

# NSW PUBLIC HEALTH BULLETIN

## Qualitative Research

### Doing good qualitative research in public health: not as easy as it looks

#### GUEST EDITORS

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**Abstract:** In this paper, we discuss qualitative research for public health professionals. Quality matters in qualitative research, but the principles by which it is judged are critically different from those used to judge epidemiology. Compared to quantitative research, good quality qualitative studies serve different aims, answer distinct research questions and have their own logic for sampling, data collection and analysis. There is, however, no need for antagonism between qualitative research and epidemiology; the two are complementary. With theoretical and methodological guidance from experienced qualitative researchers, public health professionals can learn how to make the most of qualitative research for themselves.

#### On qualitative research and public health

This issue of the *NSW Public Health Bulletin* presents examples of qualitative enquiry in public health. To introduce these papers, we will make some arguments about qualitative

enquiry. What is 'good' qualitative research? What is 'poor' qualitative research? How can we tell the difference? Why does it matter? How can you improve the quality of the qualitative research you commission or conduct?

Qualitative research is at a high-point of popularity in public health in Australia. As a rough and limited metric, we searched Medline on 19 June 2009 using the search string ((qualitative research.mp. OR Qualitative Research/ OR qualitative method\*.mp. OR qualitative stud\*.mp.) AND exp Public Health/ AND (australia.mp. or exp Australia/)). This search returned no hits before 1990, 57 papers published between 1991 and 2000, and 640 papers for the period 2001 to 2009. You might expect that, as qualitative researchers, we would be celebrating! Rather, we have shared concerns that the new-found popularity of qualitative research in public health and health services might be its downfall. We worry that it may produce so much slipshod qualitative research that audiences lose faith in it as a genre, either because the work self-evidently fails to be useful or illuminating, or because its authors are unable to defend it.

Danger lurks in the illusion that 'anyone can do' qualitative research. Epidemiological research is difficult for novices to do unsupervised. Complex statistics are more or less

unapproachable without formal training, likewise the sophisticated epidemiological designs required for publication in mainstream public health journals. In contrast, anyone who speaks a language can have a conversation with someone, write about it and call it research. This can lead to a proliferation of work calling itself qualitative research that bears little resemblance to the best practices in the field.

In this editorial, we describe what we mean by good qualitative research. As most of the studies the *Bulletin* publishes are epidemiological, we will organise our discussion by comparing epidemiological and qualitative principles. We will also focus on particular problems we have observed in the public health and health services literatures.

### The papers in this issue

This special issue of the *Bulletin* contains three peer-reviewed papers and the reflections of a participant in one of the reported studies. The authors were invited because each was working in a different substantive area of public health, and in a different methodological style. We are not arguing that these are the best or only ways of working. However, the resulting papers provide opportunities to draw out some important issues in qualitative research practice.

Julie Mooney-Somers and Lisa Maher detail a community-based participatory research (CBPR) project about blood-borne viruses and sexually transmissible infections. This project was conducted in collaboration with young Aboriginal and Torres Strait Islander people and their networks in three communities. CBPR seeks immediate benefit for participants: in this case, through the development of research capacity, building new links between community organisations and research institutions, and prioritising ethical and social considerations.<sup>1</sup> CBPR also prioritises a two-way learning process between researchers and participants. In a commentary attached to the paper, Robert Scott, a participant in the CBPR project, reflects on his experience of the process and the impact in his community.

In the second paper, Julie Leask reports on a project using role play to examine a critical moment in GP-patient communication: when a parent refuses immunisation for their child.<sup>2</sup>

In the final paper, Jenny Lewis combines qualitative and quantitative methods to ask: ‘Who is regarded as influential and what issues are considered important or difficult in health policy?’<sup>3</sup> Already you can see some of the diversity in qualitative research practice, diversity that is highly relevant to our next question.

### What is good quality qualitative research?

For epidemiologists, gold standards for good quality research are clear. Population-based random samples, random double-blind allocation in intervention trials, valid

and reliable instruments, appropriate statistical tests – all of these are shared ideals. Study types are clearly defined: case-control studies, cohort studies and randomised controlled trials each follow a well-known formula and conform to an increasingly well-articulated set of rules. However, the ‘rules’ for assessing the quality of qualitative research are less straightforward. There is a large, divided body of work on this subject.<sup>4–10</sup> Some seek to develop standardised rules for qualitative research and/or its reporting; others emphasise the need for flexibility and accountability from researchers rather than adherence to rigid principles.<sup>4,11,12</sup> It would be simplistic to attempt to provide a standard ‘formula’ for conducting qualitative enquiry here: instead we will outline some basic principles.

### Qualitative aims, research questions and general approach

Qualitative research achieves aims different from and complementary to those addressed in epidemiology.<sup>13</sup> It does this by approaching enquiry differently: through a less controlled, more open study design, by asking different kinds of research questions and by employing different ways of thinking.

Descriptive epidemiology asks questions about prevalence and its patterning. How many children are immunised? Are they unequally distributed by region? Is immunisation associated with level of education? Qualitative researchers attempt to understand what happens in participants’ everyday lives, how things work and what things mean to participants. Leask’s study, for example, asks about a process: ‘How do doctors deal with a parent who is refusing immunisation?’ Another qualitative study might ask: ‘What does it mean to a parent to have their child immunised?’ Epidemiological research studies variables pre-determined by the researcher. Variables of interest must be clearly defined before data collection starts. Qualitative researchers rarely presume which variables are important, but rather seek to discover what is relevant by speaking with participants, reading texts or observing behaviours. Qualitative studies are typically far less controlled than in epidemiology, certainly markedly less than a randomised controlled trial. Qualitative researchers seek to study the social world in its ordinary, complicated, changing state.

Epidemiological logic emphasises linearity and deductive thinking; in its idealised form, epidemiology begins with hypotheses and makes observations to test these hypotheses.<sup>14</sup> Qualitative researchers begin with induction: making observations to build theory, rather than to test theory. Then, as analysis progresses, they rely on abduction (moments of inspiration in which a hunch, clue, metaphor, explanation or pattern is imagined or recalled from existing theory to make sense of the data) and deduction (when the analyst goes back to the data to test these emerging ideas).<sup>14,15</sup> These forms of thinking create a continuous cycle of data collection and analysis.

In short, because qualitative researchers generally do not know what is important before they start, their studies are likely to be a lot more flexible than epidemiological studies, evolving to pursue new leads as they emerge in data collection and continuous analysis.

### *Qualitative sampling strategies*

A misunderstanding of the aims of qualitative research often leads to poor sampling in qualitative studies. In epidemiology, we wish to report prevalence of or association between variables in a defined population. We need to isolate those variables to prevent confounding. To achieve this, we ideally randomly select participants from the population; in intervention studies, we also randomise participants into different study arms. We collect and tabulate data on many variables, including demographic variables. The purpose is two-fold. The first purpose is to demonstrate that the participants could have been anybody in the population under study. They had the same chance of being selected or ending up in the intervention arm as everyone else; there was nothing special about them that could have confounded the results. The second purpose is to allow the researcher to statistically control for everything other than the variable of interest.

This is precisely the opposite of the logic of qualitative sampling: in fact, some qualitative researchers talk about participant ‘selection’ to distinguish it more clearly from probability sampling.<sup>16</sup> In good qualitative research, participants are not ‘average’ or ‘typical’. They are special. They are selected because they are uniquely positioned to help the researcher understand what happens or what things mean. Thus, qualitative sampling is often described as ‘purposive’; that is, chosen to serve an analytic purpose. Qualitative researchers can learn as much from atypical cases (by comparison and contrast) or from unexpected sources as they can from central cases or obvious sources. A cleaner may be able to tell you as much about pandemic control as a nurse, albeit from a different perspective. Someone who comes to work with influenza may help you understand the process of staying home when infected. In Leask’s study, for example, GPs known to have an interest in immunisation or expected to have unusual views about immunisation were included, as were parents of young children.<sup>2</sup> Lewis describes using an empirically generated map of policy makers’ reputations as a basis for selecting interviewees.<sup>3</sup> She identified eight groups of influential people. Some groups were widely considered important, others marginal. Lewis’s qualitative sampling included people from each group, thus providing a range of central and peripheral players with different kinds of expertise or disciplinary focus. Such sampling (along with the style of data collection) allows for a wide range of relevant concepts to emerge, and for examination, rather than control, of the relationship between them.

It is a terrible waste of qualitative research resources to hear exactly the same thing from 30 ‘average’ people who

are, for the purposes of the study, identical. This does little to advance the complexity or depth of the researchers’ understanding. The best qualitative samples are often determined in a dynamic way as the study progresses, the researcher constantly asking themselves questions such as: ‘Which new participants could help me better understand this important idea or process that I am starting to see in my analysis? What new questions might I ask my existing participants to help me understand? What might I need to observe to understand? What documents might help me understand?’ This dynamism requires ongoing modification of ethics approval, but in our experience Human Research Ethics Committees increasingly expect such modifications in qualitative studies, and are efficient in processing them.

### *Qualitative data collection methods*

If qualitative research is to understand what happens and what things mean, generate new and relevant concepts, and find out what is important to participants (rather than impose pre-determined variables), then data must be collected in a relatively open way. A large number of highly structured questions will generally produce yes/no or one-line answers that yield little insight. Mooney-Somers and Maher’s description of the data collection in their CBPR project provides one alternative.<sup>1</sup> Peer researchers spent time in the participating communities getting to know people, and this yielded important information despite being relatively informal and unstructured. Interviews were flexible and personal, commencing with the origins of both the peer researcher’s and participant’s families and with the participant’s history, proceeding to the participant’s own stories about their experience. This kind of open data gathering maximises the chance that important, unexpected insights will be developed.

### *Qualitative data analysis*

Analysis is a neglected area of qualitative research in public health and health services. There is generally scant description of analytic methods and reasoning in published papers. Researchers often appear to do nothing more than magically intuit and then list ‘themes’ from their data. Leask provides one alternative in her paper, making a detailed account of her analytic processes. Rather than simply stating that she generated ‘themes’, she specifies that she attended to the rhetorical styles used by the doctors (e.g. giving ‘yes but’ responses, or engaging in ‘scientific ping pong’).<sup>2</sup> Rather than focusing on counting the number of doctors who used each strategy, her analysis explains the detail of each strategy, including how they worked rhetorically in the simulated consultation.

We would argue that the best qualitative research is oriented less toward generating theme lists and counting occurrence, and more toward understanding what things mean and how they work. Experienced qualitative

## Box 1. Suggested references for beginning qualitative research

### Books and reports to introduce the field

Mason J. Qualitative researching. 2nd ed. London: Sage Publications; 2002.  
Patton MQ. Qualitative research & evaluation methods. 3rd ed. Thousand Oaks, CA: Sage Publications; 2001.  
The SAGE Qualitative Research Kit. London: Sage Publications; 2007.  
Silverman D. Doing qualitative research: a practical handbook. 2nd ed. London: Sage Publications; 2005.  
Australian Government, National Health and Medical Research Council, Australian Research Council, Australian Vice-Chancellors Committee. National Statement on Ethical Conduct in Human Research. Canberra: Australian Government; 2007.

### Series in the medical literature

There have been several useful series published in the medical literature in recent years.

#### *The 1995 British Medical Journal series*

This series introduces qualitative research and focuses on data collection methods.

Jones R. Why do qualitative research? *BMJ* 1995; 311(6996): 42–5.  
Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995; 311(6996): 2.  
Britten N. Qualitative research: qualitative interviews in medical-research. *BMJ* 1995; 311(6999): 251–3.  
Kitzinger J. Qualitative research: introducing focus groups. *BMJ* 1995; 311(7000): 299–302.  
Mays N, Pope C. Qualitative research: observational methods in health-care settings. *BMJ* 1995; 311(6998): 182–4.  
Mays N, Pope C. Qualitative research: rigour and qualitative research. *BMJ* 1995; 311(6997): 109–12.

#### *The 2008 British Medical Journal series*

This series focuses on quality assessment, use of theory, and extant qualitative methodologies.

Kuper A, Reeves S, Levinson W. Qualitative research: an introduction to reading and appraising qualitative research. *BMJ* 2008; 337(7666): 404–9.  
Lingard L, Albert M, Levinson W. Qualitative research: grounded theory, mixed methods, and action research. *BMJ* 2008; 337(7667): 459–61.  
Reeves S, Kuper A, Hodges BD. Qualitative research: qualitative research methodologies – ethnography. *BMJ* 2008; 337(7668): 512–4.  
Reeves S, Albert M, Kuper A, Hodges B. Qualitative research: why use theories in qualitative research? *BMJ* 2008; 337(7670): 631–4.  
Kuper A, Lingard L, Levinson W. Qualitative research: critically appraising qualitative research. *BMJ* 2008; 337(7671): 687–9.

#### *From the Medical Journal of Australia*

Kitto SC, Chesters J, Grbich C. Quality in qualitative research: Criteria for authors and assessors in the submission and assessment of qualitative research articles for the Medical Journal of Australia. *Med J Aust* 2008; 188(4): 243–6.

researchers generally use more subtle indicators of importance than counting. How passionately was something spoken of? What was unspoken or unable to be said? Who said what? How can we better understand the differences? What might these differences tell us about the process we are studying? How rich and complex was a concept? What consequences did participants describe in relation to it? If, for example, only a small number of people described a problem in a health service, but they described it as so profoundly undermining their faith in clinicians and the system that they would no longer attend, this may be a problem worth exploring with more participants, in order to better understand it.

One qualitative alternative to an emphasis on frequency counts is the concept of ‘saturation’. Experienced qualitative researchers generally seek to ‘saturate’ concepts: that is, to ensure that they have enough data to make a full and detailed account of the concepts that are central in their

analysis.<sup>17,18</sup> Flexibility in sampling allows qualitative researchers to return to the field to collect more data until they reach this point. The logic underpinning this strategy is: keep talking with the most informative people until you have a good understanding of how things work and what they mean. This differs from the alternative logic: list the topics that most people agreed with. Exploratory analytic logic is a good match for purposive sampling; frequency count logic is better matched to well-designed quantitative research using probability sampling.

#### *Reporting and methodology in qualitative research*

It is important in any research to distinguish between methodology and methods. Methods are the actions you take in a research project. Method is what you do: your sampling, your data collection, your analysis. Methodology is justification of your methods.<sup>19</sup> You engage in methodology for yourself throughout a study, examining each choice you make and thinking about whether it is justified in relation to



your study as it evolves. You also engage in methodology when you report a study for an audience and justify the methods you have used to them.

There is rarely adequate attention given to methodology in qualitative research papers, a problem widely acknowledged and not confined to public health or health services research. If authors do not justify their methods, it is difficult to determine the quality of their work. The critical question to ask oneself when engaging in methodology for others is: ‘What would a reader need to know to be able to evaluate my research for themselves? Which parts of my thinking and methods do I need to explain?’

This is not a matter of apologising for one’s research; conversely, it means arguing for its usefulness. This goes to the heart of the debate about what good quality qualitative research is. It is often a difficult argument for epidemiologically trained people to make, because the methodology of epidemiology is so different from the methodology of qualitative research. However, as Lucy Yardley argues:

While traditional criteria for research quality are often inappropriate, and the ethos and plurality of many qualitative methods are incompatible with fixed, universal procedures and standards, some way of evaluating the quality of research employing qualitative methods is absolutely necessary, in both senses of the word – both imperative and unavoidable. All interpretations contain an implicit claim of authority; it makes no sense to engage in a process of analysis and then deny that it has any validity!<sup>4</sup>

Qualitative research is time-consuming. Why would you recruit participants, collect data and go through the lengthy agonies of analysis, only to say apologetically, in keeping with epidemiological principles: ‘but of course the sample size is very small and you can’t generalise’? Many novices make these apologies and attempt to make their qualitative research look as ‘epidemiological’ as possible. Think about sampling. We sometimes see tables of standard demographics in methods sections of qualitative papers, purporting to demonstrate how much like the general population the sample were. The fault for this does not always lie with authors: sometimes editors or reviewers demand such details as a condition of publication. Not only are such demographics unlikely to satisfy the requirements of epidemiology, but also, as you will remember, they are inconsistent with the principles of purposive participant selection. If you succeed in ‘proving’ that your participants were ‘average’ or ‘typical’, rather than especially relevant to your research question and analysis, you will probably thereby demonstrate that your sampling was misdirected.

Rather than engaging in a doomed attempt to conform to epidemiological standards, a qualitative methodologist should justify, in detail, aims, research questions and how

they evolved, assumptions made and theories drawn on, sample selected, data collection and analysis procedures, and the evolving ethical aspects of a study. In relation to sampling, there should be a detailed account of exactly who was included and, critically, an explanation of how each group was relevant to the research question and the analysis.<sup>20</sup> The contributors to this issue have provided some illustrations of this logic. When Leask, for example, provides a detailed account of her analytic methods, and presents and explains a ‘negative case’ – a doctor who had a different approach to dealing with the mother who refused immunisation – she is doing methodological work for you as the reader.<sup>2</sup> Mooney-Somers and Maher, similarly, do methodological work when they explain that their interview questions were developed in conversation with participants and were designed to respect cultural protocols, and that this was guided by the principles underlying the study.<sup>1</sup>

A brief note about existing qualitative methodologies. There are a number of methodological traditions in qualitative research – coherent ways of working that have been honed and reiterated over time. They include ethnography, grounded theory, phenomenology and narrative methodology.<sup>21</sup> CBPR, illustrated in this issue, is another of these extant methodologies. Each of them is a terrific set of resources that can be used to guide a research project. Each of them has existed and been evolving for decades – sometimes more than a century. Each of them has considerable, complex theoretical substance. There is a tendency to slap methodological labels – especially the label ‘grounded theory’ – on anything qualitative, as a kind of badge of authenticity.<sup>12,22</sup> This is a little like going on a harbour cruise for palaeontologists and claiming to be an expert on the Permian–Triassic extinction event, when in fact you have just read a pamphlet about dinosaurs from the Australian Museum. It will become obvious fairly quickly that you do not know your marine organisms from your terrestrial invertebrates, and you will not be able to get off the boat for at least 4 hours. Traditions such as grounded theory are only useful if used actively and coherently throughout a study – to help one engage in methodology for oneself. It is only then that it makes sense to use the label when engaging in methodology for others.

### The conceptual underpinnings of research: reclaiming theory

Karl Popper, the great philosopher of science responsible for the notion of falsification, famously said that he did not care where scientists got their ideas from: the origin of ideas was a matter for psychology.<sup>14</sup> All that mattered to science was the transformation of ideas into hypotheses and the deductive testing that followed. This may help explain a somewhat unfavourable view of theory among some public health researchers.

We think ‘theoretical’ should be reclaimed as a compliment! ‘Being theoretical’ or ‘doing theory’ means contributing to a cohesive explanation of some aspect of our world. This is the highest possible purpose of research – far greater than the distillation of lonely facts. Theory is also inescapable, along with the baggage of values that theory carries. In fact, the variables in an epidemiological study are a reduction of complex values and theoretical concepts. If, in epidemiology, we classify a person according to their ‘race’ rather than their ‘ethnicity’, their ‘culture’, their ‘language spoken at home’ or the amount of ‘cultural capital’ they have access to, a theoretical choice has been made, whether or not it is acknowledged. When we treat an individual as independent in analysis, measuring nothing to do with the society, communities or cultures of which they are a part, we are making a theoretically loaded choice.

Because of its open, inductive approach to the world, qualitative research is extremely good at generating new theories. The best qualitative research will also be knowingly informed by theories of many kinds. Theories provide concepts to use in analysis. They guide study design: encouraging focus on groups (like cultures or sub-cultures) or on individuals; describing in detail or building a conceptual model.<sup>21</sup> Theories inform data creation. When you record an interview, for example, what have you recorded? People’s experiences? Their attitudes? Their beliefs? Their perceptions? Their performances?<sup>23</sup> Would these be the same in any interview, or would they be different at different times and with different interviewers? What effect do you have in the study, and how should you best be accountable for this effect? Even the way we write is a theoretically loaded choice. Our use of an active first person voice and of authors’ first names in this editorial, for example, reveals our belief that researchers should present themselves as real live human individuals, rather than ‘objective’, distant and inscrutable, as any piece of research or writing is a product of the people who have crafted it. Theories are everywhere, and good researchers of all kinds acknowledge them and use them as resources.<sup>24</sup>

Lewis argues that the theories about policy that you bring to a study of policy influence will change what you look at.<sup>3</sup> If you use a theory that suggests that influence rests in institutions, you will examine institutions; if in conflicting interests, you will study interests; if in contests of ideas, you will study the movement of ideas. These are not right or wrong, but different, and it is possible to be open to participants’ perspectives within each frame. Mooney-Somers and Maher’s paper, like most CBPR, also begins with normative theoretical commitments about what research should be.<sup>1</sup> Because of its theoretical orientation, CBPR defines good research as that which includes participants as equals and achieves concrete change in participants’ communities, a theoretical commitment that prompted Scott’s contribution to the issue.

## In conclusion: does the qualitative/quantitative distinction matter?

Do we need to make a distinction between qualitative and quantitative research? We would argue that we need distinction without antagonism: a kind of cross-cultural understanding and mutual respect. Qualitative and quantitative research can contribute differently and equally to knowledge in public health and health services.<sup>13</sup> However, if qualitative research is to keep its end of this bargain, it may need to be protected from its new-found popularity and allowed to assert and follow its own principles. We would urge those with a nascent interest in qualitative research not to attempt to take it up as a straightforward, instrumental toolbox of methods. To public health audiences, qualitative research may seem new; in fact, the ideas at its heart go back centuries, some say as far as Aristotle.<sup>25,26</sup> The methods of contemporary qualitative research were initiated in anthropology and sociology at the turn of the 20th century and have been evolving ever since.<sup>27,28</sup> Good qualitative research requires careful thought about methodology and theory in the context of this history, which is difficult for beginners to achieve without support and training. We advise public health professionals to work with experienced qualitative researchers until they have established themselves in this new world.

Qualitative enquiry is a fractured, rich and potentially highly rewarding field of endeavour: this issue of the *Bulletin* is a tiny part of it. Public health, we believe, needs both epidemiology and qualitative research. Without epidemiology we cannot answer questions about the prevalence of and association between health determinants and outcomes. Without qualitative enquiry, it is difficult to explain how individuals interpret health and illness in their everyday lives, or to understand the complex workings of the social, cultural and institutional systems that are central to our health and wellbeing. We hope that this issue of the *Bulletin* will stimulate debate about the place of qualitative enquiry in public health and health services research in Australia. At the very least, it might prevent you from getting stuck on a metaphoric harbour cruise with only a pamphlet for company.

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# The Indigenous Resiliency Project: a worked example of community-based participatory research

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**Abstract:** Community-based participatory research (CBPR) is often cited as a suitable methodological approach for academic researchers wanting to work collaboratively with Indigenous communities. This paper describes the Indigenous Resiliency Project currently being conducted in Redfern, Townsville and Perth. This case study is used to demonstrate how a group of university-based researchers and Aboriginal Community Controlled Health Services have used CBPR to work with young Indigenous Australians to explore young people's perspectives on resilience in relation to bloodborne viruses and sexually transmissible infections. This paper also describes some initial benefits gained through the process of developing the Indigenous Resiliency CBPR Project, such as: developing research capacity; establishing relationships between community organisations and research institutions; and prioritising ethical and social considerations in the conduct of research. A commentary on the experience of one health worker involved in the project accompanies the paper.

Aboriginal people have been examined, measured and asked questions ... They have been passive subjects rather than participants.<sup>1</sup>

Despite the volume of research conducted on the health of Indigenous Australians, there is a perception that Indigenous people have derived little direct benefit from these efforts.<sup>2</sup> The history of research on Indigenous

peoples, both locally and internationally, has produced a deep suspicion of research, with a recent series of community workshops indicating that Australian Indigenous communities remain suspicious of research conducted by mainstream organisations.<sup>1,3,4</sup> In 2002, the National Health and Medical Research Council (NHMRC) launched its Road Map, a set of guidelines for health research with Indigenous communities calling for 'community involvement in the development, conduct and communication of research'.<sup>5</sup> More recently, the National Statement on Ethical Conduct in Human Research states that the 'research approach should value and create opportunities to draw on the knowledge and wisdom of Aboriginal and Torres Strait Islander Peoples by their active engagement in the research processes, including the interpretation of the research data'.<sup>6</sup> Aboriginal and Torres Strait Islander organisations have developed their own research protocols for researchers wanting to work with Indigenous communities, and a number of Human Research Ethics Committees have been established to assess research affecting Indigenous people and their communities.<sup>7</sup> It is in this context that Indigenous health research increasingly involves partnerships between university-based researchers and Indigenous communities and organisations. These partnerships are seen as a way of ensuring research is responsive to community needs, conducted in a culturally appropriate manner, and beneficial to the community.

Community-based participatory research (CBPR) is an approach that allows researchers to work with communities to generate knowledge about and solutions to problems the community is facing. This framework repositions the people who would usually be the object of the research as participants in the research process; 'the researched become the researchers'.<sup>8</sup> CBPR involves more than consultation; it focuses on developing community capacity to participate as co-investigators in developing, conducting and disseminating the research.<sup>9</sup> It encompasses approaches such as participatory action research, action research, partnership research and collaborative inquiry, and is characterised by an emphasis on communities as co-researchers. A review of CBPR undertaken in the United States suggests two core elements: a reciprocal co-learner relationship between researchers and communities (which includes shared decision-making and the removal of barriers to participation); and the immediate and direct benefit



of new knowledge (which includes shared ownership of research products).<sup>9</sup>

CBPR has often been utilised in research with vulnerable or marginalised populations and is increasingly employed in research with Indigenous communities.<sup>1,9-17</sup> The principles and characteristics of CBPR are considered to have the potential to address the failings, and ‘colonising-effects’, of previous research on Indigenous peoples.<sup>8</sup> Further, by involving affected communities in the analysis and interpretation of data, CBPR has the potential to avoid the misrepresentation of ‘Indigenous societies, culture and persons by non-Indigenous academics and professionals’.<sup>8</sup> Instead of seeing ‘experts’ – usually non-Indigenous people – as the only legitimate source of knowledge, CBPR recognises and values the knowledge of ‘ordinary’ people. While the technical knowledge of researchers is valuable, it is not the only legitimate way of knowing about the world.<sup>18</sup> Moreover, prioritising community members’ knowledge of community needs and perspectives may increase the likelihood of any intervention arising from the research having beneficial outcomes for the affected community.<sup>9</sup> While a CBPR framework is increasingly used in mainstream public health research, there are few published examples of the day-to-day practicalities of using this framework to undertake research with Indigenous communities in Australia. This paper uses the Indigenous Resiliency Project as a case study to demonstrate how a CBPR approach can be employed to develop community-based research into highly sensitive and challenging health issues.

### The Indigenous Resiliency Project

The Indigenous Resiliency CBPR Project is one component of an international collaboration exploring the role of resiliency in responding to bloodborne viruses (BBVs) and sexually transmissible infections (STIs) in Indigenous communities in Australia, New Zealand and Canada. Funded by the NHMRC, the Australian component is being undertaken by a collaboration of Aboriginal Community Controlled Health Services (ACCHS): Townsville Aboriginal and Islanders Health Service (TAIHS), Aboriginal Medical Service, Redfern (AMS Redfern) and Derbarl Yerrigan Health Service, Perth (DY); a research institution, the National Centre in HIV Epidemiology and Clinical Research; and several independent Indigenous researchers. This collaboration worked with international partners to develop a funding application. The Boards of Directors of the three participating ACCHS reviewed and approved each component of the project during the initial project development stage, and again when each component began. Formal ethical review processes have been followed through the Human Research Ethics Committees of the Aboriginal Health and Medical Research Council of NSW, the Western Australian Office of Aboriginal Health and the University

of New South Wales. An Australian Steering Committee (ASC), made up of two representatives from the three community partners and the research partner, along with several independent Indigenous researchers, oversees the development of the project. The ASC provides guidance on scientific, administrative and budgetary matters and determines areas of priority for the project. The ASC plays a vital leadership role in advising on cultural matters related to the conduct of the study, including the review and approval of all project dissemination, and assists in strengthening communication with all key stakeholder communities. This is the forum through which shared decision-making is achieved and the shared ownership of research products is protected.<sup>9</sup>

The Indigenous Resiliency CBPR Project brings young Indigenous Australians, participating health services and university-based researchers together to develop and conduct qualitative research on what protects young Indigenous Australians against BBVs and STIs. It aims to build the capacity of participating health services in research practice; identify, assess and enhance the STI and BBV resilience capability of Aboriginal and Torres Strait Islander people in three project sites; and inform opportunities to decrease the risk of STI and BBV transmission in project site communities. In each project site, a locally employed (but centrally-funded) site coordinator and health service staff, under the guidance of their Board of Directors, work with a project-based qualitative study coordinator and university-based researchers to engage with young Indigenous people from the local community (peer researchers) to develop and conduct the project. The Indigenous Resiliency CBPR Project is not a multi-site project where the same protocol is implemented across all sites. Instead, each project ‘is a custom job’, with the local projects recognising diversity by developing in response to the priorities – and capacities – of the local community and health service.<sup>19</sup>

### Methods

Individual interviews and focus groups are being used to explore young people’s lived experiences of sexual behaviour and drug use, learning about STIs and BBVs in their families and communities, and accessing services for prevention, testing and treatment. These qualitative approaches offer opportunities for understanding the meaning of sexual behaviour and drug use, and the contexts in which people contract or avoid STIs and BBVs. Individual face-to-face interviews, in particular, allow peer researchers to create a space where participants can share stories of how they have drawn on their own and their community’s strengths to keep themselves protected against STIs and BBVs.

CBPR is a dynamic process, with the project emerging as the process proceeds. Project questions and processes are

likely to be progressively redefined and qualitative methods are conducive to this. It is also necessary for the project to be flexible to the developing skill and confidence of peer researchers (and health service staff). In CBPR, methods are selected on the basis that they are 'useful and useable to all those participating in the process'.<sup>18</sup> This means selecting methods that can be taught quickly to people with a broad range of educational experiences and literacy skills. To date, 20 young people and many health service staff and mentors have been trained in qualitative sampling, developing interview questions, and conducting and recording interviews. In due course, these young people, health service staff and mentors will participate in the thematic analysis of the qualitative data they have collected and disseminate findings through the preparation of community reports and involvement in community forums. People have been provided with the skills required to participate actively in each stage of the research process. The methods used do not need expensive hardware or software. Indeed, most of the data has been collected using pen and paper. This has allowed the development of a skill base that is more likely to be sustainable when the project ceases.

The relationship between interviewer and interviewee is crucial in qualitative methods as data is generated through their interactions. The Indigenous Resiliency CBPR Project concerns personal and often stigmatised behaviours, and the research teams spent a lot of time discussing how to talk about these in sensitive and culturally appropriate ways. Semi-structured interviews and focus groups allow peer researchers to use their knowledge and expertise to conduct a conversation around the interview questions and adapt their questions and style for individual participants. Interviews usually began with a conversation about where the participants' and researchers' families were from. This was an important cultural protocol to follow and the amount of time spent on this varied considerably, especially if there was a shared family connection. The first question in the interview schedule (in both Townsville and Redfern) was about the participant's history. This allowed the participant to provide a context for the interview, and for the researcher and participant to get to know each other before questions about STIs and BBVs began. Again, this was an important cultural protocol but is not usual for a qualitative research interview.

CBPR recognises local methods of knowledge gathering as valid.<sup>19</sup> Semi-structured interview schedules were developed in the research training and development workshop held at each site. This meant that the peer researchers and health service staff shaped the question content and the way questions were to be asked. Interviewers used the schedule to guide their conversation, encouraging participants to share personal experiences and stories from their lives. Data was collected by spending time meeting and

getting to know people in the community (potential participants and others). Individual interviews were conducted on the street, in parks and shopping malls and in community-owned spaces. The flexibility of a qualitative approach meant that interviews could be held when an opportunity arose, and could, if necessary, be started, paused and resumed at a different time. In the two active project sites, 95 individual interviews and seven focus groups have been conducted with young Indigenous Australians. In each case, an Indigenous researcher – peer, health service staff or mentor – was the interviewer or focus group facilitator.

At the time of writing, one project site is engaged in data analysis, a second is actively involved in data collection, and the third is developing the project, so there are no outcome data to report. However, the aims of the project are not exclusively oriented to data-driven outcomes. CBPR foregrounds action and changes occur in service provision and the lives of people participating in the research throughout the project.<sup>9</sup> The remainder of this paper will reflect on the process of the research and describe some process-driven outcomes.

## Discussion

### *Reflecting community priorities*

The ASC asked each health service to identify a priority population to engage. In TAIHS, a consultation process was undertaken internally and with key stakeholders and community members. Consensus emerged around homeless and residentially unstable young people as the priority population group.<sup>20</sup> In contrast, the AMS Redfern had an existing association with a local Aboriginal Men's Group (Babana), whom they invited to become a partner in the local project. Thus, their priority population became young men.

The university-based researchers developed a three-day research development and training workshop covering research ethics, communication, research sampling and recruitment, individual and group interviewing, participant observation, writing field notes and analysis of qualitative data (these workshops are described elsewhere).<sup>21</sup> Each workshop was tailored to the relevant priority population and the educational level of the peer researchers taking part in the project. Peer researchers, health services staff and – in Redfern – mentors, participated in the workshops. Over the course of the workshops, research processes and materials fundamental to the project were developed. These included inclusion and exclusion criteria for research participants; a recruitment plan; a list of topics and questions for the individual and group interviews; and introductory statements for interviews. In this way, peer researchers, health service staff and university-based researchers collaboratively developed project questions reflecting local priorities and meanings, and

established ways of conducting the project that were appropriate to the priority population and the local community.<sup>20,21</sup>

### *Working with peer researchers*

At the heart of CBPR is a commitment to work with people affected by the issue under investigation. For the Indigenous Resiliency CBPR Project, this means inviting young Indigenous people from the local community to engage with the project as peer researchers – from the development of research questions and materials, to data collection, data analysis and dissemination. It also means valuing the knowledge peer researchers have gained through their lived experiences, and giving them a mandate to influence the project and its process.

In Townsville and Redfern, the journeys of the peer researchers have been quite different.<sup>20</sup> In Townsville, eight young men and women who had experienced residential insecurity (either personally or through a close family member or friend) were recruited through local contacts and health promotion events. These young people participated in the research training and development workshop and four were invited to work with the local team to develop and conduct the project. By the focus group stage, most of the original peer researchers were no longer involved and a ninth young person was trained to participate in the final stage of data collection. The AMS Redfern, in partnership with Babana Aboriginal Men's Group, identified eight young men through professional or community contacts. All eight were asked to make a commitment to engage with the project for the duration (2 days per week for 4 months). The AMS Redfern and Babana Aboriginal Men's Group introduced a parallel mentoring program where members of the men's group were matched with peer researchers to provide ongoing cultural support. This unique and valuable innovation has undoubtedly been crucial in maintaining the level of peer researcher involvement, with eight peers involved throughout. In keeping with the spirit of CBPR, the role of these mentors evolved during the project and they became an integral part of the research, attending research meetings and accompanying peer researchers during field work and data collection.

There has been a lot of discussion within the project teams about changes in the young people engaged as researchers. Health service staff and mentors have commented on their increasing self-esteem and confidence, and their willingness to speak out about issues they feel the project needs to address differently. The young people themselves have spoken of an increased sense of community belonging gained from working within a community organisation. The project has increased the youth voices within the participating health services, creating opportunities for dialogue between young people and health workers. Being involved in the project has also connected the participants

to people who have become invested in their future. Opportunities for training and employment have been regularly brought to the peers' attention. Two of the peer researchers are now working in health service delivery within community-controlled and mainstream organisations. Important connections are also being made between current leaders in the local Indigenous community and the peer researchers, themselves potential community leaders. Several of the peer researchers have been invited to sit as community or youth representatives on advisory boards and committees.

### *Research as action*

The Indigenous Resiliency CBPR Project has had quite a high profile within the participating health services. For the duration of the project, there are dedicated site coordinators based within each health service and other staff who work closely with the project. In Redfern, eight peer researchers, eight mentors, two health service staff and a university-based researcher worked in the health service 2 days a week for 4 months. This is a significant presence, and raises the profile not only of the Indigenous Resiliency CBPR Project but also of research generally. The health service's support of research is demonstrated to staff, clients and other people visiting the service. More importantly, a research skill base is being developed within the health service, and in the case of the peer researchers (and in Redfern, the mentors), in the local community. This is an important outcome, and addresses the first aim of the Indigenous Resiliency CBPR Project to develop research capacity. It is too early to judge the success or sustainability of this capacity; however, in both health services conversations have begun about future programs of research, some involving a CBPR framework.

The research teams spend a significant amount of time in the community recruiting participants and collecting data. The peer researchers, site coordinators, and, in Redfern, the mentors, wear identification badges and introduce themselves as conducting a research project with TAIHS or the AMS Redfern. This is beneficial to the project as the research is *vouched for* by a respected community organisation. There is also an important benefit to the community, as the research teams are effectively promoting a community-controlled health service, often to people who are considered 'hard to reach'. In Townsville in particular, some of the more mobile young people were not aware of TAIHS and were keen to get more information about a health service run by and for their community. In both sites, people often asked about accessing the health service or sought help with making appointments. Whilst the Indigenous Resiliency CBPR Project is not a peer education project, there is a strong desire among the peer researchers to provide information to people who participate in the



project. The project formally supported the principle of 'no research without service' by organising referrals and having information available for peer researchers to distribute. More informally, peer researchers, health service staff and mentors spoke to many people (who did not necessarily participate in the project) about STIs and BBVs. Having members of the community talking openly about STIs and BBVs raises the profile of these infections and may help alleviate the shame associated with discussing them.

A less predictable outcome of the project has been the connections established between the health services and external organisations that provide services to the priority population in each project site. In Townsville, a service that provided a venue for a focus group asked for regular discussions around sexual and other health issues to be provided for the young people attending their service. During the first AMS Redfern workshop, participants visited several organisations that provide services to young people. The mentors (who include staff from local high schools and the probation and parole service) and health service staff made contact with programs that could be useful to their clients. Similarly, the mainstream organisations made contact with their local community-controlled health service, a connection that could facilitate future referrals for their Indigenous clients.

## Conclusion

Until Indigenous communities have the resources or capacity to conduct their own research, partnerships with university-based researchers who bring technical expertise are inevitable.<sup>13</sup> CBPR is an approach that simultaneously facilitates a research partnership and provides 'the training and resources that will allow the community to act on its own behalf in the future'.<sup>18</sup>

This paper has described how the Indigenous Resiliency Project has utilised a CBPR approach to build a partnership between community organisations and research institutions, and to develop a project that is community-owned, locally relevant and culturally appropriate. An early benefit of this approach, and a key objective of the project, is that community members have been trained to conduct research that responds to the health priorities set by their communities. It is too early to evaluate the long-term sustainability or success of this research capacity, which may include seeking research funding, creating research jobs, developing research partnerships and continuing to conduct research.<sup>9</sup> Nor can we assess whether the relationships between the Indigenous communities, ACCHS and research institutions that have facilitated this genuinely participatory project endure and generate new projects. The principal issue that this paper cannot address at this early stage is the effect that this project will have on the health of the participating communities.

Adopting a CBPR approach is not easy; it brings considerable challenges for researchers and communities. CBPR requires considerably more time, money, personnel and personal commitment than traditional research approaches. As Baum and colleagues note, it is messy, unpredictable and there are often differences in priorities between researchers and communities.<sup>8</sup> However, unlike other research approaches, CBPR combines research and action in a way that has the potential for communities to see the benefits of research conducted by, rather than on, them.

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## Commentary

*Robert Scott is the men's sexual health worker at the Townsville Aboriginal and Islanders Health Service (TAIHS). He has been actively involved in the Indigenous Resiliency Project. This is a reflection on his involvement.*

I remember when the researchers from Sydney made their first visit to our service (TAIHS) to talk about the project. The staff didn't think the project would have much to do with us as it seemed to be all about management and the timeline was quite long. I became involved because of my job as a sexual health worker and sat in on the teleconferences. It was like going from high school to a university lecture. There was a lot of information and background and often it was hard to understand. When I went to my first face-to-face meeting in Perth, the picture became much clearer and because I was away from work I could spend time and talk to people. I asked a lot of questions and got a good insight into the project.

In the past, research has not always been done properly, and this has caused community unease. It was hard when I got back to work because there was a lot of resistance in the service and the community to research. Our clinic staff did not understand what the project was about and put stickers on the front cover of peoples' charts that read, 'The contents of this file is not to be used for research'. This was a complete misunderstanding as we were never going to access charts but it shows how important it is to consult with people properly before you begin.

When the project started, we talked about the kind of personnel we needed. I was worried that if we had a health worker in the coordinator position they would end up doing non-project work. In the end, we did employ a registered nurse (Wani Erick). Sometimes the health service has needed Wani's and my clinical skills more than they have needed the project to progress. The tension between research and service delivery is a familiar one for Aboriginal and other health workers.

The only thing I think we could have done better was to have a male worker more available to do some of the interviews with young men. I was on clinic duty during the data collection time and was unable to help much with that aspect, so we have a bias toward women in our sample.

The project has had an impact on the TAIHS workforce. The research has made people more talkative and that has the potential to improve community knowledge. Wani and I shared a lot of information about STIs and BBVs that has been passed on to our clients. The fieldwork really raised awareness of our service in the community, especially among young people at risk who didn't access our service. Wani got a lot of requests for information, services and referrals and because she was based in the service she knew all the doctors here, when they worked and what services people could access, so she could connect them directly to the right things and organise appointments or transport.

At the beginning of the project, we used a decision matrix to identify the target population our service was going to work with. Working through the criteria in the matrix was a good way to inform people about the project, because we talked to lots of people in the service and the community. TAIHS has a very successful mothers and babies clinic so the obvious population for us was pregnant women, but in some ways that was too easy. Thinking about who would benefit from the research and who needed it meant we selected residentially insecure young people. We provide some services to this population already but this was a concentrated way to engage them and give something back. A comfortable and secure home life is so important for young people and I see a lot coming through here that have problems at home or are living in overcrowded houses. Having this documented through the research is a very positive outcome. It shows our strengths and our weakness as a service, and that young people are concerned about their health in different ways. I hope we can use this to apply for extra funding because the only real measure of success is seeing actual changes.

# How do general practitioners persuade parents to vaccinate their children? A study using standardised scenarios

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**Abstract: Objective:** To understand how general practitioners (GPs) address parental concerns about childhood immunisation using standardised scenarios. **Methods:** A combination of typical case and intensity sampling was used to recruit GPs. Interviews began with role-play vignettes of four different scenarios, exemplifying concerns about immunisation and the parents who have them. They ended with GPs' reflections on these encounters. Transcripts were analysed with the focus on describing and evaluating typical persuasive strategies. **Results:** Eleven GPs were interviewed from a range of demographic areas. In the role plays, GPs acknowledged the mother's concerns, tailored their discussion to her individual circumstances, and conveyed the notion of choice. Theoretical frameworks guided some in their responses. Less successful strategies were to enter into games of scientific 'ping pong'; to discredit a mother's source of information; or to ask confronting hypothetical questions. Attempts to negotiate with a mother refusing all vaccines for her children proved to be the most challenging role play. **Conclusions:** GPs tended to adopt the role of persuader rather than informer. Communication frameworks such as shared decision-making may help them to better balance these roles.

The analysis of health care communication has been a growing area of interest for qualitative researchers. It has required methods of data collection that access discussions that occur between patients and health professionals. Video

or audio-assisted observations of actual patient encounters have been used.<sup>1,2</sup> Another approach uses standardised patients. These are people who act out a set patient scenario with a clinician.<sup>3</sup> A widely used assessment tool in medical education, standardised patients have been increasingly used in qualitative research of doctor–patient communication.<sup>4–6</sup> This study used this method to attempt to describe how general practitioners (GPs) communicate with parents concerned about immunisation.

Discussions about immunisation occur frequently in face-to-face encounters between a health professional and a parent.<sup>7</sup> These discussions are key since health professionals are the single most important influence on a parent's decision to immunise or not immunise their children.<sup>8–11</sup> Health professionals have a public health responsibility to maximise childhood immunisation rates. They are also faced with ethical and legal obligations to ensure that parents are adequately informed about the risks and benefits of immunisation and that valid consent is given before a vaccine is administered.

This study investigated the ways GPs communicate about vaccine risk and benefit to parents who have strong concerns about immunisation. GPs were chosen because they represented 85% of immunisation providers in NSW at the time of the study.

## Methods

The study sought to assess the strategies GPs used when communicating with parents. To achieve the study's aims, direct observation of actual conversations with parents would have been the ideal method but this was costly and impractical. A second option was to talk to GPs about their experiences of communicating with parents, yet this approach was likely to result in a polemic on what GPs think 'should' happen. A middle ground was the choice of standardised patients, which would allow both an assessment of the GP's rhetoric and a way into the GP's own reflection of their experiences.

Ethical approval to conduct this study was gained from the University of Sydney Human Research Ethics Committee.

For the standardised scenarios in this study, characters and scripts were based on what is known of parents who refuse or vacillate about immunisation, and the arguments they

## Box 1. Role-play scenarios

### Scenario 1: Considering delaying immunisation

Susan Kelso, 27, lives in the inner-city and has one child, a 7 week-old girl. She is currently on maternity leave from her job in publishing.

I'm wondering whether we might be better to delay the first shot until she is a bit older.

It's always been at the back of my mind what these vaccines do to their immunity when they are so young and fragile.

### Scenario 2: Vaccine refusal

Janice Cook has two children, Nathan, 4, and Ashlyn, 6½. She is at home full-time and would like you to sign a Conscientious Objection form.\*

I'm afraid I don't believe in immunisation. Ashlyn had a terrible time after her 12 month DTP vaccine and developed allergies. Since then, I've done a lot of reading about this issue and there seems to be lots of evidence, even in the medical journals, that immunisation is not as safe as we're led to believe.

Anyhow, we've decided it's better for them to develop natural immunity. We try to give them lots of fresh fruit and vegetables, we purify all our water. Nathan hardly ever has colds compared with the other children at day care and certainly doesn't have the allergies that Ashlyn suffers.

I have chosen to vaccinate him homeopathically and am just here to get the form signed.

\*Prior to interview 5, the following trigger was used: Nathan has a deep gash in his leg, which requires suturing. You ask if he has had his tetanus immunisation.

employ.<sup>9,12–16</sup> Proposed scenarios were discussed with a team of researchers, piloted with two GPs and modified accordingly (Box 1).

### Participants

The study used a purposive sample drawn from typical case sampling and intensity sampling.<sup>17</sup> Initially, GPs who were assumed to be typical cases were sought, using a database of respondents to a previous survey who had agreed to a further interview. GPs were chosen from a mix of inner-urban and suburban locations within the Sydney metropolitan area. Each GP was sent a letter that was followed by a telephone call. Due to a poor response using this method, the sample was supplemented with GPs known to have a particular interest in immunisation (intensity sampling). Some of these were 'outliers' – interesting and divergent cases who broaden the scope of the enquiry and provide richer insights than if the study were limited to only typical cases. Similar mixed recruitment strategies have been used elsewhere.<sup>18</sup>

### Interviews

Interviews were conducted between November 2000 and February 2001. Participants who agreed to an interview were visited in their own practice. Two interstate GPs were interviewed over the telephone and another asked to email her responses. It was emphasised that the study aimed to describe how GPs communicate with parents about childhood immunisation.

In each interview, the researcher played the role of the parent, first giving the GP a brief character description and then initiating the script. GPs were asked to respond as they would in a normal encounter. The mock encounter

was followed by questions aimed at debriefing; ascertaining whether the GP felt the scenarios were similar to situations experienced with parents; and discussing their actual experiences.

All interviews were recorded and transcribed by a professional transcription service. Each transcription was checked for inaccuracies.

### Analysis

To evaluate GP communication, the analysis used previous research on what parents desire from such encounters; guidelines in the area of patient–doctor communication; the views of two mothers who read a representative cross-section of the transcripts; and the researcher's own in-character reflections.<sup>15,19,20</sup>

Qualitative analysis is interpretive by nature.<sup>21</sup> When the researcher is the instrument, he or she must be aware of how his or her beliefs and experiences shape the analysis. The qualitative literature labels this 'reflexivity'.<sup>22</sup> A journal was kept that included the author's own experiences and reflections relevant to the study. This enabled the analysis to proceed with an awareness of how these might interact with the interpretation.

Transcripts were coded according to the dual perspective of describing typical rhetorical styles and evaluating interactions. Open coding was used where each interview transcript was read and re-read, and emerging patterns and themes noted freely.<sup>23</sup> For each interview, memorandums were recorded that made brief observations about the wider meaning of the text and its connection to the emerging themes. Themes were reviewed, refined and grouped



into a hierarchical coding system.<sup>24</sup> All interviews were then coded according to this system. Passages preceding the coded text were re-read to ensure they were understood in context. Transcripts were also grouped by scenario in order to map typical discursive patterns peculiar to the scenarios. A sample of transcripts considered to most represent a cross-section of the themes was read by two women who had young children. The author met with each woman to discuss her impressions of the GPs' responses. These were used to refine the emergent thematic framework.

## Results

Twenty-eight GPs were approached via a letter and a follow-up telephone call. Of the 21 who returned calls, eight declined, with most citing lack of time and one because she was opposed to immunisation. Eleven interviews were completed.

Participants came from a range of areas, including three from semi-rural areas; three from mid-low income suburban areas; three from mid-high income suburban areas; and two from mid-high income inner-urban areas. Six of the GPs were women.

The analysis was grouped under three major categories: GPs' persuasive strategies; content of what GPs said about risk; and the contexts in which discussions with parents occur. This paper focuses on the GPs' persuasive strategies in responding to two of the four scenarios: one mother who was thinking about delaying scheduled vaccines until her baby was older and one who refused vaccines altogether. Each theme is identified in bold text.

### Scenario 1: Considering delaying immunisation

Responses to Susan's concerns could be broadly described as a '**yes, but**' strategy. The 'yes' was where the GP acknowledged Susan's concerns, sometimes with personalisation. The 'but' was usually expressed as straightforward negation or reframing. One GP even conceded his own concerns about immunisation:

I'm a parent myself... I know how awful it is to give these tiny little ones a vaccine, **but** it is safer for them to have it so that they have some protection at that young age from these quite serious diseases. (GP 2)

Many GPs **probed** for specifics, revealing that Susan held concerns about preservatives after reading about them on a website. One GP explained the strategic usefulness of this:

It's only once you have agreed with them that ... you become their ally before you can start changing them. (GP 11)

Following the acknowledgment and probing, the conjunction 'but' was often used to establish that Susan was

**wrong** using subtle and unsubtle techniques. In relation to Susan's baby's immunity, one GP said:

... what we are actually doing is stimulating it by giving the shots. We're not harming it. (GP 5)

GPs then directly addressed the preservatives issue, **discrediting her source** of information – the internet. Many compared disease risk with vaccine reaction risk. Some went on to define the possible vaccine side effects and how these might be minimised. Some reframed the vulnerability issue by focusing on the potentially damaging effects of a young child contracting a vaccine-preventable disease.

### Scenario 2: Vaccine refusal

After the fifth GP interview, this scenario was introduced differently so that Janice approached the GP to have her Conscientious Objection form signed. Initial GPs had mentioned this as the most common context for encountering vaccine refusal. The Conscientious Objection form is a declaration signed by the parent and the provider, stating that a discussion about the risks and benefits of immunisation has taken place. It allows non-immunising parents in Australia to access government allowances.

Almost all GPs engaged in concerted attempts to convince Janice to vaccinate. Some offered written information and proposed to extend the consultation over a period of time. In the tetanus scenario, some offered immunoglobulin and penicillin as a **compromise**. In the form-signing scenario, two said they would not sign the form.

This scenario took the longest to act out and was confronting and uncomfortable to role play. It was often terminated by the interviewer before resolution because of time constraints. Debriefing was therefore important. Underlying the difficulties were diametrically opposed belief systems about health and disease prevention. One GP reflected on these conflicts:

I actually think most doctors have a lot of trouble with these sort of patients. They feel quite combatant towards them and quite stupidly evangelical in the same way that these people can be evangelical. (GP 10)

Most GPs began by attempting to convince Janice that her **causal thinking** had been wrong:

The fact that it occurred at that time in your child and the child subsequently developed various allergies I think is just a coincidence. It's just a timing effect, not a cause ... it was just something that occurred more or less at the same time. (GP 6)

Some conversations with Janice descended into games of **scientific 'ping pong'** where she would present her opinion, the GP would reply, and the conversation would get lost in a duel of competing claims.

GPs appealed to Janice's sense of **social obligation** to other children who were at risk from her unvaccinated child. A repeated technique was the use of **hypothetical scenarios** to persuade Janice:

How would you feel if your child got something? Say your child got measles and another child caught it from your child and that child died? (GP 9)

GPs portrayed strong discomfort with Janice's position. Although many would later acknowledge they stood little chance of changing her mind, many explained their persistence as concern for the child's safety, particularly in the tetanus scenario:

You probably are not going to get her back. That child is at risk. But you can't actually get a court order easily to make him have a tetanus vaccination. I mean, what do you do? (GP 4)

One GP used a counselling framework to explain his persistence:

If, in a counselling situation, someone makes an invalid statement, and then goes on with something and you don't challenge it, they read that response as you agreeing with their position, or concurring with it. (GP 5)

This strategy was useful to the GP in terms of providing a reference point if Janice changed her mind. Using the transtheoretical model of behaviour change, the GP would establish the mother's position on immunisation with respect to her readiness for change and move from there:<sup>25</sup>

If you want to get behavioural change out of people, you want to try three positions, like 'don't talk to me, I don't want to know about it', 'give me the information, I'm shopping', or 'don't bother me with details, just do it'. They're the three basic levels of readiness for change. So she is number one, 'don't bother me with the information'. So you don't bother them with the information. But you've still got to let them know that there's information, that there is something out there, if they transition to stage 2. (GP 5)

Another GP, while engaged in concerted persuasive efforts, felt ultimately that keeping the 'door open' was in the interests of the child's health should future medical care be needed (GP 9).

One GP's strategy differed strikingly from most. He first established the firmness of Janice's decision by asking, 'Have you ever had any doubts about your decision?'. He then ascertained her knowledge about the consequences of her refusal and completed the discussion. In the debriefing he said:

This isn't about being successful; this is a mother's choice. I don't consider it a failure if the person doesn't choose to immunise their child. (GP 10)

Even though he shared with the other GPs a support for immunisation, his response to Janice was different in terms of brevity, content and implicit goals.

## Discussion

This study examined the communication of 11 GPs who were likely to be confident communicators and interested in immunisation. The study identified many positive aspects of GP communication, some of which are reported in this paper. Almost all GPs acknowledged the mother's concerns and sought to understand them further. Many also acknowledged the mother's choice in relation to immunisation. They would often tailor their advice to the woman's individual circumstances and the use of frameworks to guide communication appeared helpful. Perhaps less successful aspects of the encounters were when GPs entered into games of scientific 'ping pong'; discredited a mother's source of information; or asked hypothetical questions. While all these points are worthy of discussion, the latter two will be explored.

In the discussions following the role plays, GPs would explain their source discrediting strategy. For many, the internet and news media appeared to comprise an external battlefield. From it, parents brought various opinions, arguments and fashions in thinking. By implication, the GP's surgery represented the centre of calm scientific rationality – the 'war room' where those who entered equipped themselves to counter-attack the outside influences. In the discrediting of sources was the implicit message, 'Don't trust what is out there, trust what is in here'. Indeed, many GPs referred to an existing level of trust with their patients. However, where trust is not yet built – either because of a patient's transience or scepticism towards medicine – this strategy may not be helpful. Pointing women to more reliable websites provides an alternative viewpoint while not rejecting their preferred source of information.

Similarly, there are likely to be more successful strategies than the asking of hypothetical 'how would you feel if' questions, as seen in the vaccine refusal scenario. These force the respondent into a rhetorical corner where they must inhabit the GPs definition of how events would transpire. Such strategies are unlikely to be productive in risk discussions because they either alienate the respondent or manipulate them into action. A better way to convey the message might be in terms of it being a woman's own choice, which also acknowledges vaccine risks but is more value neutral. The following example does not oblige the person to answer an emotive question:

You have to consider the illnesses you are preventing and how comfortable you feel about facing those without immunisation, versus the actual immunisation and the slight risks that are associated with that. That is the balancing act you need to decide ... (GP 10)

The doctors in this study appeared to readily take on the promotion of immunisation. This mainly generated discussion of the risks of non-immunisation, leaving less time to talk about the side effects from vaccines and their magnitude (a finding not detailed in this paper). This focus on persuasion is understandable: if a parent refuses immunisation, the costs are incurred by their child and society more broadly. In addition, GPs receive financial incentives to maintain high vaccination rates within their practices. However, doctors are also obliged to help parents reach an informed decision. Balancing these obligations is challenging.

Strong persuasion, rather than achieving its goal, may be counter-productive, further polarising a parent and, at worst, eroding trust.<sup>26,27</sup> The fields of motivational interviewing and shared decision-making recommend a respectful interchange where health professionals help patients consider their options and the consequences of these.<sup>20,26</sup> This less direct approach gives parents a supportive space to make their choice in which immunisation would often be chosen.<sup>28</sup> Some, however, will stay committed in their resolve and providers must recognise their autonomy.<sup>29</sup> The ethical merits of refusing to care for a family who will not vaccinate their child have been discussed.<sup>30</sup> However, as some of the GPs in this study noted, maintaining a relationship with parents who delay or refuse immunisation leaves the door open should they change their mind.

In undertaking this study, I assumed that my findings were shaped by the research context and myself as interviewer. I had two roles in this study: that of actor and researcher. Rather than being a conflict, this approach added strength to the analysis, helping me to experience what a parent might feel in these interactions. Reflecting on my own experiences allowed me to explicitly identify how a background in nursing, my expectations and my preferences influenced my reading and evaluation of the interactions in this study. They particularly informed the categorisation of the themes into helpful and unhelpful communication, aided by the reflections of the two mothers and widely accepted principles of good communication.

## Conclusions

The GPs in this study made concerted attempts to encourage immunisation while giving some information about its risks. Balancing the promotion of public health alongside supporting valid consent is possible but remains challenging. Communication frameworks such as shared decision-making may help doctors to negotiate these tensions.

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# Understanding policy influence and the public health agenda

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**Abstract:** This paper analyses how the policy process is shaped by networks of influence. It reports on a study of health policy influence in Victoria, describing the theoretical framework and the methods used. Social network analysis, combined with interviews, was used to map the network's structure, identify important individuals and examine issues seen to be important and difficult. Which issues an individual is interested in are related to where that person sits within the network. It also demonstrates how influence structures the health policy agenda, and provides insights for public health practitioners who aim to influence policy.

Policy analysis is a broad church, covering numerous theoretical frameworks and empirical approaches. Depending on how policy and politics are defined, policy analysis can be a highly rational endeavour, focused on specific instances of policy, or highly political and concerned with examining how policy is made.

This paper is focused on politics and the policy-making process. Rather than examining a specific example of policy development, it analyses the factors that shape and constrain the policy process. Political scientists, in analysing the policy process, concentrate on institutions, interests and ideas. An institutional approach examines the impact of political institutions such as systems and regimes of government, and a range of factors that generate veto points.<sup>1</sup> Steinmo and Watts provide an exemplar of this approach applied to health insurance policy in the United States.<sup>2</sup> An interest-based approach examines the influence of powerful interest groups using Marxist or other elitist models of power in society. In health policy,

one of the best examples of this is Alford's book on health care reform.<sup>3</sup> Ideas are a less common starting point.<sup>4</sup> An ideational approach concentrates on struggles over problem definition, values and the policy paradigms that shape a particular sector.<sup>5</sup> There are very few examples of this in health policy, although an exception has been reported.<sup>6</sup> This paper analyses both influence and ideas in the making of health policy.

Just as policy analysis employs different theoretical approaches, it also uses an array of methods that borrow from – among others – anthropology, economics, political science and sociology. Documentary analysis, interviews, observations and questionnaire-based surveys are commonly employed. This paper reports on a study that combines different approaches and uses qualitative and quantitative methods side by side.

A study of influence in health policy in Victoria is used as an example. The questions this study aimed to answer, the theoretical framework behind the analysis and the methods used, are described. Combining an initial assessment of who is seen to be influential with more in-depth interviews provides a rich exploration of perceived influence in health policy, and insights into how this helps shape the health policy agenda. The findings are summarised and the benefits of using a combination of methods are highlighted. Finally, some implications for public health are discussed.

## **Influence in health policy**

Kingdon's landmark study of policy agenda setting began with asking why policy makers pay attention to some things rather than others.<sup>7</sup> Why do some issues become the focus of policy action while others languish on the periphery of policy considerations? He analysed the process that leads from the long list of potential things that are swirling around in the 'policy primeval soup', to the shortlist of issues that are the focus of serious policy attention.

While Kingdon does not explicitly discuss networks, his description of policy entrepreneurs roaming around, discussing, arguing and amending their policy proposals with others, brings the network idea to mind. The study reported here began with a similar impetus: a concern with policy agenda setting. However, it aimed to examine who was seen to be influential and how these people were

connected to each other as the foundation for understanding who was 'in the soup' and what ideas they were discussing. This represents a new approach to capturing how the policy agenda is shaped.

This study began in 2001. It aimed to identify who was seen to be influential and what they thought the main health policy issues were. It also aimed to map who recognised whom as influential, and which of them knew each other. The theoretical framework used in this research, along with the methodological approach and the analysis of data, have been described elsewhere.<sup>8,9</sup> A brief overview is provided here.

### Theoretical framework and concepts

Health policy making, like policy in other sectors, rests on the accumulation and use of power by those involved in the policy process. Examining this is, however, far from straightforward, even when power is used transparently. Several approaches at different levels have been used to understand power and policy making. One useful focus at the macro level is Alford's work on the dominant, challenging and repressed structural interests that shape health policy.<sup>3</sup> However, analysis at this level reveals only a partial story of how health policy is made. If health policy is seen as a complex network of continuing interactions between actors who use structures and argumentation to articulate their ideas about health, then a micro-level approach holds promise for stepping outside the traditional descriptions that accompany examinations of well established and powerful interests.<sup>8</sup> Using social network analysis to focus on connections between individuals provides such a framework for analysis.

The networks of interest here consisted of a set of nodes (individuals) linked by direct personal connections (or ties), based on nominations of influence. Conceiving of influence as a network resource that has symbolic utility (whether it is used or not), it is obvious that actors have resources of their own, as well as those they can access through their ties with other actors.<sup>10</sup> Mapping social networks of interpersonal ties generates a detailed picture of individual connections, which indicates who has access to resources and who exercises control within a network. The research reported here is perceptual – it is not based on who actually made decisions in a specific instance, or who won a particular debate in parliament. It is focused purely on examining who is regarded as influential. The list of people nominated in this study consisted of senior people in important positions who would be seen to hold power through their organisational positions. This provides some indication that although the network is based on perceived influence, the people nominated are indeed likely to have some influence on policy making.

Network concepts provide a theoretical focal point for thinking about influence in relational terms, and inform research design. Social network analysis was used to

design the data collection methods and to shape the data analysis for this study. It has recently started to gain favour in health research. The main concept of interest here is structural equivalence – the idea that people within a network can be seen as equivalent (and interchangeable) in the structure of the network if the patterns of relations between them and their roles are similar. Blockmodelling is a quantitative technique that partitions actors into sub-groups within a network, based on regularities of patterns of relations among actors in the network.<sup>11</sup> This means establishing who nominates others in a similar pattern, and who is nominated by others in similar patterns. A second important network concept is centrality, a measure of an individual's importance: in this case, how highly nominated an individual is by others in the network.<sup>12</sup>

### Methods

Mapping influence first requires the identification of influential actors. Some methods for doing this define influential actors as those holding positions in the top levels of relevant organisations. Other methods rely on reputation, using people to nominate others whom they consider influential. Both of these methods have shortcomings – the first by assigning influence to people in senior positions in certain organisations, regardless of their ability to influence events, and the second by potentially leading to the nomination of those who simply make the most noise. A reputational approach was used in this study since it was regarded as less problematic given the focus on individuals rather than positions and organisations.

A non-medically qualified academic, who had previously held senior positions in several different governments across Australia, was the starting point for nominations. This person was asked to nominate a list of people regarded as influential in health policy in Victoria. The definition of influence used was:

... a demonstrated capacity to do one or more of the following: shape ideas about policy, initiate policy proposals, substantially change or veto others' proposals, or substantially affect the implementation of policy in relation to health. Influential people are those who make a significant difference at one or more stages of the policy process.<sup>9</sup>

The process then snowballed from this individual's list of nominations. Details of how this was done and the criteria for stopping the process are described elsewhere.<sup>9</sup> Nominees were not provided with others' lists, and no set number of nominations was asked for. At the end of this process, 62 people had returned nomination forms, noting whether they had ongoing contact with those they nominated. The majority of ties (82%) were to people the nominator claimed to have ongoing contact with, so this group of nominators appear to have based their judgments of influence on whom they knew personally. However, an actor moving in these circles who is highly nominated as influential is sure to know other influential actors. While

the means of generating these nominations could be defined as qualitative (since people were given an open-ended question about who is influential), examining structural equivalence is based on a quantitative analysis of patterns of nominations, as described earlier.

The second part of this research identified the issues these influential people saw as important. Twenty people, spread across the network, were interviewed. They were asked to name:

- up to five issues they regarded as the most important in current Victorian health policy; and
- any issues they saw as being particularly difficult or neglected.

The interviews were open-ended, with plenty of time for interviewees to talk through the issues they nominated with some prompting. The interviews were recorded and transcribed, and the issues grouped thematically based on the interviewees' explanation of what each issue involved. These transcribed descriptions were also used to assess the way in which the interviewees spoke about particular issues, focusing on the words used and their decisiveness or hesitation in discussing them. While this is an open-ended qualitative approach, the data generated were used both qualitatively and quantitatively.

### Analysing influence and issues

Network structure, based on the data gathered from the people who completed nomination forms in this study, was analysed using a blockmodelling procedure. This generated eight blocks, two of which were central to the structure of the network and highly nominated by the other groups as influential. There was a group (block) containing actors in key positions who were both structurally important and highly visible. This included the Victorian Minister for Health, the Minister's senior political advisor and the Head of the Victorian Department of Human Services (which includes health). This was called the core group, both because all other groups nominated this group as influential, and because it contained people who held important policy positions. The other most important group – public health medicine – is, at first glance, a less obviously influential group of people. These actors were located in universities, research institutes and non-government organisations. All were medically trained and eight of the nine were men.

This analysis provided insights into the structure of this network of influence. Clearly, the core group consisted of those who held positional decision-making power in the policy process. It seems reasonable to assume that whoever occupied these positions would be widely perceived as influential, and also well-placed to exercise influence in policy making. The second group also contained individuals who held senior positions (deans and heads of departments/institutes/organisations), but they were not in designated policy-making positions.

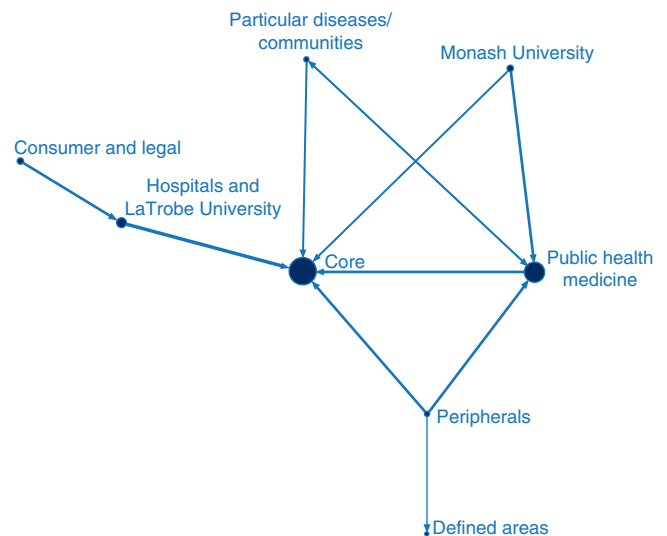


Figure 1. Example of a network of influence in health. Source: Lewis.<sup>9</sup>

A diagram of this network structure, illustrating the eight groups identified by the blockmodel, is shown in Figure 1. The lines (ties or links) between the groups have different thicknesses based on the percentage of all possible ties between them, with thicker lines indicating (relatively) more frequent nominations of influence. The arrowheads indicate the direction of the nominations. For example, public health medicine nominated the core, but this was not reciprocated, whereas the tie between public health medicine and particular diseases/communities was. The size of the circles (nodes) varies according to the mean number of nominations per person in that block, ranging from a mean of 17.5 for those in the core group, to 2.3 in defined areas. The core block had the most central position in this network, followed by the public health medicine block. The actors in the core block were nominated by people in all the other blocks except the defined areas and consumer and legal blocks.

Two or three people from each block were interviewed in order to cover the eight blocks identified. The interview material generated a list of the most frequently mentioned policy issues. Table 1 lists the top six issues nominated by the interviewees, and indicates whether they were mentioned as important or difficult. Two distinct types of issues were identified. The first were those seen to be most important: demand in public hospitals, workforce recruitment and retention, split responsibilities between the Commonwealth and the states and territories and quality of care. The second were those seen to be difficult: health inequalities topped this list. The lack of emphasis on prevention was fairly evenly nominated as important and difficult.

Across the 20 interviews, a clear distinction arose between the issues that were most frequently mentioned in terms of

**Table 1. Important issues and difficult issues in Victorian health policy – top six\* that emerged from 107 issue-mentions by 20 policy actors**

Issue in health policy	Important issues	Difficult issues	Total
1. Inequalities in health/structural determinants	4	7	11
2. Recruitment and retention of health workforce/training and planning issues	7	2	9
3. Demand in public hospitals	7	1	8
4. Disaggregation, fragmentation and split responsibilities in the health system	7	1	8
5. Lack of emphasis on prevention, health promotion, public health/focus on acute care	4	3	7
6. Improving quality of care	6	1	7

\*A total of 18 different issues were identified. A complete list can be found elsewhere.<sup>8</sup>

actions being taken to fix them and the issues that were more often seen as difficult. Difficult issues were discussed as those that nobody really knew how to deal with or those that nobody was seriously doing anything about. The important/difficult distinction was very clear on the basis of both whether an issue was nominated as important or difficult, and also in terms of how the issue was spoken about.

Some quotes from the interviews give a flavour of how the different types of issues were discussed. The first, from a participant in the core group, describes an important issue:

Our main concerns are around emergency demand in hospitals and all indicators around that, ambulance bypass, around blockages in emergency departments, about the unprecedented growth in admissions through emergency departments ...

The second, from a participant in the public health medicine group, describes a difficult issue:

... are we serious about inequalities or are we quite happy about them? ... The whole indigenous health issue ... the reality is we're not serious about it ... if we were we could do something about these things.

Finally, analysing the overall structure of the network, combined with who is discussing particular issues, generates an analysis of the link between network position and the distribution of issues. There is a high level of correspondence between an individual's centrality in the network and the importance of that person's issues compared with the overall ranking of issues. In other words, the most central people nominated the most frequently identified important issues. Those who were slightly less central tended to nominate the difficult issues. This suggests that which issues you are interested in is related to how central you are in a network. It is also apparent that which issues are being discussed relates to which subgroup you are part of. Full details of this analysis have been published elsewhere.<sup>8</sup>

## Discussion

This study attempted to understand how perceived influence shapes the health policy agenda. It employed political science frameworks and combined an interest in influence and ideas as a means for examining the policy-making process. Qualitative and quantitative methods were used in concert so that both influence and issues could be explored side by side and the relative prominence given to particular issues and the different modes of speaking about them understood.

Some limitations of the study should be acknowledged. First, it was based on perceptions of influence, not demonstrated influence. Second, it was a focused mapping of one locality of a network that had no boundaries, and not a sample across a network. A different starting point could generate a different network locale; however, the nomination of people in important positions suggests that it is representative of influence to some extent. Third, the lists of issues generated should not be taken to represent the health policy agenda in Victoria at this time. It does, however, provide insights into the link between influence and agenda setting, by mapping influential people, the issues they see as important and how they think about them, and the link between influence and issues.

This paper demonstrates the strength of an analysis that rests on strong theoretical and empirical foundations. It highlights the insights that can be gained from combining different theories and methods to analyse the policy process in public health. The quantitative component of this study (the blockmodelling) was able to provide insights into perceived influence, while the qualitative component (the interviews) provided information on the issues being discussed and how they were viewed by those working in this arena. Carrying out the first of these generates a picture of influence while the second points to important and difficult issues. Only together do they generate a picture of how the health policy agenda is shaped.

The fact that public health issues largely fell into the difficult basket has important implications for the public health



agenda. Opportunities for policy change are greatest when new voices can be heard: for the agenda to change, patterns of influence must change. This analysis suggests that for a decisive shift towards an emphasis on prevention rather than cure, and for a focus on health inequalities, either newly influential actors with these as their main agenda items are required, or those who are already central will have to be convinced both of the need to place these higher on the agenda, and that they are not unachievable.

Finally, this study throws out a challenge to those working in public health to think about their level of engagement with the policy process, and strategies for improving that engagement, through coalition building and ongoing interactions with those who hold important policy-making positions.

### Conclusion

The theoretical framework and the combination of methods used to examine influence in health policy demonstrate the link between networks, influence and agenda setting in health policy. Public health practitioners can use these findings to examine their own positions in influencing policy.

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# Syphilis

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Syphilis is an infectious disease of increasing public health significance. An estimated 12 million people are infected each year worldwide.<sup>1</sup>

## What is syphilis?

Syphilis is a bacterial infection caused by the spirochaete *Treponema pallidum*, subsp. *pallidum*.<sup>2</sup> Clinical disease encompasses three stages: primary, secondary and tertiary syphilis. Latent syphilis, or syphilis with no clinical manifestations, is divided into early and late latent infection, with early latency being within 12 months of infection. For public health and surveillance purposes, infectious syphilis includes primary, secondary and early latent syphilis (tertiary syphilis is exceedingly rare in Australia). Congenital syphilis is a foetal infection that occurs frequently as a result of untreated syphilis infection in pregnant women.

## Mode of transmission

Syphilis is transmitted sexually from direct contact with infectious exudates from obvious or concealed early lesions of skin and mucous membranes of infected people. It is also transmitted through vertical transmission from mother to child in utero. Transmission after the first 12 months of infection is rare. The incubation period for syphilis ranges from 9 to 90 days.

The clinical manifestations of syphilis include a primary ulcer (chancre) with swollen lymph nodes, skin rashes, warts, and bone, cardiovascular and neurological disease. Syphilis in pregnancy can cause abortion, premature delivery, stillbirth and congenital syphilis.

## Epidemiology of syphilis in NSW

In 2007, New South Wales (NSW) had the third highest rate of diagnosis of infectious syphilis in Australia at 6.4 per 100 000 population. The highest occurrence was in the Northern Territory where the rate was 49.0 per 100 000 population.<sup>3</sup>

Surveillance data in NSW show a rapid increase in infectious syphilis notifications since around 2001. Infectious syphilis in inner Sydney rose more than 10-fold (from six cases in 1999 to 162 cases in 2003), and the increase was confined to men.<sup>4</sup> Between 2004 and 2008, the majority of new notifications of infectious syphilis in NSW were in men, with just over half in the 30–44 year age group (55.7%) and with a median age of 37.<sup>5</sup>

In NSW the rate of infectious syphilis in Aboriginal Australians dropped from 9 per 100 000 in 2004 to 6 per 100 000 in 2006.<sup>3</sup> The rate of diagnosed infectious syphilis in non-Aboriginal Australians was lower, but also dropped from 5 per 100 000 population in 2004 to 3 per 100 000 population in 2006.<sup>3</sup>

## Public health implications

Syphilis is of public health significance due to the serious morbidity of adult and congenital infection, and its association with increasing risk of human immunodeficiency virus (HIV) transmission. Syphilis increases the risk of both transmitting and contracting HIV. Syphilis can be harder to cure, may progress more quickly and be more complicated in people with HIV. A study in the United States of 52 HIV-infected men with primary or secondary syphilis – 58% of whom were receiving antiretroviral therapy – showed that syphilis is associated with significant increases in plasma viral load and significant decreases in CD4 cell counts, a marker of cell-mediated immune function.<sup>6</sup>

It is important to understand the current epidemiology of syphilis (including behavioural risk) through enhanced surveillance to ensure prevention activities are directed at the most at-risk populations.

## Policy directions

The NSW Sexually Transmissible Infections Strategy 2006–2009 aims to reduce transmission and associated morbidities of syphilis and other sexually transmissible infections (STIs) by targeting interventions to at-risk populations.<sup>7</sup> Two specific targets have also been set in relation to syphilis: to eliminate syphilis transmission within Aboriginal communities and to reduce rates of syphilis among gay and other homosexually active men by 50%.<sup>7</sup>

Within Aboriginal communities, the target has been approached by improving syphilis care systems by enhancing surveillance, strengthening partnerships via stakeholder consultation and targeting health promotion and education strategies.

A similar approach has been taken with gay and other homosexually active men. The STI in Gay Men Action Group partnership formed in 2000 to provide leadership and strategic direction for reducing and preventing STIs, including syphilis, among gay and other homosexually active men in the (former) South Eastern, Central and Northern Sydney area health services. The group aims to strengthen surveillance and health care provider education; support health care service reorientation; undertake social marketing; and implement culturally competent health education and promotion for gay and other homosexually active men.

Syphilis testing for people born in high-prevalence countries, especially through antenatal screening programs, is also important to detect and prevent potential congenital infections, and to prevent long term consequences of untreated infection, such as neurological and cardiovascular syphilis.

### Conclusion

Since 2001, syphilis has re-emerged in NSW as a disease of public health significance. The serious consequences of adult and congenital syphilis infection, and the important role it plays in HIV transmission, mean control efforts need to be strengthened.

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# Boils and skin infections

## What are boils?

A boil is an infection of the skin, usually caused by *Staphylococcus aureus* bacteria (commonly known as 'golden staph'). Many healthy people carry these bacteria on their skin or in their nose without getting an infection. Boils occur when bacteria penetrate broken skin and cause tender, swollen sores that are full of pus.

Other skin infections such as impetigo may be caused by staph bacteria. Impetigo – commonly known as school sores as they affect school-age children – are small blisters or flat, crusty sores on the skin. When the blisters rupture they release a yellow fluid and develop honey-coloured crusts.

## How are they spread?

Boils and other skin infections are spread between people by:

- squeezing, scratching or contact with an infected area
- using unwashed clothes, towels or bed sheets that have been used by a person with a skin infection
- using grooming items (e.g. nail scissors, tweezers, razors and toothbrushes) that have been used by a person with a skin infection
- not washing hands carefully.

## How is the spread prevented?

- Hand washing is important to prevent the spread of boils and skin infections. Hands should be thoroughly washed with soap and running water for 10–15 seconds before and after touching or dressing an infected area, before handling or eating food, after going to the toilet, after blowing your nose and after touching or handling unwashed clothing or linen.
- Keep cuts, scrapes and boils clean and covered to avoid infection.
- Do not share personal items (e.g. clothes, towels or bed sheets) or grooming items (e.g. nail scissors, tweezers, razors and toothbrushes). If you share a bed with someone, keep sores or wounds covered overnight.
- Wash bed linen and clothing regularly.

## How are they diagnosed?

Most skin infections are diagnosed on the basis of their appearance and the presence of any related symptoms (e.g. fever). Your doctor may take swabs or samples from boils,

wounds or other sites of infection to identify the bacteria responsible.

## How are they treated?

- Bathe the boil or sore with soap and water or a saltwater mixture.
- Apply a hot compress to encourage the boil to come to a head.
- Keep boils and other skin infections covered and change dressings regularly.
- Do not squeeze boils or abscesses – drainage should only be performed by a doctor, trained nurse or health worker.
- In some circumstances, infections may require treatment with antibiotics.
- If the sores spread or get worse, or if the person becomes unwell with fever, consult a doctor for further advice. A doctor may prescribe antibiotics (by mouth or as an ointment). It is important to follow the recommended treatment and finish the full course of antibiotics.

## What is the public health response?

Boils and skin infections are not notifiable in NSW. Public health units can advise on the control of outbreaks.

For more information, please contact your doctor, local public health unit or community health centre.

This factsheet is available at: [http://www.health.nsw.gov.au/factsheets/infectious/boils\\_and\\_skininfect.html](http://www.health.nsw.gov.au/factsheets/infectious/boils_and_skininfect.html)



# Communicable Diseases Report, NSW, May and June 2009

## **Communicable Diseases Branch NSW Department of Health**

For updated information, including data and facts on specific diseases, visit [www.health.nsw.gov.au](http://www.health.nsw.gov.au) and click on Public Health then Infectious Diseases, or access the site directly at: <http://www.health.nsw.gov.au/publichealth/infectious/index.asp>.

Figure 4 and Tables 1 and 2 show reports of communicable diseases received through to the end of June 2009 in New South Wales (NSW).

### **H1N1 influenza 09 (human swine influenza)**

Cases of what eventually turned out to be H1N1 influenza 09 (human swine influenza) were initially reported in Mexico and North America in April 2009. In response, Australian health authorities implemented a range of interventions designed to:

- 1) delay the entry of the novel strain of influenza into the country; and
- 2) contain its spread.

On 17 June – when it was clear that community transmission was occurring in parts of Australia – the approach was changed to protecting those most vulnerable. Free anti-influenza medicine has been made available via general practitioners and influenza clinics to patients with influenza-like illness who:

- have chronic medical conditions that place them at higher risk of severe disease
- are pregnant
- are Aboriginal
- have moderate to severe disease.

The situation continues to evolve. For updated information see: <http://www.emergency.health.nsw.gov.au/swineflu/index.asp>.

### **H1N1 influenza 09 and cruise ships in NSW: preliminary report**

#### *Introduction*

In April 2009 a novel influenza strain, H1N1 influenza 09 (human swine influenza or H1N1) began to circulate around the world. Public health efforts initially focused on delaying the entry of the virus into Australia through a range of measures, including an education campaign asking travellers returning from affected countries to present to their local emergency department should they develop symptoms of influenza, enhanced measures at airports to assess returning travellers for illness, testing and isolation of possible cases, and quarantine of people in close contact with patients who tested positive for the illness. These measures successfully limited the introduction of the virus into NSW for many weeks.

In May 2009, two outbreaks of influenza were identified on cruise ships docking in Sydney. Here we report on the public health response to these outbreaks.

#### *Cruise ship 1*

In May, crew on the *Dawn Princess* cruise ship reported to the Australian Quarantine Inspection Service (AQIS) that a small number of passengers had tested positive for influenza A at the ship's clinic. While the clinic was able to perform rapid testing for influenza A, it could not determine whether the influenza A detected in passengers was H1N1 or seasonal influenza. AQIS reported this information to NSW Health the morning the ship docked in Sydney. As the cruise had included a visit to Hawaii – in a country known to have community transmission of H1N1 – NSW Health considered that there was a reasonable risk that some of the sick passengers could have H1N1. At the time, no community transmission had been identified in NSW, so a precautionary approach was taken to minimise the risk that the virus would be introduced into the state.

Discussion with the ship's doctor revealed no evidence of an outbreak of influenza-like illness onboard. Following consultation with the Australian Department of Health and Ageing, NSW Health arranged for a public health team to board the vessel and assess the situation. Passengers with respiratory symptoms were asked to attend the ship's clinic for assessment. Only four had symptoms consistent with influenza. Urgent tests were completed to determine whether

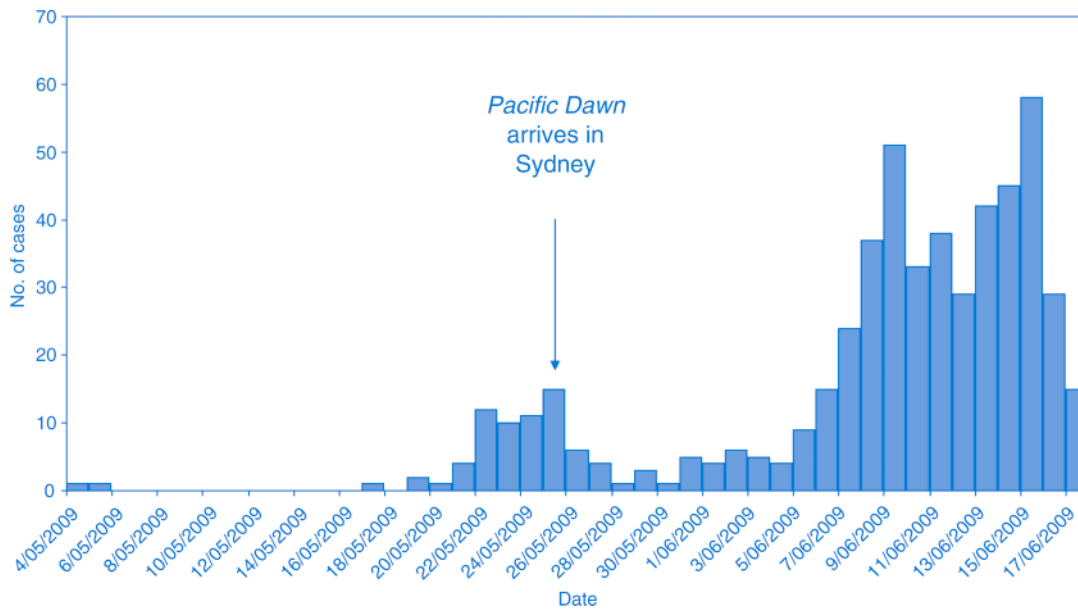


Figure 1. H1N1 influenza 09 cases in contain phase by date of symptom onset, NSW, May–June 2009.

any of these passengers had H1N1. Had this been the case, sick passengers and crew would have been isolated and others placed into quarantine to prevent the spread of the virus into the community. However, the tests returned negative and the passengers and crew were allowed to go about their business that evening.

#### Cruise ship 2

A day later, crew on another cruise ship – the *Pacific Dawn* – also reported to AQIS that a small number of passengers had tested positive to influenza A. Again, NSW Health made a careful assessment of the risk: the ship had not visited any ports where H1N1 was circulating, and none of the ill passengers had been in countries known to be affected by H1N1 prior to boarding. As there were no grounds to suspect the virus was aboard the ship, NSW Health, in consultation with the Department of Health and Ageing, allowed passengers and crew to disembark as usual, following completion of a Health Declaration Card (HDC).

As part of its enhanced public health surveillance for H1N1, NSW Health couriered samples from ill passengers for urgent testing. These were found to be positive for H1N1 later that day. NSW Health immediately began contacting all passengers who had reported illness on their HDCs, asking them to remain in isolation either at home or at their hotel for 7 days. It was believed that these passengers would be at greatest risk of transmitting H1N1 to others. The Department of Health and Ageing agreed to contact other passengers to ask them to stay in quarantine for at least 7 days. NSW Health worked with media outlets to alert passengers who had dispersed, issued a statement on the NSW Health website and set up an information telephone line.

#### Comment

These two outbreaks of influenza on cruise ships were carefully evaluated and decisions were made based on the facts at hand. At the time, Australia was attempting to contain any spread of the virus into the community in order to learn how severe H1N1-related disease might be, and what measures might be needed to control it. Public health actions such as isolation and quarantine limit the liberty of thousands of people and must not be undertaken lightly.

The measures put in place soon after the emergence of H1N1 included screening at international borders for people who had been in countries where the new virus was circulating. Where such people arrived by air into Australia, the travel time was usually too short for the virus to have circulated and caused infection among passengers. However, the situation on ships is different: cruises can last weeks – long enough for multiple generations of influenza to develop.

Several limitations emerged from the response to these outbreaks. Some of those affected reported that they would have liked clearer communication about what was happening to them and what they were required to do. Many reported inconvenience and costs due to missed travel arrangements and inability to leave home. Although the Department of Health and Ageing had developed plans to contact and place into quarantine passengers who were potentially at risk but reported no illness on their HDCs, it took a few days to do so. Quarantine packs (containing masks, hand gel and other materials) were, in some cases, slow to arrive. The national automated call back system for people in quarantine could not easily be turned off for passengers that came under the care of NSW Health. Passengers in isolation and quarantine reported

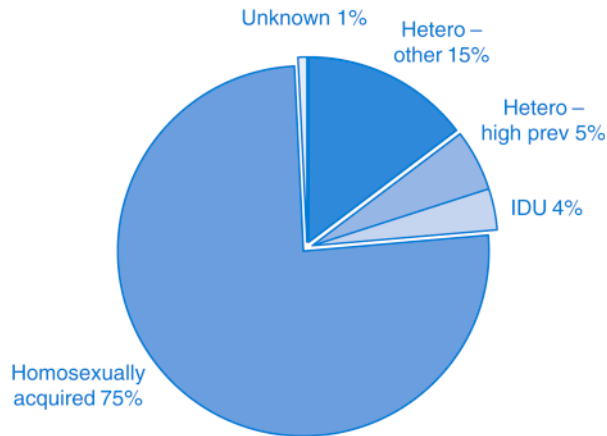


Figure 2. New HIV cases by reported exposure, NSW, 2008.

receiving multiple calls from different people, resulting in repetition and confusion. The sheer volume of laboratory testing performed in the early days of the outbreak challenged laboratory capacity, leading to delays in turnaround times and results.

NSW Health subsequently interviewed a sample of passengers who were on the *Pacific Dawn* to further understand the problems encountered. Analysis of these and other issues will contribute to an improved response in the future.

Despite these concerns, passengers and crew from the *Pacific Dawn* cooperated with public health advice and the measures worked: the outbreak aboard the ship was contained (Figure 1) and did not contribute to a broader outbreak in the Australian community.

### Human immunodeficiency virus (HIV) infections in NSW, 2008

HIV disease remains a major concern; however, new diagnoses have remained fairly stable in NSW in recent years. In 2008, 322 people were newly diagnosed with HIV infection in NSW, including 290 males and 32 females. Cases' ages ranged from 13 to 75 years. Most cases (75%) were reported to be homosexually acquired, 20% were reported to be heterosexually acquired and 4% were reported to be acquired through injecting drug use (IDU). One percent of cases did not have their exposure reported (Figure 2). Here we report some of the epidemiological features of these cases.

#### Methods

Under the NSW *Public Health Act 1991*, laboratories report all confirmed HIV infections to NSW Health and a questionnaire is sent to all notifying doctors to collect epidemiological information on cases. In 2008, additional follow-up resulted in more complete information and improved classification of cases.

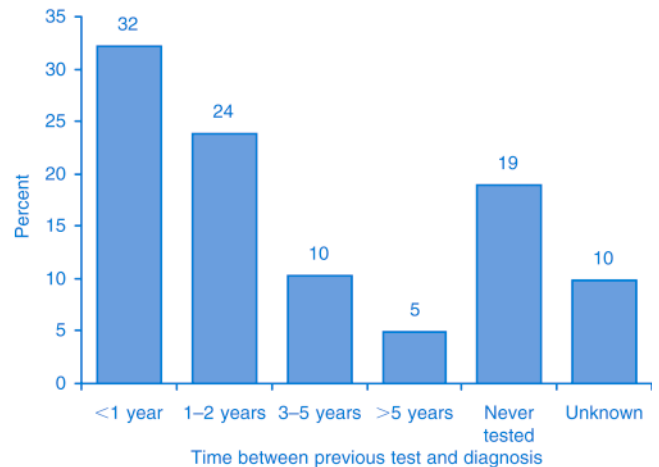


Figure 3. Proportion of homosexually acquired HIV infections by time between previous test and diagnosis, NSW, 2008.

#### Tests conducted

In 2008 in NSW, 636 HIV-positive tests were reported from reference laboratories. Of these, 322 were in NSW residents newly diagnosed with HIV. Of the remaining 314, a total of 226 were repeat tests of previously confirmed cases, 64 were for cases previously diagnosed either overseas or interstate, and 24 were for cases residing overseas or interstate.

#### Homosexually acquired HIV

Among the 322 new cases in NSW in 2008, 243 (75%) were reported to be homosexually acquired. Most (71%) were residents of central and south-eastern Sydney and 63% were Australian-born.

Only a third reported having had a previous HIV test in the last year and 19% reported never having had a test before (Figure 3). Almost half (45%) had evidence of recent infection (i.e. either a negative or indeterminate HIV antibody test or a seroconversion illness in the previous 12 months). However, 10% (24 cases) had evidence of advanced disease at time of diagnosis (CD4 count <200 or an AIDS-defining illness within 3 months of HIV diagnosis). While the median age of patients with advanced disease was 41 years, patients with recent infection were evenly spread across their 20s, 30s and 40s.

#### Heterosexually acquired HIV

Of the 322 new cases, 65 (20%) were reported to be heterosexually acquired. Of these, one-quarter were born in high prevalence countries who reported heterosexual sex with a partner from a high prevalence country. Nine were female and eight were male. Most were likely acquired outside Australia. One-quarter presented early and one-quarter presented late in their infection.

Of the remaining three-quarters of people with heterosexually acquired HIV infections, 28 were males, 19 were females and half (49%) were Australian-born. There was no geographic clustering of these cases. Of these, 19% were diagnosed early and 23% late.

#### *HIV acquired through IDU*

There were 12 cases of HIV reported to be acquired through IDU – eight males and four females. Nine were

Australian-born. There was no clustering by age or geographical location.

#### *Conclusion*

The number of HIV notifications in NSW remains stable. Homosexual acquisition is the most common exposure for HIV infection and highlights the importance of promoting safe sex practices and regular testing among this group.



**Figure 4. Reports of selected communicable diseases, NSW, January 2004 to June 2009, by month of onset.**

Preliminary data: case counts in recent months may increase because of reporting delays.

Laboratory-confirmed cases only, except for measles, meningococcal disease and pertussis.

BFV, Barmah Forest virus infection; RRV, Ross River virus infection; lab conf, laboratory confirmed;

Men Gp C and Gp B, meningococcal disease due to serogroup C and serogroup B infection;

other/unk, other or unknown serogroups.

NB: Multiple series in graphs are stacked, except gastroenteritis outbreaks.

NB: Outbreaks are more likely to be reported by nursing homes and hospitals than by other institutions.

NSW Population	
Male	50%
<5 y	7%
5–24 y	27%
25–64 y	53%
65+ y	13%
Rural	46%

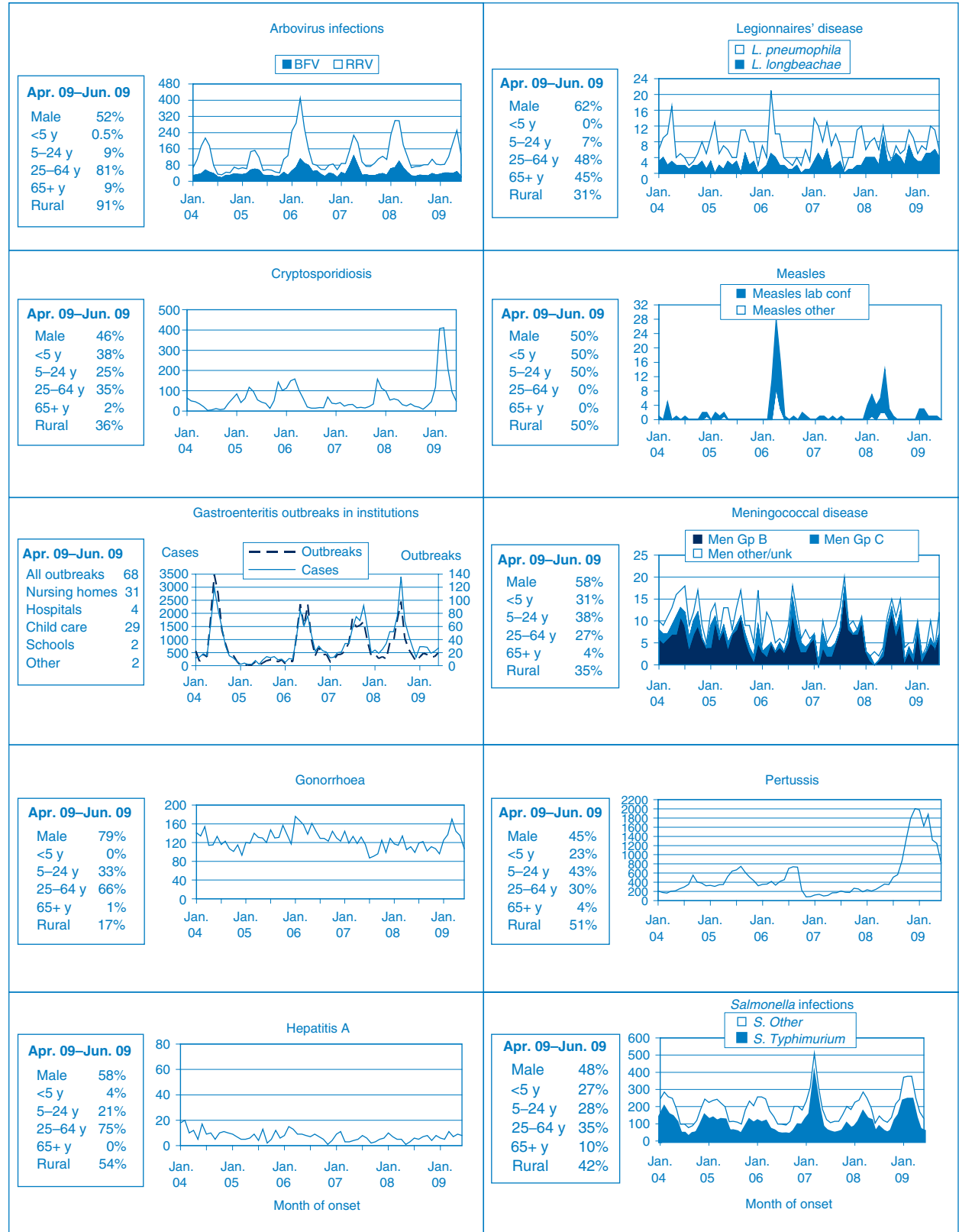


Table 1. Reports of notifiable conditions received in May 2009 by area health services

Condition	Area Health Service (2009)										Total For May <sup>b</sup>	Total Year to date <sup>b</sup>						
	Greater Southern GMA SA	FWA	Greater Western MAC	MWA	Hunter New England HUN	NEA	North Coast MNC	NRA	Central Coast CCA	Northern Sydney Central Coast NSA			Sydney Illawarra ILL	SES	Sydney South West CSA	SWS	WEN	Sydney West WSA
<b>Bloodborne and sexually transmitted</b>																		
Chancroid <sup>b</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Chlamydia (genital) <sup>a</sup>	64	37	14	17	25	37	25	67	65	104	60	221	138	119	44	138	16	6233
Gonorrhoea <sup>a</sup>	6	-	-	-	2	8	1	1	3	11	2	53	25	13	3	13	-	1444
Hepatitis B – acute viral <sup>a</sup>	-	-	-	-	-	-	-	-	-	2	-	-	-	-	-	-	-	4
Hepatitis B – other <sup>a</sup>	5	-	4	1	-	3	4	1	9	42	4	38	38	55	2	38	4	255
Hepatitis C – acute viral <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	15
Hepatitis C – other <sup>a</sup>	14	11	5	5	15	7	11	18	39	37	28	56	45	72	23	44	39	2751
Hepatitis D – unspecified <sup>b</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4
Lymphogranuloma venereum	-	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	-	1
Syphilis	-	1	6	1	2	1	1	2	2	7	4	37	25	17	-	5	-	552
<b>Vectorborne</b>																		
Barmah Forest virus <sup>a</sup>	-	2	1	-	-	1	11	15	-	-	-	-	-	1	-	-	-	51
Ross River virus <sup>a</sup>	5	1	10	7	-	6	44	52	4	4	-	3	1	3	1	1	-	221
Arboviral infection (other) <sup>a</sup>	2	-	-	-	-	-	-	-	1	3	-	2	-	1	1	1	-	9
Malaria <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	2	2	-	-	4	-	12
<b>Zoonoses</b>																		
Anthrax <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Brucellosis <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Leptospirosis <sup>a</sup>	1	-	-	-	-	-	1	2	-	-	-	-	-	-	-	-	-	4
Lysavirus <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Psittacosis <sup>a</sup>	-	-	-	-	1	-	-	-	-	1	-	-	-	-	1	-	-	3
Q fever <sup>a</sup>	-	-	-	1	1	3	-	1	-	-	1	-	-	-	-	-	-	10
<b>Respiratory and other</b>																		
Blood lead level <sup>a</sup>	1	-	-	3	-	2	-	-	2	3	-	1	1	-	2	1	-	16
Invasive pneumococcal infection <sup>a</sup>	-	1	-	-	2	7	1	-	3	2	4	5	2	4	3	3	-	38
<i>Legionella longbeachae</i> infection <sup>a</sup>	-	-	-	-	-	2	-	-	-	-	-	3	-	-	-	-	-	6
<i>Legionella pneumophila</i> infection <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	1	-	-	-	-	1	-	2
Legionnaires' disease (other) <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Leprosy	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Meningococcal infection (invasive) <sup>a</sup>	-	-	-	-	-	-	-	-	-	1	2	2	-	-	1	-	-	7
Tuberculosis	-	-	-	-	-	1	-	-	-	2	2	6	2	4	-	13	-	31
<b>Vaccine-preventable</b>																		
Adverse event after immunisation	2	1	-	1	-	3	1	-	-	1	-	8	-	-	-	5	-	22
<i>H. influenzae</i> b infection (invasive) <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	4
Measles	1	-	-	-	-	-	-	1	-	1	1	1	1	1	-	-	-	6
Mumps <sup>a</sup>	45	52	8	22	45	121	18	84	51	121	116	110	79	128	95	106	1	1282
Pertussis	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	1
Rubella <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	6
Tetanus	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
<b>Enteric</b>																		
Botulism	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Cholera <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Cryptosporidiosis <sup>a</sup>	3	-	-	-	3	9	1	4	8	27	3	27	5	11	10	15	-	134
Giardiasis <sup>a</sup>	7	6	1	6	1	17	3	3	1	32	5	37	20	17	6	27	-	199
Haemolytic uraemic syndrome	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Hepatitis A <sup>a</sup>	1	-	-	-	-	-	-	1	1	-	1	3	-	-	-	2	-	10
Hepatitis E <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Listeriosis <sup>a</sup>	-	-	-	-	-	-	-	-	-	-	1	1	-	-	-	-	-	2
Salmonellosis <sup>a</sup>	8	5	1	7	3	11	10	7	9	20	7	25	15	8	2	22	-	166
Shigellosis <sup>a</sup>	-	-	-	-	-	-	-	1	1	3	-	7	3	-	-	1	-	17
Typhoid <sup>a</sup>	1	-	-	-	-	1	-	-	-	-	1	-	-	1	-	2	-	6
Verotoxin producing <i>E. coli</i> <sup>b</sup>	-	-	-	-	-	1	-	-	-	-	-	-	-	-	-	-	-	1
<b>Miscellaneous</b>																		
Creutzfeldt-Jakob disease	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1
Meningococcal conjunctivitis	-	-	1	-	-	-	-	-	-	-	-	-	-	-	-	-	-	1

<sup>a</sup> laboratory-confirmed cases only; <sup>b</sup> includes cases with unknown postcode.  
 NB: Influenza notifications not included. See [www.health.nsw.gov.au/PublicHealth/Infectious/az.asp#fl](http://www.health.nsw.gov.au/PublicHealth/Infectious/az.asp#fl) for up-to-date information.  
 NB: Data are current and accurate as at the preparation date. The number of cases reported is, however, subject to change, as cases may be entered at a later date or retracted upon further investigation. Historical Area Health Service configurations are included for continuity/ comparison purposes to highlight regional differences.  
 NB: HUN, JUNEY 2005; Hunter New England/HS also comprises Great Lakes, Gloucester and Greater Taree LGAs (LGA, Local Government Area), Sydney West also comprises Greater Lithgow LGA.  
 NB: HUN and ADS data are reported separately in the Public Health Bulletin quarterly.  
 GMA, Greater Murray Area; MAC, Macquarie Area; NEA, New England Area; CCA, Central Coast Area; SES, South Eastern Sydney Area; HUN, Hunter Area; NSA, Northern Sydney Area; CSA, Central Sydney Area; WSA, Western Sydney Area; FWA, Far West Area; CCA, Central Coast Area; SES, South Eastern Sydney Area; WEN, Wentworth Area; ILL, Illawarra Area; SA, Southern Area; MWA, Mid Western Area; SWS, South Western Sydney Area; JHS, Justice Health Service; MNC, North Coast Area.



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# NSW PUBLIC HEALTH BULLETIN

The *NSW Public Health Bulletin* is a peer-reviewed journal produced by the NSW Department of Health and indexed in Medline. It has a NSW focus, however, it aims to support the practice of public health more broadly.

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#### Submission of articles

The *Bulletin* accepts proffered and commissioned articles along with short reports, on all aspects of public health. Articles should be 1500–2000 words, not including tables and figures, and should include an abstract of up to 100 words. Articles should follow the journal style and layout as closely as possible, as described in the Instructions to Authors. Articles should be emailed in a Word for Windows format to: [phbulletin@doh.health.nsw.gov.au](mailto:phbulletin@doh.health.nsw.gov.au), and should be accompanied by a covering letter signed by all authors and a License to Publish. The Instructions to Authors, License to Publish and other useful information can be downloaded from the *Bulletin* website.

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