the groups of cyclists more likely to crash in order to target education or promotion efforts.

Image: Cyclists. Amanda Mills. Public Health Image Library

Bicycle crash and injury data in the ACT

The main routinely collected data sources for bicycle crash injuries are the police crash data, emergency department data, and hospital inpatient data. Other in-depth, time-limited investigations have been conducted sporadically with one of the most recent and informative being the Pedal Study, a cross-sectional study of cycling crashes and injuries in the ACT between November 2009 and May 2010 where patients were recruited from the emergency department and interviewed.[5]

The police crash dataset captures cycling crashes that have been reported to police, which in the ACT is a requirement and can be done in person or online. This data is published annually by Roads ACT in the Crash Report, and more recently in an interactive map format available on data.act.gov.au. The issue with police crash data, which are not unique to the ACT, is that cycling crashes are generally significantly underreported, particularly for accidents not involving motor vehicle collisions.[5,6] Whilst these crashes could be considered more minor relative to those involving motor vehicles, they can still result in serious injury requiring hospital treatment. The Pedal Study, mentioned above, found that only 11 percent of the 313 eligible study participants who attended an Emergency Department (ED) during the six month study period reported their cycling accident to the police.[8] This increased to 71 percent for crashes involving motor vehicles. ACT studies have previously described the gross underreporting of cycling-related road trauma to the police,[9] and this is consistent with trends in other countries.[10] One of the recommendations that came out of the 2014 Legislative Assembly Inquiry into Vulnerable Road Users, which identified poor data quality an issue for cyclist injuries, was that the ACT Government conduct an awareness raising campaign to advise the community of their obligation to report all accidents.[11]

The other routinely collected data sources that can be used to investigate cycling crash injuries are the ACT Emergency Department Information System (EDIS) and the ACT Admitted Patient Care Collection (APC). EDIS covers all emergency department presentations in the ACT and contains details of patient demographics and diagnoses, triage categories and sources of referral.[12] The APC contains details of all ACT hospital inpatient records for public and private hospitals in the ACT, and includes patient demographics, diagnoses, procedures, sources and referrals.[12]

The challenge associated with emergency department data is that information is collected in a busy environment where clinicians have other priorities (such as treating patients) and often the external cause of the injury is not recorded (i.e. cycling crash), but rather just the injury diagnosis (e.g. fracture). This issue of not capturing the underlying cause of an injury is not specific to cycling crashes, but common to other types of injury, with alcohol related injury being an another example. Admitted patient data is generally better in terms of capturing the cause of injury, as there is more capacity to capture this information in the patient notes, however as patients admitted to hospital are more likely to be seriously injured, this means that hospital data does not include the substantial proportion of patients discharged from ED with serious, but not life threatening injuries.[5,6]

Image: Emergency Department. ACT Health

Bicycle crash injuries in the Australian Capital Territory: a data blind spot? *(continued)*

Ways forward

Encouraging safe participation in cycling is a priority for the ACT Government. Improving our data on cycling crash injuries is important in order to obtain information that can be used to inform injury prevention strategies, evaluate and best target infrastructure and interventions. Routinely collected police and hospital data sources in the ACT substantially underestimate cycling crashes, and are biased towards the most severe injuries that occur in particular environments (primarily on-road, and involving motor vehicles). This means that a substantial number of more minor injuries or "near misses" are going undetected.

To move forward, the ACT Government needs to adopt innovative approaches to utilising routinely collected data, or explore collecting and analysing other routinely collected data sources (such as ambulance data) that have not previously been investigated for information on cycling crash injuries. Avenues worthy of exploration, already being trialled with initial success, in other Australian jurisdictions and in New Zealand, include data record linkage and the use of ED syndromic surveillance systems.[14] Data record linkage techniques (specifically, linking police and hospital data) provide a resource-efficient opportunity to evaluate the completeness of cycling crash records across the spectrum of severity, and through this obtain a more accurate estimate of cycling crash injuries.[15] In NSW, syndromic surveillance, originally designed to monitor ED presentations potentially related to communicable diseases in a timely manner, is being trialled as a injury surveillance tool.[14] Of critical importance is establishing systems to communicate this data and knowledge back to policy makers so it can be used to determine causes of cycling crashes and develop countermeasures to prevent injuries.

*Road vehicle non-traffic crashes

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Notifiable conditions: what data do we collect and why do we need this information?

Katherine Davis, Communicable Disease Control, Population Health Protection & Prevention

What are notifiable conditions?

The monitoring and control of infectious diseases is a global concern. Notifiable conditions are infectious diseases or conditions that are critical to local, national or international public health. In developing countries, the primary aim is to detect disease outbreaks early and put measures in place to limit their spread and health impacts. In developed countries like Australia, the aim is to detect diseases and intervene early to prevent local transmission from causing an outbreak of disease and/ or the re-emergence of diseases that are now rare in Australia. In a 1995 resolution, the World Health Organization urged all members to 'strengthen surveillance for infectious diseases in order to promptly detect re-emerging diseases and identify new infectious diseases'.[1]

In Australia, the Communicable Diseases Network Australia (CDNA) provides national public health co-ordination and leadership, and supports best practice for the prevention and control of communicable diseases. This includes national surveillance programs, policy and advice on the prevention and control of communicable diseases.[2] The CDNA meets by teleconference fortnightly and currently consists of 20 members including representatives from each of the Australian states and territories; the Commonwealth Department of Health; and relevant public health organisations such as the Public Health Laboratory Network, OzFoodNet and the Australian Society for Infectious Diseases.[3]

Table 1 below shows a list of the current notifiable conditions in the ACT.

Acquired Immunodeficiency Syndrome (AIDS)
☎Anthrax
Arbovirus infections ♦
- Barmah Forest virus
- Dengue virus
- Japanese encephalitis virus
- Kunjin virus
- Murray Valley encephalitis virus
- Ross River virus
- Flavivirus infection – unspecified or not otherwise classified

☎Avian Influenza
Botulism
Brucellosis
Campylobacteriosis
Chlamydia trachomatis
☎Cholera
☎Creutzfeldt-Jakob Disease (all forms, incl. classical & variant)
Cryptosporidiosis
☎Diphtheria
Donovanosis
Equine morbillivirus
☎Food poisoning (not elsewhere specified)
☎Gastrointestinal illness cluster
Giardiasis
Gonococcal infection
☎Haemolytic uraemic syndrome (HUS)
☎Haemophilus influenzae serotype b (Hib) (invasive only)
☎Hepatitis A
Hepatitis B
Hepatitis C
Hepatitis D
Hepatitis E
Hepatitis – Infectious, not otherwise specified
Human immunodeficiency virus (HIV) infection
Influenza laboratory-confirmed ●
☎Legionellosis ●♦
Leprosy (Hansen's disease)
Leptospirosis
Listeriosis
☎Lyssavirus
- Australian bat lyssavirus
- Duvenhague virus
- Rabies
- European Bat 1 & 2
- Lyssavirus unspecified

Malaria
☎Measles
☎Meningococcal disease (invasive)
Mumps ♦
☎Paratyphoid
Pertussis ●
☎Plague
Pneumococcal disease (invasive)
☎Poliomyelitis – wild type and vaccine-associated
Psittacosis (Ornithosis) ♦
Q fever ♦
Rubella and congenital rubella syndrome ♦
☎SARS
Salmonellosis #
Shigellosis #
☎Shiga Toxin-producing and Vero Toxin-producing Escherichia coli (STEC/VTEC)
Smallpox
Syphilis
Tetanus
Tuberculosis
☎Tularemia
☎Typhoid
Varicella
☎Viral haemorrhagic fevers (quarantinable)
- Lassa
- Marburg
- Ebola
- Unspecified or otherwise unclassified

☎Yellow fever
Yersiniosis #

Table 1: Current notifiable conditions in the ACT

☎ **Items marked with a telephone are to be notified by phone on positive test result or reasonable clinical suspicion.**
● **A Nucleic Acid Test (PCR) is the preferred test method for definitive confirmation of this condition.**
Including a culture test is optimal for these conditions.
♦ **These conditions may require a second serological test to show seroconversion.**

Notifiable conditions: what data do we collect and why do we need this information? *(continued)*

What information or data do we collect about notifiable conditions?

When a notification is received, ACT Health collects general identification and demographic details of the person with the condition as well as disease specific information. Examples of data that are also often collected are shown in Table 2.

Identification and demographic details	Clinical details
Family name	Disease or condition
Given names	Disease or condition type
Date of birth	Methods of diagnosis
Gender	Dates of onset, testing, and notification
Address	Age at onset of condition
Contact phone number	Emergency department visits
Country of birth	Hospital admissions
Indigenous status	Details of doctor who reviewed the case
	Details of who provided the notification
	Suspected source of infection
	Occupation or school details
	Relevant treatments
	Public health action taken

Table 2: Data collected on notifiable conditions

How do we collect notifiable conditions data?

The ACT Reporting of Notifiable Conditions Code of Practice requires medical practitioners, authorised nurse practitioners, pathologists and hospitals to report notifiable conditions to ACT Health. In practice, most ACT notifications come from the testing laboratories once they have a positive result for a notifiable condition. For most conditions, the number of notifications received is an underestimate of the actual number of illnesses caused by the condition within the community. This is because people with a notifiable condition do not always seek medical attention or are not tested for that condition. The process that commonly leads to a notification to ACT Health is represented in Figure 1.

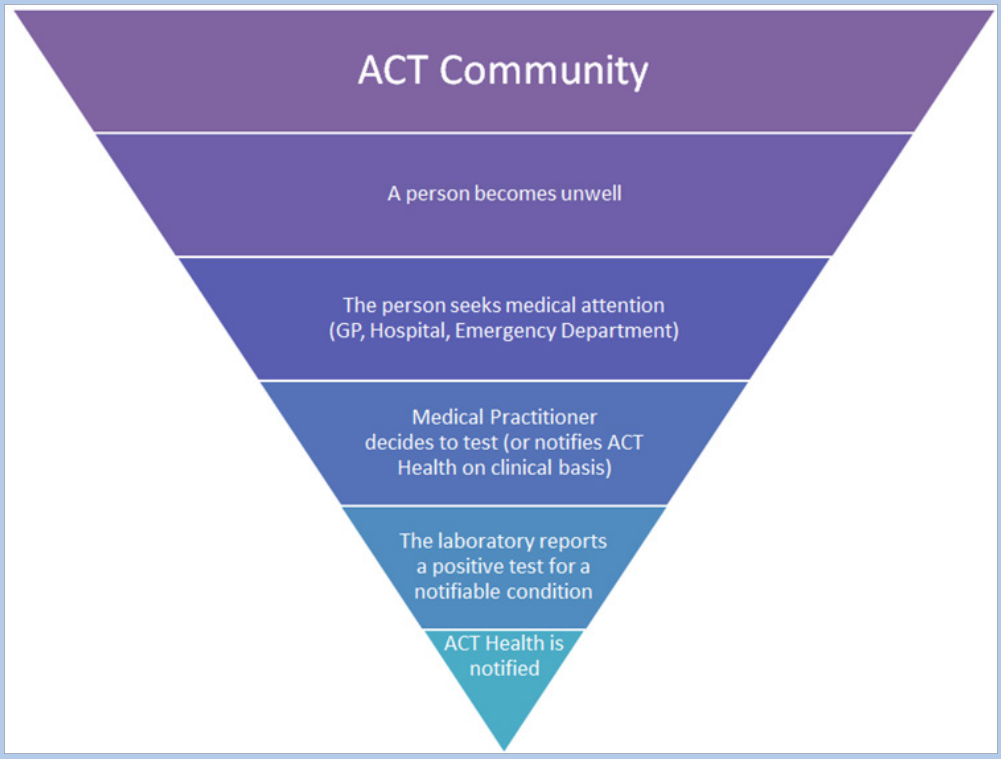

Figure 1: Process leading to a notifiable condition being reported to ACT Health

Most of the notifications in the ACT are received by secure fax or by phone. Once the Communicable Disease Control (CDC) section receives the notification, details of the patient are checked to ensure that they reside in the ACT and that the diagnosed condition meets the national surveillance case definition. Relevant information on the notifications is recorded in a secure specialised database, with access password-restricted to ACT public health staff.

Notifiable conditions: what data do we collect and why do we need this information? *(continued)*

Why do we collect data on notifiable conditions?

The reasons for collecting data on notifiable conditions fall under two main categories: conditions that require public health action or intervention to prevent further transmission, and conditions that require monitoring of local trends.

The CDC section will take appropriate public health action for some conditions that are readily transmissible in the community, such as pertussis (whooping cough), salmonella, measles, sexually transmissible infections (e.g. gonorrhea, syphilis, HIV, hepatitis B), and invasive meningococcal disease. This may include talking to people who have been diagnosed with the condition to:

- find out where the person may have contracted the illness;
- ensure the person is excluded from school and work to limit further spread (where applicable); and
- identify contacts who may:
  - be at a higher risk of severe or complicated illness;
  - need testing to see if they may have contracted the illness; and/or
  - need treatment to reduce the risk of contracting the illness.

For other conditions, notifications are important for monitoring of local trends. This information can inform targeted education and interventions, and assist in evaluating prevention programs. For example:

- Monitoring influenza notifications allows the CDC section to target seasonal health messages in line with the flu season and ensure that the health system is prepared when the influenza season begins;
- Monitoring conditions before and after a new vaccine is added to the childhood immunisation schedule can help to determine the effectiveness of a vaccine; and
- The effect of active screening and/or educational/prevention programs may be evaluated using notifiable diseases data.

What do we do with the notifiable conditions data?

In the ACT, the notifiable conditions data is stored in a secure database that has been custom built to hold this type of information; any paper records are stored in confidential files.

Australian states and territories, including ACT Health, provide de-identified surveillance data to the National Notifiable Disease Surveillance System (NNDSS). The NNDSS is managed by the Commonwealth Department of Health and contains data that is used to monitor national trends and to conduct research activities. All notifications that are sent to the Department of Health are de-identified (name, address, phone number etc. are removed) and instead a unique identifying number is assigned and used to track each record. Data provided to the NNDSS include: disease code, date of onset, date of notification to ACT Health, sex, age at illness onset, Indigenous status and the postcode where the person lives.[4] The NNDSS collates this national data and provides summary data for disease notifications across Australia on their website.

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Notifiable Disease Report

Number of notifications of notifiable conditions received in the Australian Capital Territory, 1 July to 30 September 2016 (3rd Quarter 2016).

	3rd QTR 2016	Total Q1-Q3 2016	Q1-Q3 Average 2011-2015	Ratio Q1-Q3 2016: Q1-Q3 average 2011-2015	Annual Total 2015	Annual Average 2011-2015
VACCINE PREVENTABLE CONDITIONS						
INFLUENZA	1349	1482	722.0	2.1	1205	791.0
PERTUSSIS*	138	315	333.6	0.9	486	442.2
GASTROINTESTINAL DISEASES						
CAMPYLOBACTERIOSIS	134	413	362.2	1.1	608	492.6
CRYPTOSPORIDIOSIS	14	36	20.6	1.7	26	25.4
GIARDIA	24	98	92.8	1.1	140	121.6
HEPATITIS A *	1	2	2.8	0.7	3	3.2
HEPATITIS E	0	1	0.8	1.3	0	1.0
LISTERIOSIS	0	0	0.4	0.0	1	0.8
SALMONELLOSIS	55	216	166.8	1.3	237	227.0
SHIGELLOSIS	0	4	5.0	0.8	7	7.8
STEC/VTEC	0	0	1.2	0.0	0	2.8
TYPHOID	1	1	1.0	1.0	2	2.2
YERSINIOSIS	3	12	7.2	1.7	22	9.8
SEXUALLY TRANSMITTED INFECTIONS						
CHLAMYDIA	313	1066	961.0	1.1	1266	1255.2
GONOCOCCAL INFECTION	57	145	92.4	1.6	141	118.8
VECTORBORNE & ARBOVIRUS						
BARMAH FOREST VIRUS INFECTION	0	0	2.2	0.0	2	2.6
CHIKUNGUNYA^	0	0	0.6	0.0	3	0.6
DENGUE FEVER*	11	31	13.8	2.2	19	16.8
LEPTOSPIROSIS	0	0	0.4	0.0	1	0.4
MALARIA	1	7	7.8	0.9	7	9.8
Q FEVER	0	2	0.4	5.0	0	0.6
ROSS RIVER VIRUS INFECTION	2	9	5.8	1.6	10	7.6
RESPIRATORY CONDITIONS						
TUBERCULOSIS #	6	21	14.8	1.4	16	20.2

All Diseases except Tuberculosis are reported by onset date or closest known test date. Tuberculosis is reported by notification date.

* This condition includes cases that meet the probable and confirmed case definitions. Both probable and confirmed cases are nationally notifiable.

^ Chikungunya infection is received as a notification of an arbovirus not otherwise specified, as it is not currently notifiable. As a result, it is possible that reporting may be incomplete.

For the relevant year, Q1 refers to 1 January to 31 March, Q2 refers to 1 April to 30 June, Q3 refers to 1 July to 30 September, Q4 refers to 1 October to 31 December.

N.B. Data reported are the number of notifications received by ACT Health. Data are provisional and subject to change.

The number of notifications received for all notifiable diseases in the ACT is available at: http://www9.health.gov.au/cda/source/cda-index.cfm

HIV data are reported annually by the Kirby Institute: http://www.kirby.unsw.edu.au/surveillance/Annual-Surveillance-Reports

Notifiable Disease Report

Number of notifications of notifiable conditions received in the Australian Capital Territory, 1 July to 30 September 2016 (3rd Quarter 2016).

Vaccine-preventable Diseases

Between 1 January and 30 September 2016, there was one notification of mumps and two notifications of invasive meningococcal diseases (one serogroup W and one serogroup B) in the ACT. There were no cases of measles, tetanus or rubella notified during the same period.

The 2016 influenza season occurred during the third quarter of 2016 (1 July to 30 September 2016), with 1,349 notifications of influenza reported to ACT Health during that period. The majority of influenza notifications in Q1-Q3 2016 were influenza A (n=1403), and of those influenza A samples that were subtyped (n=341), 81 percent were influenza A/H3N2.

During the third quarter of 2016, there were 14 cases of invasive pneumococcal disease notified to ACT Health, bringing the total during Q1-Q3 to 23 cases, which is 1.5 times the 5-year Q1-Q3 mean. Pneumococcal disease is caused by the bacteria *Streptococcus pneumoniae* and infection can cause pneumonia, otitis media (ear infection), and meningitis. People most at risk of infection include children younger than two years, the elderly, Aboriginal and Torres Strait Islander people, people who smoke, have had their spleen removed, as well as those with lung disease, heart disease, cancer, kidney disease, HIV infection, and malnutrition.

There were 138 cases of pertussis notified during the third quarter of 2016 and 315 cases during Q1-Q3 2016. The number of pertussis cases in 2016 is below the Q1-Q3 average over the past five years (2011-2015).

Gastrointestinal Diseases

During the third quarter of 2016, there were 232 notifications of gastrointestinal diseases. While overall notifications were slightly lower than the five year third quarter average, notifications of salmonellosis and cryptosporidiosis were higher.

Thirty two outbreaks of non-foodborne gastroenteritis were investigated during the third quarter of 2016. There were no foodborne outbreaks identified during this quarter.

Vectorborne and Arbovirus infections

There were 11 notifications of dengue virus infection in the third quarter of 2016, in addition to the 20 notified during the first and second quarters. In total during Q1-Q3, there have been 31 cases of dengue, which is more than double the five year average for this time period. Dengue is a viral illness spread by the *Aedes aegypti* mosquito. The virus itself is not endemic in Australia, but there is potential for transmission locally due to the presence of *Aedes aegypti* in parts of northern Australia. Symptoms typically include sudden fever, chills, severe headache with pain behind the eyes, swollen glands, muscle and joint pain and extreme fatigue. All 31 cases diagnosed with dengue infection this year acquired their infections overseas, primarily in countries in south and south-eastern Asia. The best way that travellers can reduce the risk of becoming infected with a mosquito-borne virus is to take measures to prevent being bitten by mosquitos. This includes using appropriate repellents, mosquito nets and covering up with light coloured long clothing.

In 2016, there have been a total of 9 cases of Ross River virus notified to ACT Health. All cases reported possible exposures interstate (including in NSW) or overseas. Ross River virus is spread through the bite of infected mosquitos. Symptoms can include: an influenza-like illness (fever, chills, headache, muscle aches); joint pain, swelling, or stiffness; a rash over the body, arms or legs; and a general feeling of being unwell, tired or weak. As for dengue, the best way to reduce the risk of infection is to take measures to avoid being bitten by mosquitos by using appropriate repellents and covering up with light coloured long clothing.

Two cases of Q fever have been notified in Q1-Q3 2016. Both cases reported possible exposures in coastal areas of New South Wales. Q fever is a bacterial illness caused by *Coxiella burnetii* and is usually spread to humans from infected animals; however, the bacteria can survive for long periods in the environment. Many infected people have few or no symptoms. Those that do become sick have a severe influenza-like illness, including high fevers and chills, severe headaches, sweats, muscle and joint pain, and extreme fatigue. Q fever is usually an acute infection but it can, in a subset of cases, lead to a chronic illness.

Respiratory conditions

There were six notifications of tuberculosis (TB) during the third quarter of 2016, making a total of 21 notifications in Q1-Q3 2016, which is 1.4 times the five year Q1-Q3 average (2011-2015). TB is caused by *Mycobacterium tuberculosis* and it can cause lung disease (pulmonary TB), disease in any other part of the body, most commonly the lymph nodes (extrapulmonary TB), or both pulmonary and extrapulmonary disease. Symptoms of pulmonary TB can include cough, fever, sweats, weight loss, and haemoptysis (coughing up blood). Approximately 10 percent of people infected with *M. tuberculosis* develop clinical illness during their lifetime, sometimes many years after the original infection. In Q1-Q3 2016, ten notified cases had pulmonary TB, ten cases had extrapulmonary TB, and one case had both pulmonary and extrapulmonary TB.

Section Highlight

Introduction

The Epidemiology Section (ES) of the Health Improvement Branch in Population Health Protection & Prevention, provides the latest available and most accurate information on the health of the ACT population. The core functions of the ES are collect, collate, analyse and disseminate population health information to be used as evidence in the development of programs and policies to improve population health outcomes. The ES also:

- Undertakes projects to examine emerging public health issues;
- Provides advice and assistance relating to research and evaluation; and
- Conducts research related to key public health issues.

To support these functions, the section undertakes various surveys and holds (or has access to) a wide range of population health data sets on which to base its analyses.

Epidemiology section structure and staff

Teams cover the following functions:

- Health outcomes and knowledge translation
- Data linkages and epidemiological implication (including Cancer Registry)
- Survey and health status monitoring
- Health Informatics and Population Health Data management
- Support (administrative and statistical analysis)

This new structure is enabling:

- Smarter and more efficient ways of working.
- Expanding the input into each project/work areas as the individuals in each team work together
- Enhanced content focus with each team focusing on their type of work.
- Development of human capacity and skills

Staff in the section come from a wide variety of work experiences and academic backgrounds. Expertise includes graduate and post graduate qualifications in epidemiology, population health, bio-statistics, psychology, education, microbiology, information technology, database management & programming and data entry. The ES is supported by an office manager.

Key Section work programs

The ES work program includes:

- Manage the ACT Cancer Registry
- Manage The ACT Maternal and Perinatal Data Collection
- The production of the biennial Chief Health Officer's Report
- The production of regular reports on cancer, maternal and perinatal health, general health status and health related behaviour in the ACT
- The conduct and commissioning of surveys on the health of specific population groups, for example children, young people and older people
- The management and analysis of a range of population health data sets
- The provision of advice and analytical services to organisations involved in public health promotion and program work, both internal and external to the health portfolio.

Surveys currently administered by the section include:

- ACT component of the Australian Secondary Student Alcohol and Drug Survey (3 yearly);
- ACT General Health Survey (continuous); and
- ACT Physical Activity and Nutrition Survey (3 yearly).

Back row: Rosalind Sexton, Lindy Fritsche, Frances Gibson, Tracey Docherty, Wayne Anderson, Dr Hai Phung, Alexandra Raulli, Elizabeth Chalker, Rebecca Smith, Dr Oscar Yang

Front row: Leah Newman, Deborah Schaler, Bridget O'Connor, Louise Freebairn

Absent: Mirka Smith, Cecilia Xu

ACT Government Health

FOCUS on smoking in pregnancy

An overview of smoking in pregnancy

Why is it important?

- Smoking in pregnancy is the most important preventable cause of a wide range of adverse pregnancy outcomes. Smoking causes poor outcomes for mother and baby and there is growing evidence of serious harm extending into childhood and even adulthood.
- Unfortunately, most smokers who become pregnant continue to smoke and most of those who quit relapse after delivery. Smoking interventions in pregnancy can significantly reduce the relative risk of low birthweight and pre-term birth.[1]
- To maximise the benefits of smoking cessation in pregnancy, the mother should stop smoking in the first 20 weeks.[2,3]

How are we progressing?

Overall, we are doing well, with the percentage of ACT women who smoke during pregnancy decreasing from 11% in 2009 to 7% in 2014. However there is still room for improvement.

Younger women were more likely to smoke during pregnancy with over 30% of teenage women reporting smoking in pregnancy in 2014. The percentage decreases significantly in older age groups, with 7% of women aged 21 to 34 years and 5% of women aged 35 years and over reporting smoking in pregnancy.

Smoking in pregnancy is also higher for Aboriginal and Torres Strait Islander women who were four times more likely to smoke during pregnancy than non-Aboriginal and Torres Strait Islander women.

What do we measure?

Information about tobacco smoking in pregnancy is collected at antenatal visits at two points in time, once early in pregnancy (first 20 weeks) and again later in pregnancy (second 20 weeks). Women are asked whether they currently smoke tobacco and if they answer yes, they are asked how many cigarettes per day they smoke.

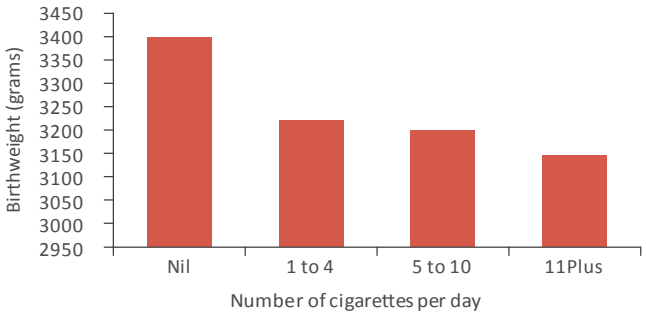
Information on characteristics of women giving birth is also collected such as age, Aboriginal and Torres Strait Islander status, country of birth, and weight status. Information relating to birth outcomes is collected including type of birth, birthweight, and pre-term births. More information is available here: http://stats.health.act.gov.au/

What is the impact of smoking?

The birthweight for babies of women who smoked during pregnancy was significantly lower than for babies of women who did not smoke and the number of cigarettes smoked per day also negatively impacted on birthweight (Figure 1).

Low birthweight is an important determinant of a baby's chance of survival and good health. Low birthweight is a risk factor for physical and neurological disability and the development of conditions such as Type 2 diabetes and high blood pressure later in life.[4]

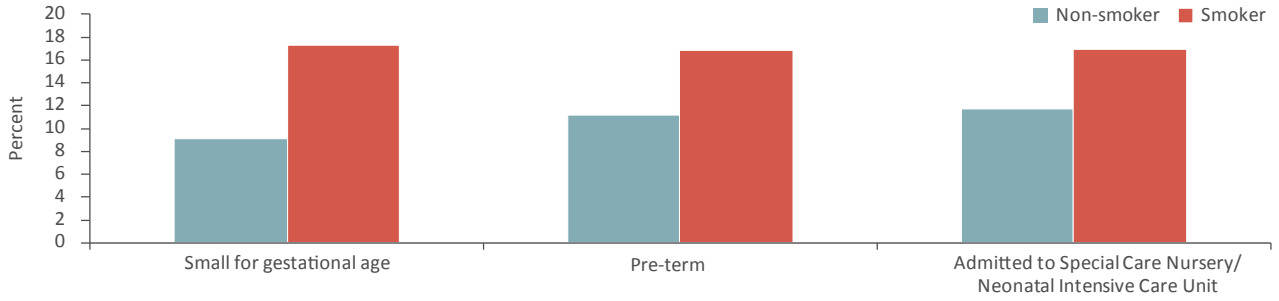
Figure 1: Average birthweight by estimated number of cigarettes smoked per day during pregnancy



Source: ACT Maternal Perinatal Data Collection, 2009–14.

Babies of women who smoked in pregnancy were more likely to be born pre-term, require an admission to a special care nursery and to be small for gestational age (Figure 2).

Figure 2: Birth outcomes by smoking status of mother



Source: ACT Maternal Perinatal Data Collection, 2009–14.

Where to from here?

ACT Health has commenced the Smoking in Pregnancy Project, which aims to:

Prevent smoking uptake amongst all young women in the ACT.

Reduce smoking rates during pregnancy amongst young women aged 15 to 24, and also support their partners and families in quitting.

Reduce smoking rates during pregnancy for all Aboriginal and Torres Strait Islander women, and also support their partners and families in quitting.

The strategies used include:

Behaviour change campaign.

A pilot of free, medically-supervised Nicotine Replacement Therapy for nicotine dependent young pregnant women and their cohabitants, where quit attempts using behavioural counselling alone have not been successful.

Capacity building for organisations which work with young pregnant women such as smoking care training for health and other professionals.

Smoking in pregnancy will continue to be measured over time to monitor our progress.

For more information about the Smoking in Pregnancy Project please contact the Health Improvement Branch on healthpromotion@act.gov.au.

For more information about quitting or reducing your smoking please contact your health professional.

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www.health.act.gov.au | www.act.gov.au | Enquiries: Canberra 13ACT1 or 132281

Zika Virus – A Global Public Health Concern

Dr Sonia McCarthy, Public Health Medicine Registrar, Population Health Protection & Prevention

Ed: Although the World Health Organization declared an end to the Zika "Global Emergency on 18 November 2016, the issue remains a clear threat to global public health, with much research still required and a vaccine in development.

Zika virus came to global attention in early 2016 and was declared by the World Health Organization to be a public health emergency of international concern.[1] Up to this point in time, Zika had been a relatively unknown virus, first identified in 1947 in monkeys in Uganda and subsequently detected in humans in 1954. Since the 1950s time limited outbreaks have occurred in tropical Africa, Southeast Asia and the Pacific Islands.[2]

Zika virus is predominantly transmitted by the Aedes mosquito (*Aedes aegypti* and *Aedes albopictus*), but can also be spread from a pregnant woman to her foetus or through sexual intercourse. The disease is typically asymptomatic. Mild symptoms may include a rash, low-grade fever, joint pain and conjunctivitis.[3]

In late 2015, Brazil reported an outbreak of Zika virus infections associated with microcephaly (babies with small heads). Subsequent research has confirmed that Zika virus infection during pregnancy is a cause of microcephaly and other severe foetal brain defects. The virus is also strongly associated with Guillain-Barré syndrome – a rare disorder where the body's immune system attacks the nervous system.[4,5]

With the 2016 Summer Olympics scheduled to be held in Rio de Janeiro, the widespread outbreak of Zika virus in Brazil and its potentially severe complications caught the attention of the media. Brazil was listed as a 'high-risk country' for Zika virus by the Australian Department of Health[6] and other major public health agencies around the world and there was public concern in Australia about the implications this would have on athletes and tourists attending the Olympic Games. In addition, there is no specific treatment or vaccine for Zika virus infection.[5]

To date, all known cases of Zika virus infections in Australia have been acquired overseas.[7] However, the *Aedes aegypti* mosquito, a prolific biter, is found in parts of Queensland and so there is a risk, in these areas, of local transmission to others from an infected person. Although there are no Aedes mosquitoes in Canberra, the ACT Government remains alert and concerned about the potential threat of a Zika virus outbreak in Australia.

Travellers to Zika virus affected countries are advised to take precautions, including avoidance of mosquito bites and safe sex practice. The Australian Government Department of Health also provides specific recommendations for pregnant women or women planning pregnancy.[5]

Public health strategies include multi-sectoral engagement, mosquito control measures and surveillance at international ports of entry, including the newly opened international terminal at the Canberra airport. Preparedness of our health system for early detection of Zika virus infection and the ability to mount a rapid, coordinated response is also crucial to prevent an outbreak of Zika virus in Australia.

For further information about Zika virus, including prevention and the public health management of a laboratory confirmed case, see: http://www.health.gov.au/internet/main/publishing.nsf/content/ohp-zika-health-practitioners.htm

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Survey about antibiotic use and antibiotic resistance

The University of Sydney invites medical, dental and veterinary practitioners who are registered to practise in Australia to complete an online survey about antibiotic use and antibiotic resistance in Australia. The survey explores attitudes towards antibiotic use and antibiotic resistance, what influences prescribing decisions and investigates education and resource needs. The survey takes about 15-20 minutes to complete. Responses are anonymous and confidential. Complete the survey for a chance to win an iPad.

The findings from this study will assist national policy-makers to enhance national policy and education interventions about antibiotic use and antibiotic resistance in Australia.

Your views are important. To participate or for more information, please click here: https://www.surveymonkey.com/r/researchab

For more information, please contact Dale Dominey-Howes – email: dale.dominey-howes@sydney.edu.au or call: +61 2 9351 6641.

Thank you for your assistance in this study.

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