## REPRESENTATIVE POPULATION HEALTH SURVEYS: IMPROVING PUBLIC HEALTH THROUGH RIGOUR, DIVERSITY OF METHODS AND COLLABORATION

Anne W Taylor BA, MPH

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> Department of Medicine The University of Adelaide South Australia

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### ABSTRACT

Prevention and slowing the progression, of chronic diseases (such as cancer, heart disease, arthritis, diabetes, asthma, osteoporosis, dementia and incontinence), and influencing risk factors and health behaviours of a population, relies on the best available data-driven evidence. The quality of measurement techniques to collect representative population health survey and surveillance data is, as a consequence, brought under scrutiny. The presentation of this thesis is the culmination of 17 years work that has been focused on contributing to improving public health in South Australia. It is premised on the understanding that continual epidemiological assessment using representative population health surveys can deliver evidence-based information needed by health policy makers, health planners and health promoters to make appropriate, timely and efficient evidence-based decisions.

The objective of the portfolio of published papers was to demonstrate the contribution to producing quality data-driven evidence using population surveys through rigour in collecting self-reported data, diversifying surveillance data collection methods and facilitating collaboration.

This portfolio presents papers that have addressed a range of methodological and chronic disease and risk factor epidemiological issues. In terms of demonstrating rigour the publications have addressed the bias associated with non-response, the methodological rigour inherent in face-to-face surveys, the differences in estimates that can occur based on mode of administration, the science of telephone surveying and the importance of good questionnaire design to produce valid and meaningful data.

The literature presented has also demonstrated the first South Australian population-wide prevalence survey dealing with the consequences of domestic violence and associated issues (for males and females) in the community, and in

doing so, demonstrated the use of the telephone to collect large-scale data in Australia on domestic violence and associated factors in the population. In addition, the first time the importance of undertaking an array of methodological precautions during the data collection phase associated with collecting data on sensitive health issues on the telephone was demonstrated in Australia as was the assessment of the bias obtained in health estimates dependent upon which telephone-based sample was used.

In demonstrating the need for diversity in data collection the research submitted within this thesis has demonstrated the range of telephone surveying development issues and challenges in Australia and the benefits and the value of both face-to-face and telephone as survey data collection tools in Australia. The publications also made a significant contribution to the literature in the survey methodology area, in particular, within the systematic error in questionnaire design, the measurement error in BMI self-reported measurements, validity of self-reported height and weight, and the overall CATI methodology area. Epidemiological collaborative research in particular in the areas of social capital, HRT, mental health, suicide ideation, osteoporosis, interpersonal violence, chronic disease epidemiology and risk factor epidemiology was demonstrated.

As a consequence of my research, surveying populations about their health is now entrenched into public health and health service sectors in SA. Rigour in collecting self-reported data, diversifying survey and surveillance data collection methods and facilitating collaboration, has produced quality date-driven evidence for South Australia.

### **STATEMENT**

This work contains no material which has been accepted for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made in the text.

I give consent to this copy of my thesis being made available in the University Library.

The author acknowledged that copyright of published works contained within this thesis (as listed below) resides with the copyright holder/s of those works.

Anne W Taylor

Date

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To the population of South Australia for their willingness to be interviewed. Without the compliance, openness and trust of the South Australian population to give freely of their time the population wide view of the world, as highlighted throughout this document, would not be available.

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**To** my family. To my late father whose wisdom and enduring love keeps me focused. To my mother – thanks for your understanding and support – I will now return to the daughter with time on her hands to share with you in your autumn years. To Andrew and Megan – thank you for your understanding and continued support. Your pride in my achievements is more than matched by the pride I have in both of you. To Greg – thanks for your continued love and support. [Does this mean I will now have to help with the dishes?]

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# STATEMENTS OF AUTHORSHIP OF JOINTLY AUTHORED PAPERS PRESENTED WITHIN THIS THESIS

NOTE: Statements of authorship appear in the print copy of the thesis held in the University of Adelaide Library.

### **ABBREVIATIONS**

ABS Australian Bureau of Statistics
BEU Behavioural Epidemiology Unit

BMI Body Mass Index

BRFSS Behavioral Risk Factor Surveillance System
CAPI Computer Assister Personal Interviewing
CASI Computer Assisted Self Interviewing
CATI Computer Assisted Telephone Interviewing
CIDI Composite International Diagnostic Interview

CDC Centers for Disease Control
CVD Cardiovascular Disease
DHS Department of Human Services

EWP Electronic White Pages

GHQ28 General Health Questionnaire (28 items)

GIS Geographic Information Systems

HOS Health Omnibus Survey

HRT Hormone Replacement Therapy

IOCA Interviewer Quality Control of Australia

NHS National Health Survey

NPHP National Public Health Partnership

NT Northern Territory

NWAHS North West Adelaide Health Study

PROS Population Research and Outcome Studies

RDD Random Digit Dialing

SA South Australia

SAMSS SA Monitoring and Surveillance System

SEIFA Social Economic Index for Areas

SERCIS Social, Environmental and Risk Context Information System

SES Social Economic Status

SF1 \* Short Form questionnaire (1 item)
SF36 \* Short Form questionnaire (36 items)

SNAPS Smoking, nutrition, alcohol, physical activity and stress

TQEH The Queen Elizabeth Hospital

UK United Kingdom

USA United States of America
VOIP Voice Over Internet Protocol

WA Western Australia

WANTS Western Australia, Northern Territory and South Australia survey

WHI Women's Health Initiative
WHO World Health Organization

### **PREFACE**

My initial involvement in population health began in 1990. I was employed to work in South Australia (SA) on population surveys and surveillance systems when there were very few state health surveys and limited numbers of people working within a state health authority on methodological applications in health. I was also employed as a chronic disease epidemiologist when population-wide research of non-registry based chronic conditions, and their associated risk factors, was being increasingly acknowledged as an important area of research. Chronic disease and risk factor health surveys and surveillance systems developed in SA have progressed chronic disease risk factor data collection from ad-hoc population surveys to timely, relevant systems with improved access, use and application of data-driven evidence. Well-informed policy decisions, modification of risk factors associated with chronic diseases, increased emphasis on promotion of good health practices, appropriate targeting of health promotion campaigns (including an understanding of who is at risk and why and how interventions can be undertaken), and early detection of the conditions are all reliant on this evidence.

One of my first projects within the (then) South Australian Health Commission (now the Department of Health) was to organise and manage the first Health Omnibus Survey (HOS). This face-to-face survey vehicle, based on a clustered, multi-stage, systematic, self-weighting area sample, is now in its 17th year of continuous operation and within this time, my contribution to its development, scientific rigour and use by public health researchers is demonstrated by many of the peer-reviewed publications presented within this thesis.

The next major development of population health surveys within the SA Department of Health was the expansion of the available survey tools to include Computer Assisted Telephone Interviewing (CATI) methodology. By 1995, the Department undertook regular population surveys using this methodology. The

survey content, the technical difficulties and challenges, and the methodological developments are also documented in the publications included within this thesis. A range of diverse and sensitive health issues were addressed, often for the first time in Australia and hallmarked the acceptance of this form of data collection as a valid, cost-effective way of obtaining valid and reliable public health data.

A further significant development within the survey/surveillance field in SA was the development of a continuous chronic disease and risk factor surveillance system in which data are collected and disseminated in an on-going, structured way. After a visit to the Centers for Disease Control (CDC) and attendance at the Global Behavioural Risk Factor conferences in Atlanta in 1999 and Helsinki in 2001, I developed the SA Monitoring and Surveillance System (SAMSS) based on CDC's Behavioural Risk Factor Surveillance System (BRFSS). During this period, Professor David McQueen, the 'grandfather', global promoter and primary advocate of non-communicable surveillance systems visited Adelaide, at my invitation, and met with the Minister of Health and officially launched the new department service. Surveillance of chronic diseases and associated risk factors is crucial for controlling chronic diseases and the system developed in SA, and my involvement in the establishment and continued provision of quality surveillance information, is recognized as best practice nationally and internationally.

The early 2000s also saw the development of the North West Adelaide Health Study (NWAHS), a biomedical cohort study in which randomly selected participants were recruited and interviewed using survey methodology. As joint chief investigator of this project, I have been instrumental in the design, sampling, data collection, analysis and dissemination of the research findings. The continuous success of this major cohort study completes the full complement of SA population health surveys. These now range from a face-to-face annual survey (HOS), to topic specific telephone surveys, to a continuous telephone based surveillance system (SAMSS), to a biomedical cohort study (NWAHS).

It was interesting for me when deciding to undertake this peer-reviewed publication-based thesis, how rigour, diversifying data collection methods and collaboration were strongly associated with most of the 60+ publications I have authored over these years. I present my first-authored or principal authored published papers within these over-arching themes.

### Published papers contributing to this thesis

Selected published papers have for clarity of presentation been organised around the following themes:

## Theme 1: Improving the use of the telephone in the collection of self-reported data in population surveys

I have established rigour in the collection of self-reported large-scale data collection using the telephone. Over the course of my career the issues addressed include determining a) survey error characteristics; b) the appropriateness of using Electronic White Pages (EWP) as a valid and cost effective sample frame and c) the importance of good questionnaire design to produce valid and meaningful data when using the telephone, particularly when surveying a topic not normally surveyed via the telephone.

**Reference Paper 1:** Differences in health estimates using telephone and door-

to-door survey methods – a hypothetical exercise.

**Authors:** Taylor AW, Wilson DH, Wakefield M.

Journal citation: Australian and New Zealand Journal of Public Health.

1998; 22: 223-226.

The use of the telephone as a mode of self-reported data collection relies on the use of a quality, error-free sampling strategy. This publication was the first in Australia to assess the bias obtained in health estimates and made a significant contribution to the telephone survey literature and in particular to the question of survey error producing inherent bias. While bias was found in both hypothetical comparisons

(electronic white pages (EWP) and the random digit dialing (RDD) methodologies), based on cost-benefit comparison and ease of use, the publication recommended telephone sampling based on the EWP sampling.

This publication influenced other state-based health survey teams on the appropriateness of EWP as a valid and cost effective sample frame for chronic disease and risk factor epidemiological investigations and assessments. The publication was significant in demonstrating that the telephone, despite being a relatively new health survey mode in Australia, could collect valid, rigorous and quality health data, and Computer Assisted Telephone Interviewing (CATI) was acceptable as a surveying tool to collect data on health related issues. The publication highlighted the credibility of the survey team and the science of telephone surveying.

Reference Paper 2: Mental health status of the South Australian population.

Authors: Taylor AW, Wilson DH, Dal Grande E, Ben-Tovim D,

Elzinga RH, Goldney RD, MacFarlane AC, Cheok F,

Kirke K.

Journal citation: Australian and New Zealand Journal of Public Health.

2000; 24(1):29-34.

The publication was significant in highlighting in Australia the telephone as a viable, timely and appropriate survey tool to collect large scale data on the population on health issues where surveying was not the normal mode of data collection. The research determined the population prevalence of mental health disorders and the association of these conditions with other relevant issues such as known risk factors and health service utilisation. The publication drew attention to, for the first time in SA, the mental health status of the community-living, non-institutionalised population. The research indicated that nearly 20% of the adult population in SA had a mental health problem as measured by the 28-item General Health Questionnaire (GHQ28). The analysis brought to light univariate and multivariate evidence for decision-makers and highlighted the inequalities,

especially in service use. The research assisted in promoting more equitable mental health policies and services. Issues on mental health status are now routinely examined in chronic disease and risk factor surveillance systems around Australia. The research was important in demonstrating this survey method as appropriate in collecting valid population estimates and challenged commonly held norms and perceptions on survey content and what was appropriate to ask over the telephone.

**Reference Paper 3:** The second computer assisted telephone interviewing

(CATI) forum. The state of play of CATI survey

methods in Australia.

Authors: Wilson D, Taylor A, Chittleborough C.

**Journal citation:** Australian and New Zealand Journal of Public Health.

2001; 25:272-274

The breadth of work being undertaken in telephone based surveys in Australia is discussed in this publication and the range of development issues and challenges that lay ahead predicted. The significance of SA's place in the Australian Computer Assisted Telephone Interviewing (CATI) survey field was shown, as were the benefits of the telephone as a survey data collection tool, the value of collaboration and the science of telephone surveying. In addition, this publication demonstrated the level of development of CATI in Australia and authenticated CATI as a valid public health research tool.

Reference Paper 4: Domestic violence in South Australia: A population

survey of males and females.

Authors: Dal Grande E, Hickling J, Taylor AW, Woollacott T.

**Journal citation:** Australian and New Zealand Journal of Public Health.

2003: 27: 543-550.

In relation to reporting South Australia's first population-wide prevalence of domestic violence, this publication was also the first in Australia on a population level to highlight the domestic violence prevalence among males and associated issues in the community. It was unique in its use of the telephone to collect data

that had not previously been undertaken on both males and females in Australia. In addition, the range and rigour of methodological precautions undertaken during the survey process proved that the telephone was a safe and valid medium to collect quality, meaningful data on sensitive issues.

In total, nearly 20% of SA adults reported a domestic violence incident. Compared with previous estimates, which were based on police, hospital or women's shelter records, these data provided policy makers and service planners with important, previously unattainable information on this often hidden public health issue. The publication also reported the important health, social and economic consequences associated with domestic violence as well as the relationship with known risk factors. As such, domestic violence policies and preventive targeting efforts are now provided for domestic violence for males against females, and females against males, as well as same gender situations.

The importance of the publication centres on challenging commonly held assumptions regarding survey content of CATI and demonstrated the benefit of the telephone as an appropriate mode of data collection for sensitive issues. The value of collaboration between the diversity of partners involved in this study was also intrinsic within this publication as were the measurement of inequalities and providing information for evidence-based decision-making.

**Reference Paper 5:** Beware the pitfalls of ill-placed questions – revisiting

questionnaire ordering.

Authors: Taylor AW, Dal Grande E, Gill TK.

**Journal citation:** Social and Preventive Medicine. 2006; 51(1):43-44.

One of the concerns of the survey methodology literature is survey errors – those errors which are inherent in surveys and which are either sample or non-sampling based. This paper made a contribution to the literature surrounding systematic error, especially the measurement error obtained with incorrect or inappropriate

wording or ordering of questions. The first question of the Short Form 36 (SF36) set of questions is often used within surveys as an overall level of self-reported health status. This paper demonstrated that the different placement of this question within the questionnaire produces significantly differences and biased results. This publication demonstrated the importance of good questionnaire design in producing meaningful data.

**Reference Paper 6:** Detecting determinants of suicidal ideation – South

Australian surveillance system results.

Authors: Taylor AW, Dal Grande E, Gill, T, Fisher L, Goldney R.

**Journal citation:** Social and Preventive Medicine, 2006 (in press).

The paper highlighted the use of CATI interviews to collect data on the sensitive issue of suicidal ideation. The SA Monitoring and Surveillance System (SAMSS) is a telephone monitoring system that involves the collection of data over several years. Multivariate analysis indicated that adults more likely to report suicidal thoughts were statistically significantly more likely to be separated, divorced or never married, to not have enough money to save, to experience psychological distress and report several unhealthy behaviours. The value and importance of a telephone-based surveillance system to collect these types of data are highlighted in this paper, as is the survey content, the measurement of inequalities and the use of data for evidence-based decision-making.

### Theme 2: Diversifying chronic disease surveillance

Selected publications demonstrate how collecting surveillance data on chronic diseases and risk factors through diversifying data collection methods has been achieved through the SA Monitoring and Surveillance System (SAMSS) and the North West Adelaide Health Study (NWAHS).

**Reference Paper 7:** The South Australian Health Omnibus Survey 15 years

on – has public health benefited?

Authors: Taylor AW, Dal Grande E, Wilson DH.

**Journal citation:** South Australian Public Health Bulletin, 2006 (1):30-32.

This publication, demonstrating the value of the Health Omnibus Survey (HOS), drew attention to the importance of population-wide estimates of the problems, rather than clinic approximations, for chronic disease and risk factor epidemiology. While the Health Omnibus Survey (HOS) has been a lynch-pin between chronic disease epidemiology, medical specialists and other public health researchers and practitioners interested in community prevalence, knowledge, attitudes and behaviours associated with chronic diseases, the publication highlighted the methodological rigour inherent in this face-to-face survey vehicle. SA is unique in Australia in having one prominent survey vehicle that has proven over 17 years the benefit to the SA public health and medical community by being able to satisfy, using one survey tool, a wide range of public health data needs. The publication highlighted the methodology, based on the use of the highest standards of population survey methodology, with rigorous adherence to formal statistical and surveying techniques. In addition, the publication described the wide range of issues that are incorporated within this survey, the value of face-to-face survey methodology and the value of collaboration.

**Reference Paper 8:** Chronic disease surveillance in South Australia.

**Author:** Taylor AW.

**Journal citation:** South Australian Public Health Bulletin, 2006(1):6-9.

This publication described the range of survey methods available to collect data on chronic diseases and risk factors — most importantly the SA Monitoring and Surveillance System (SAMSS) and the North West Adelaide Health Study (NWAHS). These two data collection systems are prominent, best-practice chronic

disease and risk factor data collection tools. They provide, firstly, a continuous data collection vehicle that can provide seasonal trends and time series analyses and secondly, via the bio-medical cohort study, Australia's best estimates on the relationship between risk factors and disease outcome and the incidence of the major chronic conditions. It also demonstrates the movement, over time, across the disease continuum from good health to poor health and death.

The publication highlighted the inherent under-reporting of the self-reported risk factors and the under-diagnosis (or over-diagnosis) of the major chronic diseases and demonstrated the use and value of two different but complementary population survey modes of administration for evidence-based decision making.

Reference Paper 9: Measuring social capital in a disadvantaged urban

community.

Authors: Taylor AW, Williams C, Dal Grande E, Herriot M.

**Journal citation:** Australia and New Zealand Health Policy. 2006; 3:2.

This paper detailed problems associated with measuring social capital, and its relationship to health status, in the community. Representative population data were collected from adults in a known disadvantaged area of Adelaide using similar questions, but with different modes of collection (telephone and face-to-face). Univariate and multivariate analysis were undertaken to determine the relationship between health status and a wide range of social capital variables. The publication demonstrated the complexity of social capital and the problems inherent in its use in population surveys. This paper was significant in detailing survey content differences, mode of administration and the use of representative population surveys data for evidence-based decision-making.

### Theme 3: Improving population surveys through collaboration

Improving health outcomes and addressing measurement error can be improved through collaborative research. I have highlighted the mismatch between community perception of risk of getting the condition and the actual risk and the need to work with other collaborative researchers who might be ready to embark on costly randomly selected bio-medical studies.

Reference Paper 10:

A population perspective of Osteoporosis: How

common? What impact? How modifiable?

Authors:

Taylor AW, Gill T, Phillips P, Leach G.

Journal citation:

Australian Health Promotion Journal. 2003;14:61-5.

This publication demonstrates the significance in collaboration between government and non-government agencies (such as Osteoporosis SA) dedicated to improving health outcomes. Osteoporosis, compared to other chronic diseases, is often under-researched although the ramifications for the health system of this condition, based on the ageing of our society, are large. The research demonstrated the value of using a large representative quantitative study, and the recruitment of relevant individuals interviewed in the data collection phase, to a series of focus groups to qualitatively investigate the main findings from the survey. This publication highlighted the mismatch between community perception of risk of getting the condition and the actual risk. The publication also highlighted the benefits of large population samples for small prevalence diseases and the under-diagnosis of this condition.

Reference Paper 11:

Do people with risky behaviours participate in bio-

medical cohort studies?

**Authors:** 

Taylor AW, Dal Grande E, Gill, TK, Chittleborough C,

Wilson DH, Adams R, Grant J, Phillips P, Ruffin R.

Journal citation:

BMC Public Health. 2006 6:11.

A further publication submitted for inclusion within this thesis highlighted the bias associated with non-response, when randomly selected persons refused to participate in representative population surveys. This publication showed that participants were not different from the population being researched and the wider community they represent. The significance of this paper rests with other collaborative researchers who might be ready to embark on a costly randomly selected bio-medical cohort study and need to assess the possibility of bias associated with non-response.

Reference Paper 12: Post menopausal hormone therapy. Who takes it now

and do they differ from non-users?

Authors: Taylor AW, McLennan A, Avery J.

**Journal citation:** Australian and New Zealand Journal of Obstetrics and

Gynaecology. 2006; 46(2):128-135.

The monitoring of Hormone Replacement Therapy (HRT) use has been undertaken using the SA Health Omnibus Survey (HOS) representative population health survey since 1991. These time trends are the longest published in the world and this paper added to the series. The research showed that HRT usage is increasing, following the dramatic fall after the release of the Women's Health Initiative adverse findings which reported that HRT use increased the risk of cancer and stroke. HRT is now seen as beneficial for women who experience menopausal symptoms and new research is also showing positive benefits between HRT use and cognitive decline. This paper demonstrated significant contribution to the women's health, menopause and HRT literature and the value of the sustained and productive collaboration on this issue over many years.

**Reference Paper 13:** How valid are self-reported height and weight? A

comparison between CATI self report and clinic

measurements using a large representative cohort study.

Authors: Taylor AW, Dal Grande E, Gill, TK, Chittleborough C,

Wilson DH, Adams R, Grant J, Phillips P, Ruffin R.

Journal citation:

Australian and New Zealand Journal of Public Health. 2006; 30(3): 238-46.

Collaboration was crucial in identifying the important differences in measurement between self-reported and clinical measurements of height and weight (and the derived Body Mass Index (BMI) measurement). Given that many research activities in regard to the obesity epidemic use data based on self-reported estimates the paper detailed measurement error considerations and the value of collaboration.